The Abstract book

ISPID International Conference
Florence 2023

ISPID International Conference on Stillbirth, SIDS and SUDI

Baby Survival: Global Achievements and Future Challenges

FLORENCE 6-8 October 2023

www.ispid2023florence.com

ISPID
International Society for the Study and Prevention of Perinatal and Infant Death

Semi per la SIDS

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Welcome Letter

Dear Friends and Colleagues,

As co-chairs of the 2023 ISPID International Conference, we warmly welcome you to Florence, Italy. The theme of this year's conference is Baby Survival: Global Achievements and Future Challenges. It has been 21 years since Florence hosted its first and very successful ISPID SIDS and SUDI conference. We are looking forward to another wonderful conference in this beautiful city known for its Renaissance Art, architecture and monuments, culture and food. The venue for the conference is the magnificent Palazzo dei Congressi.

Members of the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID), and gracious hosts Semi per la SIDS ONLUS and Fondazione Meyer, will join other delegates from around the world to further our knowledge through research initiatives and families' experiences to improve outcomes for our future generations and protect precious lives.

The multidisciplinary nature of this conference will provide something for everyone who is involved in the provision of care for our families. A key aspect of the conference will be to listen and learn from the parents and relatives who have experienced the tragedy of losing a baby, taking forward common goals for improved provision of healthcare and education, promoting global research in this field and encouraging every professional to seek innovative ways to improve their service. Enjoy this opportunity to network with each other, share ideas, and engage in stimulating discussions.

We wish you a successful conference!

Dr. Raffaele Piumelli
Florence, Italy

Dr. Fern R. Hauck
Charlottesville, Virginia, USA

Welcome Letter

Dear Colleagues, Dear Parents,

We are very pleased to invite you to the next ISPID Conference to be held in Florence, Italy, on October 6-8 2023.

The conference is a great opportunity for listening to leading public figures and experts from all over the world who will gather in Florence to present their works and discuss the most recent findings on Stillbirth, SIDS and SUDI.

The meeting will be also a significant occasion to share personal experiences and be part of an international network of outstanding researchers and activists.

As bereaved parents, we invite you to join us also at the events of remembrance and at the workshops dedicated to self and mutual help. The scientific sessions in fact will be paralleled by a specific program for parents, that will include bereavement seminars, moments of sharing and many other valuable activities for all family members.

The conference will be closed by a memorial service and a light ceremony of iconic monuments in Florence.

We look forward to welcoming you in October 2023.
Yours sincerely,

Allegra Bonomi
Semi per la SIDS Onlus, Florence, Italy

Alfredo Vannacci
Ciao Lapo, Prato, Italy

Organizing Committee

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Società Italiana di Medicina Perinatale

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società italiana per le malattie respiratorie infantili

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Foreword and Disclaimer

This book is a collection of the abstracts that the Scientific Committee received from the Conference speakers, so it does not cover papers for which the material has not been submitted.
The book is organized according to the final program and has been produced for the exclusive use of the participants.
Under no circumstances should the materials herein be disseminated without the prior and explicit permission of the authors.

In the hope that we have done a pleasant thing,
I wish you good reading,

Allegra Bonomi
President - Semi per la SIDS Onlus
Board Member - ISPID

In memory of Carla Cattaneo the first bereaved mother in Italy to organize an International Conference

SALA VERDE – PLENARY SESSION 1 – Bereavement

Chairs: Barb Himes - Atlanta, Georgia USA & Allegra Bonomi - Milan ITA

The science of emotional pain and yearning

Richard Goldstein - Boston, Massachusetts USA

Until infants no longer die from SIDS and SUDI, bereft parents will be part of the illness experience. As their lives continue in the absence of their baby, parents after SIDS must reckon with loss and try to find their way in a world that has changed forever. How do they go on? We will review research efforts examining the grief experiences of parents after SIDS and ask what science can do to help parents after loss

Conceiving the inconceivable: the representation of perinatal death in art and literature

Claudia Ravaldi - Florence ITA

From Grievance to Grief: Appeasement, Adversity, Accountability

Stacy Scott - Toledo, Ohio USA

SALA VERDE – PARALLEL SESSION 1 – European SUDI Epidemiology

Chairs: Peter Blair - Bristol UK & Adele Engleberts - Sittard NL

O-001 Back-to-sleep recommendations in French maternities: frequency and determinants in a national population-based study

Sophie de Visme - Nantes FRA

O-002 Impact of the COVID-19 pandemic on the sudden unexpected death in infancy (SUDI) incidence rate: study from the French SUDI registry

Sophie de Visme - Nantes FRA

O-003 Inconsistency between pictures printed on baby diaper packaging in Europe and safe infant sleep recommendations: a systematic assessment and a call for urgent legislation

Sophie de Visme - Nantes FRA

O-004 Understanding differences in infant care practices between families at more or less risk of sudden infant death syndrome: results from an online national survey in England in 2022

Anna Pease - Bristol UK

O-005 The Dutch Postmortem Evaluation of Sudden Unexplained Death in Youth for identifying cause of death

Annelotte Pries - Rotterdam NL

O-006 Identifying families with infants at increased risk of Sudden Infant Death Syndrome (SIDS): A predictive algorithm using observational data

Nicholas Turner - Bristol UK

This Session available Abstracts

O-001 Back-to-sleep recommendations in French maternities: frequency and determinants in a national population-based study

by Sophie de Visme | Béatrice Blondel | Christèle Gras-Le Guen | Anne Chantry | Elie Azria | Hugues Patural | Sabine Plancoulaine | Pauline Scherdel | Laurence Foix-L'Hélias | Jérémie F. Cohen | Martin Chalumeau | INSERM UMR 1153 CRESS | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM | CHU de Staint-Etienne | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM

Objective: Sudden infant death in infancy (SUDI) rates are persistently high in several high- income countries implementing of "back-to-sleep" recommendations is not optimal. We aimed to study the frequency and the determinants of a lack of "back-to-sleep" recommendations after delivery in French maternities.

Methods: We used the data from the French national perinatal survey, a cross-sectional population-based study conducted in 2016 in all French maternities over a one-week period. Mothers aged 18 years and older were interviewed in metropolitan France and overseas territories during their postpartum stay. Mothers were asked whether, "since giving birth, maternity staff advised them always to lay their babies on their backs to sleep". We identified the determinants of mothers' responses among mother-, their newborn-, and the maternity-level characteristics using crude and adjusted analyses. Multivariate analyses were adjusted on the time between the delivery and the interview and used hierarchical logistic models and interactions terms when appropriate.

Results: Among the 11,072 mothers with available data (89.2% of the initial sample), 6,350 (57.4%) declared they had not received any "back-to-sleep" recommendation. Factors independently and significantly associated with the lack of "back-to-sleep" recommendations were multiparity (aOR=1.3; 95%CI 1.1-1.5), not having been advised not to drink alcohol during pregnancy (aOR=1.6; 95%CI 1.4-1.8), exclusive breast- or mixed- feeding (aOR=1.2; 95%CI 1.0-1.3), and giving birth in a maternity with more than 1,000 deliveries per year (aOR=2.0; 95%CI 1.3-3.2) or lacking a breastfeeding assistance referent (aOR=1.4; 95%CI 1.1-1.7).

Conclusions: In France, the high frequency of mothers declaring not have been informed during their postpartum stay in maternities of the "back-to-sleep" recommendations should prompt changes in national and local health educational policies. The identified factors could inform the development of targeted messages for parents and maternities most at risk.

O-002 Impact of the covid-19 pandemic on the sudden unexpected death in infancy (SUDI) incidence rate: study from the French SUDI registry

by Pauline Scherdel | Adeline Ricard | Naim Ouldali | Jarry Bérengère | Léa Ferrand | Karine Levieux | Christèle Gras-Le Guen | Sophie de Visme | Camille Aupiais | Nantes Université, CHU de Nantes, INSERM, UIC Femme-Enfant-Adolescent, CIC 1413, F-44000 Nantes, France. | Pediatrics Emergency Care Unit, Nantes University Hospital, F-44000 Nantes, France. | Department of General Pediatrics, APHP, Pediatric Infectious Disease and Internal Medicine, Robert Debré University Hospital, F-75019 Paris, France; ACTIV, Association Clinique et Thérapeutique Infantile du Val-de-Marne, F-94000 Créteil, France; Université Paris Cité, Inserm, ECEVE, F-75010 Paris, France. | Nantes Université, CHU de Nantes, INSERM, UIC Femme-Enfant-Adolescent, CIC 1413, F-44000 Nantes, France. | Nantes Université, CHU de Nantes, INSERM, UIC Femme-Enfant-Adolescent, CIC 1413, F-44000 Nantes, France. | Pediatrics Emergency Care Unit, Nantes University Hospital, F-44000 Nantes, France. | Pediatrics Emergency Care Unit, Nantes University Hospital, F-44000 Nantes, France. | Nantes Université, CHU de Nantes, INSERM, UIC Femme-Enfant-Adolescent, CIC 1413, F-44000 Nantes, France. | Université Paris Cité, Inserm, ECEVE, F-75010 Paris, France; Department of General Pediatrics, AP-HP, Hôpital Universitaire Jean-Verdier, F-93140 Bondy, France.

Objective: In France, sudden unexpected death in infancy (SUDI) is the first cause of infant death in post-neonatal period. The role of viruses or bacteria in the physiopathology of SUDI has been often suggested, but without strong evidence. Our objective aimed to study the temporal trend of SUDI incidence rate and those with viral or bacterial identification before et during the COVID-19 pandemic period.

Methods: From the French SUDI registry, SUDI cases under one year of age who died between January 2016 and December 2021 in metropolitan France were included. We analyzed the temporal trends of monthly incidence rates of SUDI cases using Poisson regression models, accounting for seasonality and we studied the impact of COVID-19 pandemic period on these trends. With a similar approach, we also studied the temporal trends of monthly incidence rates of SUDI cases with viral or bacterial identification.

Results: Among 989 infants included, 744 and 254 infants were recorded during prepandemic (January 2016-March 2020) and pandemic (April 2020-December 2021) periods, respectively. Among them, 576 (66.4%) with viral or bacterial identification. Compared with the pre-pandemic period, the SUDI incidence rate significantly decrease during the pandemic period (adjusted incidence rate ratio [confidence interval 95%], 0.82 [0.71-0.95]). We observed a significant reduction of incidence rate in SUDI cases with viral or bacterial identification, but no significant difference in the trend of SUDI cases without viral and bacterial identification was found.

Conclusions: We observed a marked decrease of incidence rate of SUDI cases during the COVID-19 pandemic period in metropolitan France, which specifically concerned the SUDI cases with viral or bacterial identification. The protection of young vulnerable infants against infections, especially respiratory infections through barrier measures and immunization, appears to be a key message for SUDI risk-reduction strategies.

O-003 Inconsistency between pictures printed on baby diaper packaging in Europe and safe infant sleep recommendations: a systematic assessment and a call for urgent legislation

by Sophie de Visme | Daniel A. Korevaar | Christèle Gras-Le-Guen | Alix Flamant | Martina Bevacqua | Anna Stanzelova | Nhung TH Trinh | Dalia-Alexandra Ciobanu | Ana Araújo Carvalho | Ifigeneia Kyriakoglou | Maria Fuentes | Yacine Refes | Elisabeth Briand-Huchet | Anne-Laure Sellier | Inge Harrewijn | Jérémie F. Cohen | Martin Chalumeau | Université Paris Cité, CRESS, INSERM | Amsterdam University Medical Centers | Université Paris Cité, CRESS, INSERM | Cliniques Universitaires Saint-Luc | University of Trieste | AP-HP, Necker-

Enfants Malades Hospital | University of Oslo | Children's Hospital "Doctor Victor Gomoiu" | Centro Hospitalar e Universitário de Lisboa Central | Aristotle University of Thessaloniki | AP-HP, Necker-Enfants Malades Hospital | Université Paris Cité, CRESS, INSERM | Naître et vivre | HEC Paris | CHU de Montpellier | Université Paris Cité, CRESS, INSERM | Université Paris Cité, CRESS, INSERM

Objective: Sudden unexpected death in infancy (SUDI) rates are high and stagnate in several European countries with suboptimal implementation of safe infant sleep recommendations (SISR). Pictures conveying implicit or explicit health messages have proven effective in modifying health practices. We aimed to describe the level of inconsistency between pictures on baby diaper packaging, an influential surface to which parents are frequently exposed, and SISR in Europe.

Methods: We identified all packaging of baby diapers sold in 11 European countries for infants weighing less than 5 kg through Internet searches in July-November 2022. For each packaging, we extracted whether there was a picture depicting a baby, whether the baby was sleeping, and, if so, whether the picture of the sleeping baby was inconsistent with ≥1 of 3 SISR assessable on pictures. Data were aggregated at the country level, and random effects meta-analysis of proportions was used to obtain summary estimates and assess between-country heterogeneity (I^2).

Results: Overall, we identified 631 baby diaper packaging, and 49% (95%CI: 42-57; I2=73%) displayed a picture depicting a sleeping baby. Thirty-nine percent (95%CI: 32-45) of all packaging were inconsistent with ≥1 SISR (substantial between-country heterogeneity, I2=66%), including non-supine sleeping position (22%; 95%CI: 17-27; I2=52%), soft objects or loose bedding such as pillows or blankets (25%; 95%CI: 21-29; I2=25%), and sharing the sleep surface with an adult (5%; 95%CI: 2-10; I2=76%).

Conclusion: In Europe, pictures on baby diaper packaging are often inconsistent with current SISR. SUDI prevention requires urgent actions by manufacturers and legislators to stop parents' exposure to misleading pictures that can trigger dangerous practices.

O-004 Understanding differences in infant care practices between families at more or less risk of sudden infant death syndrome: results from an online national survey in England in 2022

by Dr Becky Ali | Professor Peter S Blair | Professor Jenny Ingram | Professor Peter Fleming | Dr Alice Keegan | Dr Nicholas Turner | Dr Anna Pease | Population Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol, UK

Objective: Interventions to prevent sudden infant death syndrome (SIDS) often rely on improving the uptake of safer sleep advice by caregivers. We conducted a national survey in England to investigate the prevalence of risk factors for infants identified at birth to be at higher risk.

Methods: Between June and November, 2022, carers in England of infants under 12 months of age were surveyed. An algorithm of family demographics and characteristics surrounding the birth was used to identify families with infants at increased risk of SIDS. Our analysis compares infant care practices of higher risk infants with the rest.

Results: A total of 3100 responses were received, 75 (2.4%) represented infants with an increased risk of SIDS. Those in the higher risk group were less likely to be breastfeeding (60.5% vs 30.7% higher-risk) and more likely to have a social worker (1.6% vs 16.0% higher-risk). They were less likely to have co-slept 'last night' (42.4% vs 28.4% higher-risk), but more likely to have shared a sofa (0.4% vs 4.1% higher-risk). In the higher risk group infant illness was more likely to be cited as a reason for co-sleeping (6.7% vs 23.8% higher-risk), or not having a suitable infant bed available (0.4% vs 14.3% higher-risk). There were more likely to be disruptions to the usual routine for infants with increased risk (14.1% vs 22.7% higher-risk). There were no differences in usual or last night sleep position between risk groups; non supine positions usual practice (14.9%

vs 16.3% higher-risk).

Discussion: Differences in the infant sleep environment are seen for infants with increased risk scores, and despite less co-sleeping overall, our algorithm picked up rarer instances of sofa sharing in the higher risk group. Reasons for co-sleeping and availability of safe sleep spaces need to be explored further.

O-005 The Dutch Postmortem Evaluation of Sudden Unexplained Death in Youth for identifying cause of death

by Annelotte Pries | Jopje Ruskamp | Esther Edelenbos | Joris Fuijkschot | Ben Semmekrot | Krijn Verbruggen | Elise van de Putte | Patrycja Puiman | Erasmus MC - Sophia | UMC Utrecht | Amsterdam UMC | Radboud UMC | Canisius Wilhelmina Hospital | UMC Groningen | UMC Utrecht | Erasmus MC - Sophia

Objective: In the Netherlands 50 children per year die suddenly by unexplained natural causes. A diagnostic procedure was nationally implemented in 2016 to investigate these deaths: the Postmortem Evaluation of Sudden Unexplained Death in Youth (PESUDY) procedure. This procedure aims to provide a cause of death and gain insight in life- threatening medical emergencies in children. This study evaluates the diagnostic value and national outcomes of the PESUDY procedure.

Methods: Suddenly deceased children aged 0-18 years in the Netherlands were investigated if their death was deemed natural but unexplained and parents gave consent. The procedure is performed nationally and consists of an extensive history, pediatric and forensic examination, biochemical and microbiological testing, skeletal survey, CT scan or MRI, autopsy and a multidisciplinary audit. Retrospective observational data on history, modifiable factors, performed diagnostics and cause of death were collected from October 2016 - December 2021.

Results: 212 cases were included with a median age 11 months (interquartile range 3.0 – 72.5). 56% of cases were boys and 33% had a known comorbidity. In 28% of cases the parents sought medical help for symptoms their child showed before fatally collapsing. Microbiological, toxicological and metabolic testing was performed in 93%, 34% and 32% of cases. In 95% of cases either a CT scan or MRI was done and in 62% an autopsy was performed. A cause of death was determined in 71% of cases. Most children died from infection (n=90). Non-infectious cardiac causes were the second leading causes of death found. Modifiable factors were identified in a third of cases and mostly involved overlooked alarming symptoms or an unsafe sleeping environment.

Conclusion: The PESUDY procedure is valuable and effective for determining the cause of death in children with sudden unexplained deaths providing answers to grieving parents and involved health care professionals.

O-006 Identifying families with infants at increased risk of Sudden Infant Death Syndrome (SIDS): A predictive algorithm using observational data

by Nicholas Turner | Anna Pease | Peter Flemming | Tom Williams | Jenny Ingram | Karen Patrick | Karen Luyt | Becky Ali | Vicky Sleap | Kieren Pitts | Peter Blair | Population Health Sciences, Bristol Medical School, University of Bristol UK | Population Health Sciences, Bristol Medical School, University of Bristol UK | Population Health Sciences, Bristol Medical School, University of Bristol UK | Translational Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol UK | Royal United Hospital Bath NHS Foundation Trust UK | Translational Health Sciences, Bristol Medical School, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol UK | Translational Health Sciences, Bristol Medical School, University of Bristol, UK | Research IT, University of Bristol, UK | Population Health Sciences, Bristol Medical School, University of Bristol UK

Objective: The aim of this study was to develop a risk prediction model to identify families with infants at higher risk of Sudden Infant Death Syndrome (SIDS) soon after delivery using demographic characteristics and factors pertaining to the birth.

Methods: Two existing observational studies conducted in England in 1993-96 and 2003-2006 were combined to provide the data for model development. Internal validation via Bootstrapping was done to produce an optimism corrected C-statistic. National Child Mortality Database and Livebirth statistics data from 2020 were used to explore the prevalence and relevance of the identified predictors in an external dataset.

Results: The model was developed using 402 SIDS cases and 1387 control infants matched or weighted for age and whether the sleep was a day or night sleep. A final risk prediction model was derived consisting of 8 variables relating to demographic characteristic and birth factors (male sex, low birthweight, admission to Neonatal Intensive Care Units, birth to multiparous mother, younger mothers, support of a partner and whether the mother or partner smoked). The model C-statistic was 82.4% [95%CI:80.1% to 84.7%], whilst the calibration plot and Hosmer-Lemeshow test suggested goodness of fit of the predicted to observed data. The optimism corrected C-statistic was 81.2%, and the prevalence of the model predictors was largely comparable to external NCMD data of 133 SIDS deaths.

Discussion: The developed SIDS prediction model has a good level of accuracy. Further reduction of SIDS deaths may be achieved by using the model to offer targeted intervention to vulnerable families.

SALA VERDE – PARALLEL SESSION 2 – Caregiver Perceptions

Chairs: Eve Colson - St. Louis, Missouri USA & Kala Frye Bourque - Washington DC USA

O-007 Caregiver decision-making for the infant sleep environment in at risk populations

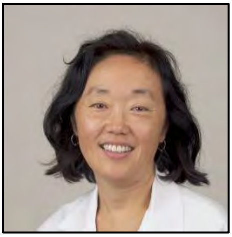
Alice-Amber Keegan - Bristol UK

O-008 Evaluation of a novel intervention program to change parents' attitudes and practices of infants' safe sleep

Anat Shatz - Ganey Tikva IL

O-009 Maternal Perceptions of the Tension between Following Safe Sleep Guidelines and Optimizing Infant and Maternal Sleep

Rachel Y Moon – Charlottesville, Virginia USA



O-010 Involving families with infants at increased risk of SUDI in safer sleep research using creative methods

Alice-Amber Keegan – Bristol UK

O-011 Easy to breathe – Safe to Sleep: Impact of The Pēpi-Pod® Program in reducing infant mortality in Queensland

Jeanine Young – Herston, Queensland AUS

O-012 A Safer Sleep Guideline informed by Risk Minimisation: Partnering with families to plan safer infant sleep environments

Jeanine Young – Herston, Queensland AUS

This Session available Abstracts

O-007 Caregiver decision-making for the infant sleep environment in at risk populations

by Alice Keegan | Becky Ali | Jenny Ingram | Peter S Blair | Peter Fleming | Anna Pease | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK

Background: The 2020 English Child Safeguarding Practice Review highlighted the influence of peers and family members in decisions about the infant sleep environment, and a lack of studies that included their practices, knowledge, and sources of information.

Aims: To understand factors influencing decision-making for the infant sleep environment by primary and secondary caregivers within families of infants at increased risk for Sudden Unexpected Death in Infancy (SUDI).

Methods: Families who responded to the Baby Sleep Project Survey and were either deemed high risk using an algorithm at birth or described engaging in behaviors that went against safer sleep advice were invited to participate. Telephone interviews were conducted between August-December 2022.

Results: 37 interviews were conducted (26 biological mothers, 6 biological fathers, 3 foster mothers, 2 mothers-in-law) with 31 families. Three major themes were identified; Balancing the needs of the baby with other members of the family, fear and shame around parenting decisions, seeing infant sleep as a behavioral issue. Participants demonstrated a knowledge of safer sleep guidance, however, decisions about the infant sleep environment were weighed up against the wider needs of the family, in particular the need to manage the impact of sleep disruption. Sleep was described as a behavioral issue rather than a health issue, with personal

perceptions of risk and individual narratives influencing the interpretation of advice about infant care. Parents of infants at increased risk for SUDI were conflicted about their behaviour and felt fear of being referred to social services or shame when discussing infant sleep with professionals or peers.

Conclusions: Decision-making for infant care is based on a multitude of factors which must be considered in context to support vulnerable infants and their caregivers. The needs of the wider family should be considered in order to encourage effective adherence to safer sleep guidance.

O-008 Evaluation of a novel intervention program to change parents' attitudes and practices of infants' safe sleep

by Anat Shatz | Liat Korn | Pediatric airways service, Shaaree Zedek Medical Centre, Jerusalem Israel, Atid-Israeli foundation for the study and prevention of Sudden Infant Death | Department of Health Management, School of Health Sciences, Ariel University, Ariel, Israel.

Objective: to evaluate the effectiveness of a novel intervention program using home visits by trained students acting as change agents.

Type of Study: A quantitative longitudinal study at two points in time: before and after the intervention, comparing study to control groups.

Study population: 437 parents of infants from fifty-nine localities in Israel, who received individual safe sleep guidance at home (intervention group), and 95 parents of infants who did not participate in the intervention program (control group).

Methods: undergraduate students were trained (lectures, simulations, and practice modeling) to serve as change agents for promoting safe sleep practices. Parents were trained to avoid risky behaviors during home visits. A questionnaire examining knowledge, attitudes, and behavior with respect to infants' safe sleep practices was administered before and after intervention. Parents serving as the control group completed the questionnaires at the same time as the intervention group, without receiving any training.

Results: Individual, training in a home setting contributes significantly to parents' knowledge of safe-sleep guidelines (sleep and wake position, separate bed, soft bedding and overheating avoidance), strengthens their positive attitudes towards the guidelines’ (greater trust in the guidelines, confident they knew them better, decrease in external focus of control)and increases compliance with the guidelines, reflected in the actual execution of safe sleep practices in comparison to pre intervention and to control group($p<0.01$).

Conclusions: Preliminary research results revealed a gap between knowledge and implementation of safe sleep recommendations. This study’s findings indicate that at-home training conducted has proven effective in reducing the gap by achieving greater levels of knowledge and implementation of the guidelines.

O-009 Maternal Perceptions of the Tension between Following Safe Sleep Guidelines and Optimizing Infant and Maternal Sleep

by Rachel Y. Moon, MD | Jodi A. Mindell, PhD | Sarah Honaker, PhD | Sarah Keim, PhD | Kristin J. Roberts, MS, MPH | Rebecca J. McAdams, MA, MPH | Lara B. McKenzie, PhD | University of Virginia | Children\'s Hospital of Philadelphia | Indiana University | Nationwide Children\'s Hospital | Nationwide Children\'s Hospital | Nationwide Children\'s Hospital | Nationwide Children\'s Hospital

Objectives: Two contributors to unsafe sleep practices are the perception that infants sleep poorly in safe sleep environments and caregivers’ need for sleep. The aim of this qualitative study was to understand the tension between safe sleep and the perception that “the baby” or “I” “sleep better.”

Methods: Four virtual focus groups were conducted with mothers of infants ≤ 6 months who used an unsafe sleep position or sleep location at least twice in the past week.

Results: Twenty-five mothers (M_{age} =28.1 years; M_{baby} age =3.7 mos; 80.0% White, 12.0% Black, 8% Hispanic; 76.0% married) participated. Almost all were aware of the ABCs (Alone, Back, Crib) of safe sleep, and all had intended to follow them before their infant's birth. However, many felt that the ABCs were unrealistic and contributed to infant challenges falling and staying asleep, especially at naptimes. Mothers allowed their infant to sleep in unsafe locations and positions because they perceived them as uncomfortable on the back or on a firm surface. Mothers were more willing to use unsafe sleep practices during the day when they were awake and believed they could closely monitor their baby's sleep safety. Some questioned whether the ABCs are the only way to achieve safe sleep, and some prioritized other safety concerns, such as preventing falls, over safe sleep. Mothers expressed confidence about getting their baby to sleep in general, but were less confident that they could do this while strictly following safe sleep guidelines.

Conclusions: Despite awareness of the ABCs, mothers regularly engaged in unsafe practices to improve their baby's sleep. They found the ABCs unrealistic. Justifications for unsafe sleep practices included confidence in keeping their baby safe, especially during the day, and prioritizing other safety concerns. Interventions are needed to improve infant/caregiver sleep while maintaining sleep safety practices.

O-010 Involving families with infants at increased risk of SUDI in safer sleep research using creative methods

by Alice Keegan | Becky Ali | Jenny Ingram | Peter S Blair | Peter Fleming | Anna Pease | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK | Bristol Medical School, University of Bristol, UK

Background: Sudden Unexpected Deaths in Infancy (SUDI) cluster among the most vulnerable; most notably within families experiencing poverty, disadvantage or marginalisation. Targeting research and intervention development towards these families can reduce inequalities in infant deaths, and involving them in research development is essential to ensuring successful engagement with SUDI prevention work.

Objective: To assess the potential added value of “Photovoice”, a visual research methodology that encourages research participants to capture their individual perspectives using photographs, as a way of understanding the experiences of these families.

Methods: Eight baby groups run by Children’s Centres in Bristol were attended over 4 months (April – July 2023), input and feedback were gathered from attending families. Groups that support vulnerable families were targeted, most notably those in areas of high deprivation as well as groups for young parents. Three mothers agreed to participate in a mock Photovoice exercise and provided feedback on the process.

Results: We found that it was essential to build prior relationships, establish trust and be flexible when involving families, with the option to enforce a ‘no face’ rule in photographs to promote anonymity. Building relationships and establishing trust prior to engaging in research activities empowered families to take ownership of the Photovoice process. Flexibility was essential to involving families, the unpredictability of their baby’s routines meant that they found it difficult to attend consistent appointments.

Conclusions: Photovoice can be a useful method for engaging families with vulnerable infants, particularly with those for whom verbal or written communication may be a barrier to research participation. However, prior work needs to be done to build relationships and understand the needs of this group.

O-011 Easy to breathe - Safe to Sleep: Impact of The Pēpi-Pod® Program in reducing infant mortality in Queensland

by Professor Jeanine Young AM | Associate Professor Julie McEniery | Dr Diane Cruice | Ms Stephanie Cowan | Associate Professor John Thompson | University of the Sunshine Coast, Australia | Queensland Paediatric Quality Council, Australia | Queensland Paediatric Quality Council, Australia | Change for our Children Ltd, New Zealand | University of Auckland, New Zealand

Objective: The Pēpi-Pod® Program is a three-part program (sleep space, safe care, family as safe sleep influencers) designed for infants with vulnerabilities that increase risk of suffocation. The underpinning message is ‘Easy to breathe - Safe to sleep’. In partnership with Aboriginal and Torres Strait Islander communities and Change for our Children New Zealand the program was successfully introduced as a staged research intervention in 2012-2018 to determine cultural, community and individual acceptability, safety and feasibility in Queensland. The original study was not designed to assess mortality benefit. This study objective was to determine if Pēpi-Pod® Program implementation was temporally associated with infant mortality reduction in Queensland.

Methods: Informed by program participant data (n=617), linked population data and geographic location, research locations were stratified into three subgroups based on participation rate within postcodes and participant identification as First Nations as a proportion of the location’s Indigenous population. Infant Mortality Rate (IMR) was the primary outcome; defined as all-cause post-neonatal infant mortality between one and six months of age. Outcomes within and between research location subgroups, and whole of Queensland Study IMR before and after the research intervention, were compared.

Results: Study IMR fell in two of the three research location subgroups following program implementation. The greatest fall occurred in Subgroup 1 (75% reduction) with the highest rate of participation and participant Indigeneity (Rate Ratio 0.25, {95% Confidence Intervals 0.06,1.08}, *P*=0.08). Whole of Queensland Study IMR decreased significantly, by 22%, after the intervention (RR 0.78 {95%CI 0.65,0.92}, *P*=0.004).

Conclusion: No other systemic, targeted safe sleep interventions in Subgroup 1's population were apparent for this age group of infants during this time. The Pēpi-Pod® Program was hypothesized to be responsible for Study IMR reduction. This Program presents a practical and tangible strategy to reduce infant mortality experienced by priority populations.

O-12 A Safer Sleep Guideline informed by Risk Minimisation: Partnering with families to plan safer infant sleep environments

by Professor Jeanine Young | Dr Diane Cruice | Dr Julie McEniery | University of the Sunshine Coast | Queensland Paediatric Quality Council, Australia | Queensland Paediatric Quality Council, Australia

Objective: Approaches which promote idealistic expectations of where a baby sleeps have been demonstrated to alienate parents. Risk minimisation approaches which support 'safer sleep' in the context of unique family circumstances offer flexible, practical strategies more likely to engage families in risk reduction and infant health promoting behaviors. This presentation will introduce a Safer Infant Sleep clinical guideline co-designed with parents.

Methods: Queensland's Clinical Guidelines framework was used to design a safer sleep guideline to assist health professionals in maternal child health services to be responsive to family needs. Review of contemporary safe sleep strategies informed a structured guide that addressed safer sleep messages, communication with caregivers, airway protection mechanisms, and specific strategies to help parents plan for safer infant sleep in the context of risk. Using multiple consultation rounds with a working party (n=133 multidisciplinary, policy, consumer members) led by three co-clinical leads, the guideline was refined through a collaborative feedback process.

Results: Learnings from contemporary infant care practice studies and death reviews informed this collaborative process, including specific strategies to address common barriers. Gist messaging complements list messaging with rationales provided in simple language to assist health professionals is more effectively supporting parents in translating advice into practice. Safer sleep conversations commence during pregnancy (by 28 weeks) and continue post-birth to address infant's dynamic development. The guideline reflects a tiered approach to tailor interventions for priority families based on identified vulnerabilities designed to develop safer sleep plans for every sleep; missing in previous Australian safe sleep guidelines.

Conclusion: Many families encounter difficulties in implementing safe sleep advice; these challenges negatively impact infant care practices. The Safer Sleep guideline provides families a voice for collaborative and informed decision-making and provides professionals a tiered approach to support families whilst recognizing clinical judgement and reasoning to meet the needs of families.

SALA VERDE – PLENARY SESSION 2 – Nora Davis Epidemiology Symposium

Chairs: John Thompson - Auckland NZ & Fern Hauck - Charlottesville, Virginia USA

A brief history of the epidemiology of SIDS
John Thompson – Auckland NZ

The SAFE PREP study
Margaret Parker – Worcester, Massachusetts USA

Partnering for impact: The Journey of the Queensland Pêpi-Pod® Program
Jeanine Young – Herston, Queensland AUS

Findings from the CDC SUDI case registry
Sharyn Parks Brown – Atlanta, Georgia USA

A Novel Approach to Increasing Infant Safe Sleep Practices Through the Pediatric Emergency Department in The East Baltimore Community
Kala Frye Bourque – Washington DC USA

Summary and where to from here
Fern R. Hauck – Charlottesville, Virginia USA

This Session available Abstracts

Partnering for impact: The Journey of the Queensland Pēpi-Pod® Program.

By Professor Jeanine Young, University of the Sunshine Coast, Qld, Australia

Objective: Queensland had continued to experience a 30% higher rate of sudden unexpected death in infancy (SUDI) with Australian Indigenous babies dying at four times the rate of non-Indigenous babies. Change for our Children New Zealand and the University of the Sunshine Coast collaborated to introduce a novel portable sleep space program through partnerships with Aboriginal and Torres Strait Islander controlled and government maternal and child health service providers in 2012. This presentation will share the journey of the Pēpi-Pod® Program over the last decade highlighting the importance of co-design, partnerships, and effective messaging in reducing preventable infant mortality.

Methods: Designed for infants with vulnerabilities which increase risk of suffocation, particularly in shared sleep environments, the Pēpi-Pod® Program comprises three core elements: sleep space; safe care underpinned by 'Easy to breathe-Safe to Sleep' messaging; family as safe sleep influencers. Adapted for the Queensland context this program was introduced into communities as a research intervention (2012-2017) and subsequently as a limited ongoing program (2017-onwards). Evaluations have included acceptability, safety, feasibility (2016-2018) and impact on infant mortality (2022).

Results: Health professional and parent feedback relating to implementation supported the program as culturally appropriate, feasible, accessible and sustainable to deliver within existing maternal and child health service models, and built local workforce capacity in safe sleep health promotion [1,2,3]. An evaluation of Queensland infant mortality rates (IMR) before and after the intervention found IMR fell significantly by 22%. Comparisons within and between research location subgroups based on participation rates identified that the greatest falls (75%) occurred in regions with the highest rate of participation and participant Indigeneity [4].

Conclusion: Evidence supports the Queensland Pēpi-Pod® Program as culturally appropriate and effective, providing a 'low-cost high return' on investment, estimated to save 15 infant lives each year. A scaled state-wide approach to maintain program fidelity with an embedded evaluation has been presented to Queensland government.

Summary and Where We Go from Here

By Fern R. Hauck, MD, MS
Professor of Family Medicine and Public Health Sciences
University of Virginia, Department of Family Medicine

The four excellent presentations in the Nora Davis Epidemiology Symposium have several things in common. All focus on infants at high risk of SUDI and all present ways for us to approach prevention to lower the disparities that all countries face—be they racial/ethnic or socioeconomic. The infants at highest risk are from families that we consider the "hardest to reach." That can be due to a whole host of factors including lack of access to healthcare, lack of access to safe sleep spaces, lack of understanding of the safe sleep guidelines, health literacy, language and cultural barriers. However, it is more complex, with social determinants of health, racism, lack of trust in health professionals and campaigns likely playing an even larger role.
Campaigns and interventions that don't involve the target audience in their design and take into account these factors are likely to fail – or at least be less successful.

Many interventions are currently being implemented and evaluated in different locales and settings. These and future interventions need to take into account previous projects and the lessons learned from them—successes, failures, barriers. They need to focus on the target audience, engaging them in the design, implementation and evaluation stages, and then adjustments should be made based on these results.

Great attention should be paid to cultural backgrounds, health literacy and competing social demands that make it difficult for parents to follow the guidelines. Providing resources, beyond safe sleep spaces, to include transportation to health clinics, food, baby supplies, etc. may be needed. A combination of targeted campaigns and individual conversations between caregivers and trusted people who deliver the messages is also needed.

We must all work together to develop Innovative and creative interventions to truly eliminate SUDI and the disparities in these tragic deaths.

ROOM 4 – PARALLEL SESSION 1 – Physiology/Pathology

Chairs: Russel Scott Ray - Houston, Texas USA & Lauren Luijerink - Sydney, New South Wales AUS

O-013 Withdrawn

O-014 Sudden Unexpected Infant and Perinatal Death: Pathological Findings of the Cardiac Conduction System

Giulia Ottaviani - Milan ITA

O-015 Cerebral oxygenation during sleep in preterm infants after hospital discharge

Rosemary Horne - Melbourne AUS

O-016 Infants diagnosed as SIDS cases had higher organ weights at autopsy than non-SIDS controls in the Chicago Infant Mortality Study

Josyf Mychaleckyj - Charlottesville, Virginia USA

O-017 Upper Respiratory and Inner Ear Viral Infections in Sudden Unexplained Deaths in the Paediatric Age Group: Is there a link?

Marta Cohen – Sheffield UK

O-018 Immunological protein profile in sudden infant death syndrome (SIDS)

Linda Ferrante – Oslo NO

This Session available Abstracts

O-014 Sudden Unexpected Infant and Perinatal Death: Pathological Findings of the Cardiac Conduction System

by Giulia Ottaviani | Patrizia Leonardi | Graziella Alfonsi | Anatomic Pathology, Lino Rossi Research Center for the study and prevention of unexpected perinatal death and sudden infant death syndrome (SIDS), Department of Biomedical, Surgical and Dental Science, Università degli Studi di Mila Italy | Anatomic Pathology, Lino Rossi Research Center for the study and prevention of unexpected perinatal death and sudden infant death syndrome (SIDS), Department of Biomedical, Surgical and Dental Science, Università degli Studi di Mila Italy | Anatomic Pathology, Lino Rossi Research Center for the study and prevention of unexpected perinatal death and sudden infant death syndrome (SIDS), Department of Biomedical, Surgical and Dental Science, Università degli Studi di Mila Italy

Objective: Sudden infant death syndrome (SIDS), sudden neonatal unexpected death (SNUD), and sudden intrauterine unexpected death (SIUD) are major unsolved, shocking form of death that occur frequently and can happen at any time without warning. The body of literature on the anatomo-pathological substrates in the cardiac conduction system of SIDS-SIUD and their possible relationship with risk factors and triggers is fragmentary and scarce. The main objective of this work is to analyze the cardiac conduction system findings collected at the national referral center for SIDS-SIUD.

Methods: A total of 123 autopsied cases of SIDS (59.35% males, 40.65% females, mean age ± SD: 103.49 ± 67.17 days), 36 cases of SNUD (61.11% males, 38.89% females, mean age ± SD: 8.4 ± 9.17 days), and 127 cases of SIUD (45.67% males, 54.33% females, mean age ± SD: 36 ± 4.59 gestational weeks) were analyzed. In-depth pathological examinations of the cardiac conduction system were performed on serial sections according to the Lino Rossi Research Center's protocol.

Results: Among the studied cases, the following findings were observed:

resorptive degeneration (SIDS: 88.7%, SNUD: 88.88%, SIUD: 56.69%), fetal dispersion (SIDS: 73.17%, SNUD: 91.66%, SIUD: 78.74%), Mahaim fibers (SIDS: 40.65%, SNUD: 44.44%, SIUD: 32.28%), cartilaginous meta-hyperplasia (SIDS: 56.91%, SNUD: 25%, SIUD: 33.07%), septated atrio-ventricular junction (AVJ) (SIDS: 21.14%, SNUD: 33.33%, SIUD: 38.58%), AVJ duplicity (SIDS: 6.5%, SNUD: 11.11%, SIUD: 2.36%), intramural bifurcation (SIDS: 3.25%, SNUD: 2.77%, SIUD: 4.72%), without significant differences.

Conclusions: The prevalence of cardiac conduction findings was consistent across the SIDS, SNUD and SIUD groups. These findings provide valuable insights into the pathological characteristics of the cardiac conduction system in SIDS-SIUD that might be potential morphological substrates for the development of cardiac arrhythmias. Further investigation and study of the conduction system are needed to understand the underlying mechanisms of these forms of death.

O-015 Cerebral oxygenation during sleep in preterm infants after hospital discharge.

by Alicia Yee | Marisha Shetty | Lisa Walter | Flora Wong | Monash University, Melbourne, Australia | Monash University, Melbourne, Australia | Monash University, Melbourne, Australia | Monash University, Melbourne, Australia | Monash University, Melbourne, Australia

Background: Preterm infants are at increased risk for sudden unexpected death in infancy (SUDI) which peaks between 2-4 months of age. Preterm infants frequently experience central apnoeas which can occur in isolation or in a repetitive pattern (periodic breathing). Currently these short apnoeas are considered benign. We investigated the relationship between central apnoeas experienced before and over the 6 months after hospital discharge and cerebral oxygenation.

Methods: Preterm infants born between 28-32 weeks gestational age (GA) were studied during supine daytime sleep at 32-36 weeks post menstrual age (PMA) (n=40), 36-40 weeks PMA (n=27), 3-months corrected age (CA) (n=20) and 6-months CA (n=26). The percentage total sleep time spent having central apnoeas at each study was calculated. Cerebral tissue oxygenation (TOI), peripheral oxygenation (SpO2) and heart rate were recorded continuously. Cerebral fractional oxygen extraction (SpO2-TOI/SpO2) was calculated.

Results: %TST spent in central apnoeas decreased with increasing age in both active sleep (AS) and quiet sleep (QS). TOI was significantly lower at 3 months compared to 32-36 weeks in QS ($p<0.01$). Across all studies TOI was positively correlated ($R=0.230$, $p<0.001$) and cerebral fractional oxygen extraction negatively correlated ($R=-0.227$, $p<0.001$) with % time spent in central apnoeas. There was no correlation with SpO2.

Conclusions: Clinically stable very preterm infants continued to have central apnoeas after hospital discharge which were associated with falls in cerebral oxygenation. The nadir in TOI at 3 months of age coincides with the peak risk period for SUDI and this may contribute to increased risk in these infants.

O-016 Infants diagnosed as SIDS cases had higher organ weights at autopsy than non-SIDS controls in the Chicago Infant Mortality Study

by Josyf C. Mychaleckyj | Cornelius Normeshie | Fern R. Hauck | University of Virginia | University of Virginia | University of Virginia

Objective: There remains considerable interest in whether SIDS infants have small but detectable changes in gross anatomy, as measured by autopsy organ weight differences, compared to non-SIDS controls. These analyses are challenging and can give misleading results where confounding variables are insufficiently controlled. Our goal was to analyze data from the Chicago Infant Mortality Study to address this question.

Methods: We assessed the differences in the weight of brain, thymus, kidneys, lungs, liver, spleen, and total body weight in SIDS-diagnosed infants compared to controls. We created 4 exact matching strata (gender x race) and used coarsened exact matching to address age at death confounding within these strata by matching on post-conception age. We ran conditional Bayesian regression models for these strata with the organ/body weight as an outcome, including other confounders or mediators as non-stratified variable.

Results: After matching on gender, race, and 10-day age bins, we matched a range of n=109-131 control infants with n=204-211 SIDS cases for different organs. The mean weights (95% Highest Density Interval) of brain:+38.5g (24.5-53); thymus:+7g (4.5-9.5); lungs:+16.5g (10.5-22.5); liver:+22.5g (14-31); spleen:+3g (1.5-4); and total weight:+278g (75-469) were greater in SIDS infants than controls. These associations were relatively insensitive to size of age matching bin (in days), and were not substantively mediated by maternal smoking or drug use in pregnancy, nor by pre-term birth, suggesting that the association of SIDS with organ weight is largely independent of these factors.

Conclusions: After careful analysis we found that the mean autopsy weights of brain, thymus, lungs, liver, spleen, and total weight were greater in SIDS-diagnosed infants than controls, but not heart or kidneys. These results are consistent with other recent, well- powered studies and suggest the primary organ sites for more detailed mechanistic research into the biological dysregulation contributing to underlying pathophysiology of SIDS.

O-017 Upper Respiratory and Inner Ear Viral Infections in Sudden Unexplained Deaths in the Paediatric Age Group: Is there a link?

by Professor Marta C Cohen | Dr Erick H Yturralde | Dr Daniel Rubens | Professor Marcelo Rivolta | Dr Daniela Cacciabue | Professor Jan Marino Ramirez | Professor Peter Fleming | Sheffield Children's NHS FT, Sheffield. UK | International Fellow in Paediatric and Perinatal Pathology, Philippine General Hospital and Histopathology Department, Sheffield Children's Hospital NHS FT, Sheffield, UK | Department of Anesthesiology Swedish Hospital, Seattle Washington USA | Centre for Stem Cell Biology School of Biosciences University *of Sheffield, UK | University Teacher and Anatomy Lead for the School of Biosciences , University of Sheffield, UK | Center for Integrative Brain Research, Seattle Children's Research Institute and Department of Neurological Surgery, University of Washington School of Medicine, Seattle, USA | Centre for Academic Child Health, Bristol Medical School, University of Bristol, UK*

Objectives: The underlying mechanism of SIDS and SUDC remains uncertain. SIDS is at the intersection of exogenous stressors (including a respiratory viral infection), in a vulnerable infant going through a critical developmental period. Previously, we identified that 1 of the 4 SIDS cases and none of the controls had evidence of expansion of MALT in the inner ear, and in the lungs, suggesting a potential role of a viral infection in the interplay of the different mechanisms involved in the processes leading to SIDS.
We aim to identify and correlate viral isolates from inner and middle ear and upper airways in SIDS and SUDC cases, and the association to risk factors for SIDS.

Methods: Retrospective study of coronial autopsies conducted in Sheffield Children's Hospital in England between January 2021 - March 2023 with SIDS or SUDC as the cause of death. Patient demographics, clinical data related to known risk factors for SIDS and results of virology studies were collected.

Results: Forty-three (43) SIDS and six (6) SUDC cases were included in the study: 10/43 SIDS and 3/6 SUDC had a virus identified in the inner ears (7c Rhinovirus; 2c Parechovirus 1 case each: SARS-CoV2; seasonal coronavirus; Parainfluenza-3; and Enterovirus). Prematurity, co-sleeping, male sex, parental alcohol/smoking and drug use were the prevalent risk factors in SIDS cases. In 11 /13 cases the same/additional viruses were identified in upper airways and 9/13 cases had cold symptoms the preceding days.

Conclusion: Respiratory viruses can infect the inner ear and immunocompetent cells can mount an inflammatory response. The peripheral axons of auditory and vestibular nerve fibres connect with the cochlear nucleus of the brainstem. We hypothesize that the inflammatory process may (either directly or indirectly through cytokines and interleukins) reach the brainstem, affect the respiratory nuclei and trigger sudden death.

O-018 Immunological protein profile in sudden infant death syndrome (SIDS)

by Linda Ferrante | Siri H. Opdal | Roger W. Byard | Oslo University Hospital, Oslo, Norway | Oslo University Hospital, Oslo, Norway | Oslo University Hospital, Oslo, Norway/The University of Adelaide

Objective: The aim of this study was to investigate a panel of immune proteins in cases of sudden infant death syndrome (SIDS). Our hypothesis is that, in at least a subset of SIDS cases, a dysregulated immune response is a contributing factor leading to death.

Methods: The subjects in this study included 46 SIDS cases (median age 16.3 weeks, range 1.5-47 weeks) and 41 controls (median age 58 weeks, range 0-215 weeks), all autopsied at the Department of Forensic Sciences, Oslo University Hospital. The causes of death in the controls were accidents/trauma. Samples of cerebrospinal fluid (CSF) were analyzed quantitatively by Proximity Extension Assay (PEA) technology developed by Olink, using the Immune Response PEA panel from Olink® Proteomics.

Results: The initial results revealed that normalized protein expression differed between SIDS cases and controls for 28 of the proteins. This abstract will focus on five proteins that are involved in immune system regulation. IFNLR1 ($p=0.003$), IL10 ($p=0.007$), IRAK4 ($p<0.001$) and IL6 ($p=0.035$) all had lower protein concentrations in SIDS cases compared to controls, while for CD28 ($p=0.024$) higher protein concentrations were found in SIDS cases compared to controls.

Conclusion: The results from this study confirm previous research indicating that a dysregulation of the immune system may be a predisposing factor for SIDS. We found that the CSF concentration of several immune proteins, including IL6, IL10 and IFNLR1 (the latter being an interleukin receptor associated kinase) was significantly different in SIDS cases compared to controls. The results indicate that these aberrant protein concentrations may point to a cytokine storm and uncontrolled defense mechanisms toward the common cold or other non-fatal infections. This may be lethal if the infant at the same time is at a vulnerable developmental stage, and is exposed to external risk factors such as maternal smoking or prone sleeping.

ROOM 4 – PARALLEL SESSION 2 – Stillbirth Bereavement

Chairs: Judith Bannon - Pittsburgh, Pennsylvania USA & Alfredo Vannacci - Florence ITA

O-019 Using graphic medicine to affect change in perinatal death review processes and ensure that bereaved parents are seen and heard

Marita Hennessy - Cork IRL

O-020 “Bridging the gap” in perinatal mortality reviews: views on parents’ involvement and facilitators and barriers in a standardized review process

Sara Leitao - Cork IRL

O-021 The impact of COVID-19 pandemic on pregnant women with previous perinatal losses: health concerns and perinatal care satisfaction

Alfredo Vannacci - Florence ITA

O-022 "Developing a Picture of Us" – Photovoice study of parents' experience of high-risk pregnancy

Sara Leitao – Cork IRL

O-023 Miscommunication influence how women act when fetal movements decrease - an interview study with Swedish Somali migrant women

Anna Andrén – Stockholm SE

O-024 The CiaoLapo model of psychotherapy group for pregnancy after loss: coping with storms and embracing rainbows

Claudia Ravaldi – Florence ITA

This Session available Abstracts

O-019 Using graphic medicine to affect change in perinatal death review processes and ensure that bereaved parents are seen and heard

by Marita Hennessy | Änne Helps | Amy Lauren | Sara Leitao | Daniel Nuzum | Keelin O'Donoghue Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Cork, Ireland; INFANT Research Centre, University College Cork, Cork, Ireland | Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Cork, Ireland | Amy Lauren Illustration, Dublin, Ireland | Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Cork, Ireland; National Perinatal Epidemiology Centre, University College Cork, Cork, Ireland | Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Cork, Ireland | Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Cork, Ireland; INFANT Research Centre, University College Cork, Cork, Ireland

Objective: The death of a baby at any stage of pregnancy or shortly after birth has a devastating impact on parents, families and staff involved. Perinatal death (death in utero or after birth at 24 weeks) remains a neglected area of research and resourcing, and is steeped in stigma. Innovative ways of engaging knowledge users–including policy-makers, clinicians, and bereaved parents–are needed to promote communication around late pregnancy loss, raise awareness, change practice, and prevent future deaths where possible.

Methods: Graphic medicine–the “intersection of the medium of comics and the discourse of healthcare”–is an impactful method of sharing health-related experiences and information. There are few examples relating to pregnancy loss.

Results: In this paper we will discuss our experiences of developing a comic based on the findings of a qualitative study involving 20 bereaved parents, who shared how they could be better involved in maternity hospital perinatal death review processes. Themes reflect their journey through the different stages of the review process, and form the basis of the comic: Throughout process; On leaving the hospital; Interaction with the hospital 'waiting in limbo'; Review itself. Parents wished to provide feedback and be included in the review of their baby's death, in a way that was sensitive to their needs and the hospital's.

Conclusion: The comic – which we will showcase – reveals important, actionable insights for bereaved parents, clinicians and policymakers. We will evaluate its impact as a new method of research communication and dissemination, as well as a teaching resource and counselling aid.

O-020 "Bridging the gap" in perinatal mortality reviews: views on parents' involvement and facilitators and barriers in a standardised review process

by Sara Leitao | Emily O'Connor | Keelin O´Donoghue | Richard Greene | National Perinatal Epidemiology Centre, UCC, Ireland | INFANT Research Centre & Pregnancy Loss Research Group, University College Cork, College Road, Cork, Ireland | Pregnancy Loss Research Group, Department of Obstetrics and Gynaecology, University College Cork, Ireland | National Perinatal Epidemiology Centre, UCC, Ireland

Objective: Comprehensive review of perinatal deaths investigates the causes of perinatal mortality (PNM), identifies potentially avoidable factors and may help prevent further deaths. A standardised PNM review process in Ireland has been recommended. This study aimed to explore the experiences of maternity services staff with PNM reviews and their views on introducing a standardised review process.

Methods: Semi-structured interviews (May-December 2022) with staff from three maternity units, of various sizes, in Ireland discussed the existing perinatal mortality review process, staff experiences with reviews and proposed changes and parents' involvement. Thematic analysis was performed.

Results: Participants (N=32) included medical and midwifery staff with varying levels of seniority and experience with perinatal mortality reviews.

Leadership culture and transparency were highlighted as essential aspects of the review process. The importance of regular and appropriate communication with bereaved parents was emphasized. Participants felt strongly that parents should be more involved in the reviews: keeping parents up to date on the review progress and allowing them to provide feedback regarding their experience is essential. The need for a "point of contact" or advocacy/liaison officer and providing bereaved parents with continued support on their loss and throughout the review process that follows, was also recognized. Resistance to change and concerns on adequate parents' involvement were mentioned as barriers to a new standardised review system. Facilitators included a less time-consuming, national approach ensuring same standards are applied and with clear guidance on involving parents.

Conclusion: The importance of implementing a standardised perinatal mortality review system is broadly recognised. However, addressing the highlighted barriers to change is important. A standardised perinatal mortality review tool may help strengthen the review process, provide more information, offer an opportunity for bereaved parents' involvement and provide them with adequate supports and resources. This can improve care and help reduce future perinatal deaths.

O-021 The impact of COVID-19 pandemic on pregnant women with previous perinatal losses: health concerns and perinatal care satisfaction

by Claudia Ravaldi | Laura Mosconi | Giada Crescioli | Roberto Bonaiuti | Valdo Ricca | Alfredo Vannacci |PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | Department of Health Sciences, University of

Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy

Objective: This study explores the impact of COVID-19 pandemic on pregnant women with previous perinatal losses in Italy, where health services, including maternity ones, were significantly reorganized in 2020.

Methods: COVID-ASSESS is a web-based questionnaire comprising four sections: a) sociodemographic information and medical history, b) a survey to examine concerns about COVID-19 pandemic (health issues and future), c) women's childbirth expectations, d) women's perception of information and communication by healthcare providers during the pandemic. Data were collected during phase 1 (lockdown) and phase 2 (re-opening) of COVID-19 pandemic in Italy.

Results: 906 women (499 pregnant, 407 post-partum) out of 2448 reported a previous pregnancy loss. Women's health concerns (in particular, the elders' and baby's health) were higher during phase 1 than phase 2 ($p<0.001$). Concerns for the future didn't change during the pandemic phases. Several domains of perinatal care were affected especially during phase 1. The greatest difficulties reported were receiving clear information on hospitalization, birth plan and partner's presence at birth. These difficulties significantly improved during phase 2. Compared to women without previous losses, women with previous losses had more fear of losing their baby or having a complicated pregnancy, more lack of emotional, psychological and medical support, difficulty in coping with grief and giving meaning to their loss, more sadness, anguish, guilt, inadequacy and loneliness.

Conclusions: Maternity services during COVID-19 pandemic in Italy seemed to be fragmented. Women's concerns about health issues improved during phase 2, but not for concerns about the future. Women with previous losses had different concerns than women without previous losses, focused on having a living baby and not on pandemic.

O-022 "Developing a Picture of Us" – Photovoice study of parents' experience of high-risk pregnancy

by Sara Leitao | Indra San Lazaro | National Perinatal Epidemiology Centre, UCC, Ireland | National Perinatal Epidemiology Centre, UCC, Ireland

Objective: High-risk pregnancies are a difficult time for future parents leading to added anxiety and distress which require special care and support. These pregnancies may end in adverse outcomes or may be the result of a pregnancy after loss. This study aimed to describe parents' experiences of high-risk pregnancies, providing insights on often overlooked issues affecting them.

Methods: Qualitative study applying photovoice methodology. Women (and partners) were invited to document their experience of high-risk pregnancy with photography. Outpatient (in ante-natal clinics) and inpatient (in maternity ante-natal wards) individuals were recruited in an Irish tertiary maternity hospital. Following submission of photographs, unstructured interviews provided insight into participants images and experiences. Thematic analysis of interview transcripts was done.

Results: Eleven families contributed with photographs and reflections. Three themes and 8 sub-themes were identified: Spending time in hospital (Poor comfort/impersonal environment; Separation from home/family; Poor communication with services/staff); Managing mental wellbeing, anxiety/stress (Before birth; After birth; Dealing with previous traumatic birth experiences or adverse outcomes); Having a baby in NICU (Hopelessness and helplessness; Marking milestones). These themes and the lessons they provide are discussed further.

Conclusion: These findings provide important insight for improvement of the quality of maternity care especially for complicated pregnancies or outcomes. Interventions can improve pregnancy outcomes and the wellbeing of parents. Fostering peer-support groups and pastoral support, family centered care, family rooms, allowing greater privacy in hospital (e.g. soundproof barriers/curtains), and promoting mental health strategies can make a big difference for these families. Staff training on communication with colleagues and patients and on mental-health issues during complicated pregnancy is also invaluable. More can be done to raise awareness on the challenges faced by parents in these circumstances and to support them during this especially difficult time in their pregnancy and in the maternity services.

O-023 Miscommunication influence how women act when fetal movements decrease - an interview study with Swedish Somali migrant women

by Anna Andrén | Anna Akselsson | Ingela Rådestad | Salma Burhan Ali | Helena Lindgren | Hodan Mohamoud Osman | Kerstin Erlandsson | Department of Health Promoting Science, Sophiahemmet University, Sweden | Department of Health Promoting Science, Sophiahemmet University, Sweden | Sophiahemmet University, Sweden | Enköping Hospital, Department of Gynecology, Region Uppsala, Sweden | Department of Health Promoting Science, Sophiahemmet University, Sweden; Department of Women's and Children's Health, Karolinska Institutet, Sweden | College of Health Science and Medicine, Faculty of Nursing and Midwifery, Hargeisa University, Somaliland | School of Health and Welfare, Dalarna University, Sweden; Department of Women's and Children's Health, Karolinska Institutet, Sweden

Objective: Previous research indicates that, compared to Swedish-born women, Swedish Somali migrant women seek care for decreased fetal movement to a lower extent during pregnancy. Given their increased risks of stillbirth, more knowledge is needed about Swedish Somali migrant women's experiences of observing fetal movements and what influence their decision to seek care. Therefore, the objective of this study was to explore how women with Somali background process information about fetal movements and take actions if decreased fetal activity occurs.

Methods: Individual semi-structured interviews with Swedish Somali migrant women (n=15), pregnant in their third trimester or recently have given birth. The interviews were analysed using content analysis.

Results: Information about fetal movements was difficult to understand when not provided in first language. When not being able to understand the information, women searched for additional information on the Internet or asked their family and friends for advice. Some women lacked knowledge about why decreased movements may occur. Instead, the presence of movements was interpreted based on own explanatory models described in the generic categories: trusting life, the baby and God; patiently waiting and hoping to sense movements again; and finding explanations through own investigations and beliefs. When contacting their health care provider due to decreased movements, women were advised to drink cold water before seeking obstetric care, which further risked delaying care.

Conclusion: Miscommunication on fetal movements is an obstacle for Swedish Somali migrant women that may have impact on stillbirth prevention and the quality of care they receive. Information tailored to individual needs, starting in the women's own understanding, is essential to ensure that all women understand the information provided about fetal movements and when to seek care.

O-024 The CiaoLapo model of psychotherapy group for pregnancy after loss: coping with storms and embracing rainbows

by Claudia Ravaldi | Micaela Darsena | Claudia Piccioni | Laura Mosconi | Alfredo Vannacci | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | CiaoLapo Charity, Prato, Italy | CiaoLapo Charity, Prato, Italy | CiaoLapo Foundation for Perinatal Health, Prato, Italy, PeaRL - Perinatal Research Laboratory, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy

Objective: Pregnancies after loss are challenging: women and partners are at risk of developing mood disorder, and are more likely to struggle for perinatal attachment. Moreover, the grieving process does not stop during subsequent pregnancies and many parents report a worsening in grieving's symptoms and signs. For this reason, couples need to receive high quality support from the moment of the loss up to the first thousand days of the subsequent child. The aim of CiaoLapo's "Rainbow project" is to provide support to parents during pregnancy and after the birth, in order to improve coping strategies, reduce stress and increase responsive caregiving.

Methods: The "Rainbow project" program is composed of 12 on-line group meetings of two hours and half (3 weekly meetings, 6 meetings every two weeks and 3 every three weeks after childbirth). Psycho-education on grief and grieving, subsequent pregnancies and emotions' management, instruments like mindfulness exercises, expressive techniques and bibliotherapy with picture books are the main tools that parents learn to use. Groups are led by psychotherapists, specifically trained in perinatal psychology, perinatal loss support, psycho-traumatology and mindfulness. Every group has a minimum number of 8 and a maximum number of 16 participants.

Results: Since October 2022, 15 couples and 5 mothers have attended 3 groups. 70% suffered the loss of their first child and waited more than 12 months to conceive. As homework, parents perform mindfulness exercises, and work on intertwined emotions of grief and pregnancy through cognitive behavioral techniques and bibliotherapy: reading aloud picture books was highly appreciated and increased the amount of time bonding with the baby.

ROOM 5 – PARALLEL SESSION 1 – Workshop 1

Chair: Joanna Garstang - Birmingham UK

W-01 Child Death Review Workshop

Difficult conversations with bereaved families - an opportunity to build confidence through practicing together

Emily Cooper - Preston UK
Joanna Garstang - Birmingham UK
Nikki Speed - Leicester UK
Jennifer Ward - London UK
Jeanine Young - Herston, Queensland AUS

ROOM 5 – PARALLEL SESSION 2 – Workshop 2

Chair: Barb Himes - Indianapolis, Indiana USA

W-02 Innovative ways to reach and support bereaved families

Barb Himes - Indianapolis, Indiana USA
Rhian Mannings – Pontypridd UK
Brian Scruton – Fairfield, Connecticut USA

SIDS, SUID and other sleep-related infant deaths claim the lives of far too many babies each year, the death of an infant affects not only parents, but also grandparents, family members, friends, and others in the community. Now more than ever, families need somewhere and someone to turn to after the death of their baby. Hearing and talking to others who have experienced the painful grief of losing a baby provides comfort and hope to newly bereaved families. Finding resources and culturally appropriate support is difficult while trying to make sense of the loss, coping with birthdays, anniversaries, holidays, the thoughts of having another child and how to honor the memory of their baby at the same time, continuing to maintain daily responsibilities.

This session will address three parent experiences and how they have turned their grief into positive actions as they are helping others navigate the journey through grief. Their innovative efforts include the use of podcasts, social media, virtual and in-person groups and written mediums. Participants will understand the feelings and struggles of seeking and finding authentic support that provides healing. Bereavement resources for families and health professionals will be disseminated. Time for questions and answers will conclude this powerful presentation.

ROOM 6 – PARALLEL SESSION 1 – Bereavement SUDC/SUDI

Chairs: Keren Ludski - Melbourne AUS & Stacy Scott - Toledo, Ohio USA

O-025 What do bereaved families want from a bereavement service post-covid? What types of support are needed and when?

Jennifer Ward - London UK

O-026 Stories That Move – Telling And Reaching Out With Stories About Losing A Child

Trine Giving Kalstad - Oslo NO

O-027 Ensuring the sustainability of the Care of Next Infant (CONI) programme – learning from the COVID-19 pandemic

Stella Parkin - London UK

O-028 A website for grieving young people and their social network

Trine Giving Kalstad - Oslo NO

O-029 Am I a Criminal? A qualitative analysis of bereaved parents' experiences of the police investigation after the sudden and unexpected death of a child

Pål Kristensen - Bergen NO

O-030 Deaths in the neonatal units – A parental perspective on guidelines for professionals

Trine Giving Kalstad - Oslo NO

This Session available Abstracts

O-025 What do bereaved families want from a bereavement service post-covid? What types of support are needed and when?

by Jenny Ward | Sinead Oskan | The Lullaby Trust | The Lullaby Trust

Background: The Lullaby Trust offers confidential support to anyone affected by the sudden and unexpected death of a baby or young child, through a helpline, email, resources, Facebook group, a befriending service, and family days out. The Lullaby Trust commissioned Fiveways to conduct research to better understand the needs of bereaved families post- covid.

Methods: A short, online "list building" survey was developed. It described the aims of the research, asked profiling questions and contact details from those who wished to be involved in the research (either via an online insight community or completing the main survey).

Results: Bereaved families feel traumatised and isolated, and most (52%) want resources to use following the death. A third wanted peer support. Most (53%) wanted online groups when they need to talk, and wanted to use activity groups in the period of 'beginning to build life around loss'. Nearly half wanted family days in the period of 'moving on'.

Conclusions: Bereavement services need to be led by families, and with regular feedback to ensure continual review. Families say they welcome any support, but are also clear about what support works during which period. As their needs are multiple and changeable a variety of support options accessed in different ways, at different times according to need is ideal. Participants reported that it would be useful to be given a "road map" of their bereavement journey, i.e.

communicating to them at the start of the journey what is likely ahead, and what support would be available to them to help them navigate their way through their grief.
Fiveways supports charities to gain a deep understanding of their audiences and activities, so they can make better decisions and increase their effectiveness.

O-026 Stories That Move – Telling And Reaching Out With Stories About Losing A Child

by Trine Giving Kalstad | The Norwegian SIDS and Stillbirth Society

Background: In the Norwegian SIDS and Stillbirth Society we experience that it is supportive for the bereaved to hear about others' similar experiences of loss. It creates recognition and assurance that you are not alone. Working with your own stories also has a therapeutic effect. Therefore, we decided to invite bereaved individuals to share their stories both in written form and as part of our podcast "The Grief podcast".

Method: Twelve bereaved parents, grandparents, and one sibling have received individual guidance from an author to write their stories of coping with loss. The selected participants represent various types of losses and explore different topics of grief.

Results: All the stories are published on LUB's webpage and in our magazine in 2020-2022. In 2022 the stories were also published as a podcast to reach out to even more people and especially those who don't like read so much or they experience less capacity to read when grieving. Two of the stories are told by the storytellers themselves, while the others are read by professional actors. In most of the episodes the storytellers give their comments at the end, giving us insight into their current life a while after they wrote their story.

Conclusion: The combination of high literary quality and the strength of personal experience has been a success. The stories have reached many people and have been well- received by other bereaved. The storytellers found it both challenging and rewarding to tell their story. They express that writing their story with expert help has helped them to process the grief. It has also been a way to remember and to make the child known to the world.

O-027 Ensuring the sustainability of the Care of Next Infant (CONI) programme – learning from the COVID-19 pandemic

by Stella Parkin | The Lullaby Trust

Objective: To make The Lullaby Trust's Care of Next Infant (CONI) program, provided to bereaved families after the birth of a subsequent baby, as sustainable as possible for community public health services to deliver, following the impact of the COVID-19 pandemic on public health services in the UK.

Methods: Anecdotal feedback from the health visitors (community public health nurses), who deliver CONI locally, and feedback from bereaved parents via the parental Feedback Form were used to adapt the program initially, and then to inform decisions about what measures to keep in place.

Results: Redeployment, working from home, and social distancing measures during COVID-19 negatively impacted on the delivery of the CONI program at local level. Enrolment numbers onto CONI went from 102 in January 2020 and 143 in February 2020, to 43 in March 2020 and remained low during the pandemic. This necessitated adaptations to ensure bereaved families still received some degree of support following the birth of their new baby. It involved The Lullaby Trust's national CONI Team providing support, resources and equipment direct to families. They created a series of 'bitesize' online presentations to augment the limited health visitor support and printable pdf leaflets to replace physical leaflets. The Team also provided support and advice to health visitors, and replaced face to face training with online training.

Conclusions: The effects of the COVID-19 pandemic on community public health services is still being felt in the UK. Many of the measures that were put in place during the pandemic were found to benefit the delivery of CONI in the longer term, and so have continued. The program has become more sustainable for community public health services to continue to provide as a service for bereaved families.

O-028 A website for grieving young people and their social network

by Trine Giving Kalstad | The Norwegian SIDS and Stillbirth Society/University of Bergen, Norway

Background and objectives: Adolescents express and process grief in a variety of ways depending on their age, personality, past experience of loss, the support they may have received etc. Often they struggle in coming to terms with their grief after the death of a close person. The teenage years is an emotional time, being in the process of detaching yourself from your parents and searching not to be different from your friends. Therefore, we wanted to create a website describing young people's experiences with grief and what kind of help and support they perceive as helpful.

Method: The project team consisted of young individuals with different experiences of loss, school nurse, grief counsellors and a teacher. The website is based on interviews of adolescents, parents, healthcare personnel and friends, and literature studies.

Results: Based on research and personal experiences from grieving adolescents and professionals we provide knowledge about what is common to think, feel and do when grieving, how to support yourself and where to seek help when struggling to cope. We also have targeted information to teachers, public nurses, parents and friends to help them to understand and support young grievers. Most importantly, we share personal stories of bereaved young people loosing their brothers or sisters, parents or friends in stillbirth, SIDS, suicide, illnes, accidents etc. We use various techniques and graphic tools to make the stories expressive, delicate and easy to read. The website is worked out in collaboration with other NGO's and promoted by different organizations and official websites.

Conclusion: Through this new website we want to help young peole to navigate their grief experience, by normalizing their reactions and make them feel they are not alone. The presentation will describe the process of creating the website and demonstrate how we communicate the personal stories of the youth.

O-029 Title: Am I a Criminal? A qualitative analysis of bereaved parents' experiences of the police investigation after the sudden and unexpected death of a child

by Pål Kristensen | Anita Fjærestad | Georg Nielsen | Center for crisis psychology/University of Bergen | Center for crisis psychology/University of Bergen | Center for crisis psychology/University of Bergen

Objective. Police are regularly involved when children die suddenly and unexpectedly in their home. In Norway, a police investigation is mandatory after all sudden and unexpected deaths in children 18 years of age or younger. Still, little research exists on how the involvement of the police affects bereaved parents' coping with their loss. The aim of the study was to explore how parents react to the police investigation after the sudden and unexpected death of their child. Method. In-depth interviews were conducted on fifty-nine parents (32 mothers and 27 fathers) 5-6 weeks after the death of their child. The interviews were transcribed verbatim and analyzed according to Braun & Clark's thematic analysis.

Results. The qualitative analysis identified three main themes: police investigation as an additional strain, police investigation as a necessity, and police investigation as professional and supportive. Lack of information about the police investigation enhanced the feeling of being under suspicion of a crime. Inappropriate or insensitive attitudes were experienced by parents as an additional strain. Some parents were more indifferent to the police investigation or viewed it as a necessity in order to protect children's legal rights. Finally, some parents experienced the police presence as empathic and professional giving adequate information of the investigation. Conclusion. Police investigators do not seem fully prepared to manage the challenging task of empathically meeting bereaved parents in acute grief while performing their investigative police duties. More education about grief and bereavement and training could improve their practice.

O-030 Deaths in the neonatal units – A parental perspective on guidelines for professionals

by Janne Teigen | Line Christoffersen | Trine Giving Kalstad | Telemark Hospital Trust | Oslo Metropolitan University | The Norwegian SIDS and Stillbirth Society

Background and objectives: Psychosocial care and support when an infant dies in a neonatal intensive care unit have previously not been included in the national guidelines of the Norwegian Society of Pediatricians. Research shows that immediate care and support facilitates a healthy grieving process. When updating the guidelines in 2022, the Norwegian SIDS and Stillbirth Society was invited to write a chapter about psychosocial care for bereaved families to ensure appropriate and consistent support. The target group are doctors and nursing staff in neonatal wards.

Method: The knowledge base has been threefold:
Literature search for updated research on psychosocial care. Mapping existing local procedures or guidelines from all the 20 neonatal units in

Norway. A survey among parents who have experienced losing a child in a neonatal unit.
The project group has consisted of senior physicians, nurses, one midwife, service researcher, and a psychologist as well as four bereaved parents.

Results: This chapter provides user friendly and easily accessible advice and recommendations for inclusive care. The result is a well-structured digital text with links to webpages with more information and literature. The guideline provides benchmarks for best practice and is published on the public website for health care guidelines in Norway.
Based on advice from parents, the guidelines emphasize the importance of individualized care and distributing information to primary healthcare services to ensure follow-up when leaving the hospital. There are also links to associations offering support and help.

Conclusion: To ensure adequate and not random follow-up of bereaved families the neonatal staff needs written and user-friendly routines. By including a parental perspective, we have highlighted the importance of guidelines being based on empathy and understanding combined with clear and fact-based information.
The presentation will describe the working process and the guidelines.

ROOM 6 – PARALLEL SESSION 2 – Thematic Panel 1

Chair: Richard Goldstein – Boston, Massachusetts USA

TP-001 Genetic and phenotypic analysis of SIDS and SUDC cases

Bree Martin – Boston, Massachusetts USA
Ingrid A. Holm – Boston, Massachusetts USA
Monica Wojcik – Boston, Massachusetts USA
Sara Vargas – Boston, Massachusetts USA

The genetic analysis of SIDS and SUDC cases (referred to as SUDP) is hindered by a vague "phenotype" denoting death and the lack of a certain explanation. Review of the clinical history and autopsy material can provide further evidence for a phenotype to inform genetic analysis. We discuss our approach to case genetic analysis, and how we use phenotypes incorporating the family history and autopsy findings to provide answers to families for why their child died. We also discuss how we approach cases where there is a genetic finding without evidence for a phenotype beyond death, and cases where there are pathologic findings that suggest a potential cause in the absence of any genetic findings. This thematic panel demonstrates an integrated approach to SUDP that includes clinical, pathologic, and genetic data and highlights how interdisciplinary precision medicine methods can lead to answers in some cases.

ROOM 9 – PARALLEL SESSION 1 – Prevention

Chairs: Rebecca Carlin - New York USA & Alice-Amber Keegan - Bristol UK

O-031 The costs and benefits of incentivizing smoking cessation during pregnancy

Nicola Mcmeekin – Glasgow UK

O-032 Connecting Safe Sleep and Tobacco Cessation: A Failed Research Project with Positive Outcomes

Carolyn Ahlers Schmidt – Wichita, Kansas USA

O-033 Interviews with U.S. Mothers with Low Income to Inform a Breastfeeding Intervention

Eve Colson – St. Louis, Missouri USA

O-034 Promoting Safe Sleep Practices in Neonatal Units at Shaare Zedek Medical Center, Jerusalem, Israel

Anat Shatz – Ganey Tikva IL

O-035 Eyes on the Baby: a multi-agency approach to SUDI prevention for vulnerable families

Helen L. Ball – Durham UK

O-036 Parental Safe Sleep Perceptions and Practices Following Free Portable Crib Provision

Kourtney Bettinger – Kansas City, Kansas USA

This Session available Abstracts

O-031 The costs and benefits of incentivising smoking cessation during pregnancy

by Dr Nicola McMeekin | Dr Kathleen Boyd | Professor David Tappin | Health Economics and Health Technology Assessment, School of Health and Wellbeing, University of Glasgow | Health Economics and Health Technology Assessment, School of Health and Wellbeing, University of Glasgow | Child Health, School of Medicine, Dentistry and Nursing, University of Glasgow

Objective: Smoking during and after pregnancy increases the risk of sudden unexpected death in infancy. In 2010 the UK National Institute for Health and Care Excellence (NICE) recommended offering nicotine replacement therapy and structured support to quit during pregnancy. However, few engaged with cessation support (11%), and only 3.5% had quit four weeks later. Pregnant smokers need additional help. We conducted two trials to establish effectiveness and cost-effectiveness of offering financial incentives to pregnant smokers to quit.

Methods: The Smoking Cessation in Pregnancy Incentives Trials (CPITII & III) recruited from Scotland - CPITII and Scotland, England and Northern Ireland – CPITIII. We compared offering up to £400 financial incentives plus usual care to usual care alone to quit smoking.

Results: Both studies found that the additional offer of financial incentives resulted in better engagement and a much higher quit rate towards the end of pregnancy CPIT II - RR 2.63 (95% confidence interval 1.73 to 4.01) P<0.001; CPIT III - AOR 2.78 (1.94 to 3.97) P<0.001,a highly cost-effective intervention: CPIT II - £482($734) per Quality Adjusted Life Year (QALY) gained; CPIT III – long term UK National Health Service cost saving of £37($47) per mother/infant pair with an 0.17 increase in QALYs gained.

Conclusion: Evidence from CPITII informed 2021 UK NICE guidelines, which recommend adding financial incentives to UK pregnancy smoking cessation support. CPITIII results guided the Khan report 2023, recommending the UK government create a national funding stream to add financial incentives. This change has implications for babies' health in the UK with wider implications for policy makers in similar high-income countries.

O-032 Connecting Safe Sleep and Tobacco Cessation: A Failed Research Project with Positive Outcomes

by Carolyn R. Ahlers-Schmidt | Christy Schunn | Ashley Hervey | Maria Torres | Matthew Schrock | Lisa Frey Blume | University of Kansas School of Medicine-Wichita Center for Research for Infant Birth and Survival (CRIBS) | Kansas Infant Death and SIDS (KIDS) Network | University of Kansas School of Medicine-Wichita Center for Research for Infant Birth and Survival (CRIBS) | Kansas Infant Death and SIDS (KIDS) Network | Kansas Department of Health and Environment | Kansas Department of Health and Environment

Objective: The impact of tobacco use on poor birth outcomes, including sleep-related death is well established. If maternal smoking during pregnancy were eliminated, SIDS deaths could be reduced by a third. The Kansas Tobacco Quitline offers free cessation services, but <2% of pregnant smokers access services annually; further sleep-related deaths continue. The Quitline and KIDS Network partnered on a research project to increase use of Quitline services and offer a Safe Sleep Crib Clinic (education and crib) to perinatal Quitline users. This presentation will describe the outcomes of the research project, changes in policy, practice and partnerships following the project, and trends in tobacco use and safe sleep data over time.

Methods: Based on the Health Belief Model, a social marketing campaign recruited pregnant persons to the Quitline. The Quitline provided their standard ten counseling sessions but added a referral to the KIDS Network for a Safe Sleep Crib Clinic. Safe sleep and tobacco use intentions were assessed pre and post Crib Clinic; participants were also interviewed six weeks following their estimated delivery date.

Results: The social media campaign reach was 12,863 individuals, of whom, 369 (3%) visited the Quitline website. Of the 12 (3%) who connected with the KIDS Network, 10 (83%) participated in a Crib Clinic, 4 (40%) completed interviews. Increases in knowledge and intentions for safe sleep and tobacco cessation were observed pre to post-test.

Conclusion: COVID-19 resulted in University restrictions on research, low call volume to the Quitline, and no national Quitline promotion for pregnant participants, which impacted study outcomes. However, following the conclusion of the project, the Quitline and KIDS Network maintained their partnership, providing 10 additional Crib Clinics. The Quitline also enhanced their focus on pregnant persons and instituted financial incentives for them. Statewide PRAMS data suggests improvements in tobacco- and safe-sleep related variables.

O-033 Interviews with U.S. Mothers with Low Income to Inform a Breastfeeding Intervention

by Emma Forbes | Katherine E. Boguszewski | Fern R. Hauck | Ann Kellams | Marc T Kiviniemi | Chanel Peguero | Rachel Y Moon | Boston University School of Medicine | University of Virginia School of Medicine | University of Virginia School of Medicine | University of Virginia School of Medicine | University of Kentucky | Boston University School of Medicine | University of Virginia School of Medicine

Objective: Breastfeeding decreases the risk of post-neonatal infant death. In the U.S., the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides food and nutrition education to low-income pregnant/new mothers and infants. Although breastfeeding education and support are primary WIC tenets, WIC clients have lower rates of any and exclusive breastfeeding. We sought to understand facilitators and barriers to breastfeeding through interviews with WIC clients to directly inform the content and delivery of an intervention to increase breastfeeding rates.

Design/Methods: Using qualitative methods, we conducted in-depth, semi-structured interviews with pregnant women and women with infants <6 months old participating in WIC in Massachusetts and Virginia, U.S. Interviews focused on facilitators and barriers to starting and continuing breastfeeding, and how mothers overcome barriers. Data collection and analysis followed an iterative process using constant comparison with multiple, diverse researchers with expertise in qualitative methods.

Results: We interviewed 20 women and found factors influencing feeding choices included beliefs about logistics such as expense and time, as well as the impact on health and infant bonding. Initiation and continued breastfeeding were impacted by returning to work, support from family and friends, competing priorities, ownership of the decision, and guidance from healthcare providers. Participants were influenced by a variety of sources including family, friends, healthcare providers including WIC staff and social media. They shared ideas for addressing barriers and suggested strategies to help support breastfeeding such as being specific about the "why" behind recommendations and to make the information accessible to important others.

Conclusion(s): Participants identified facilitators and potentially modifiable barriers to breastfeeding and offered strategies for improving interventions. The information provided was incorporated into the content, design, and implementation of an intervention to improve breastfeeding rates. This study exemplifies the critical role of participants in developing interventions to change health-related behaviors.

O-034 Promoting Safe Sleep Practices in Neonatal Units at Shaare Zedek Medical Center, Jerusalem, Israel

by Anat Shatz | Gabrielle Lewis Adut | Shaaree Zedek Medical Centre Jerusalem Israel, Atid-Israeli foundation for the study and prevention of Sudden Infant Death | Shaaree Zedek Medical Centre Jerusalem Israel

Objective: To develop and implement a safe sleep program aimed at decreasing SUID rates by reducing the disturbing gap between infant sleep practices in our newborn nurseries and preferred practice as recommended by the American Academy of Pediatrics (AAP), Atid Foundation and the Israeli Ministry of Health.

Methods: A plan started in 2017 included the following steps:
Staff education: Offering guidelines for a proper safe sleep environment and stressing the lifesaving imperative.
Developing a checklist of 12 crucial parameters for staff to follow and monitor.
Mandatory completion of an e-learning program including a short video and an exam upon completion.
Parents' education by modeling, face to face training, group and individual discussions and distribution of brochures to increase awareness.
Replacing all baby blankets with sleep sacs.
Over the course of four years beginning in 2018, ten babies were randomly checked daily for compliance with the 12-parameter checklist.

Results: Weaknesses were noted and re-enforced in an ongoing staff education. The presentation will show that compliance was increased steadily over time in all measured parameters (including sleeping on back, cots meeting safety standards, firm mattress, fitted sheets, appropriate room temperature, exclusive breast feeding, pacifier use, flat sleeping surface).

Conclusion: It appears that ongoing education program in the wards contributes to successful implementation of safe sleep practices aimed at reducing the risk of SUID

O-035 Eyes on the Baby: a multi-agency approach to SUDI prevention for vulnerable families

by Professor Helen L. Ball | Durham University, UK

Objective: In the UK SUDI predominates in vulnerable families for whom universal infant sleep safety guidance is ineffective. Recent reports recommend multi-agency working (MAW) approaches. This project aimed to co-produce, pilot, implement and evaluate a MAW SUDI prevention program in County Durham with public health, safeguarding and local council leads.

Methods: We identified staff groups whose work brought them into contact with vulnerable families in County Durham. Job roles were grouped into 3 strands based on the nature and frequency of contact with vulnerable families. Training was co-produced and delivered via an online learning platform. Pre-and post-training surveys assessed staff knowledge and confidence; follow-up surveys captured staff feedback and engagement. Normalisation Process Theory (NPT) was used to support staff engagement and embed SUDI prevention into everyday practice. This initial phase of the project was evaluated using surveys, interviews, and group discussions.

Results: Staff in 47 MAW roles were invited, and 993 staff registered for training. Strand 1 staff were most likely to complete the training, whilst Strand 3 were least likely, but the greatest volume of uptake was from Stand 2. Training increased SUDI prevention knowledge and confidence in all strands. MAW staff commitment to SUDI prevention increased over time. SUDI Champions played an active role in embedding SUDI prevention into everyday practice. Key stakeholders engaged effectively in co-production, and promoted engagement in this project to their staff.

Conclusion: Multi-agency SUDI prevention targeting vulnerable families is feasible to implement with buy-in from relevant local stakeholders. Staff expressed commitment to MAW SUDI prevention beyond the end of the project which will now become part of local safeguarding training. We will expand Eyes on the Baby to other local authorities. Impact on SUDI rates will be monitored over time.

O-036 Parental Safe Sleep Perceptions and Practices Following Free Portable Crib Provision

by Kourtney Bettinger | Maheen Bangash | Danica Dodd | Carolyn Ahlers-Schmidt | Christy Schunn | Faith Butler | Ann Davis | University of Kansas School of Medicine | Mayo Clinic College of Medicine and Science | University of Kansas School of Medicine | University of Kansas School of Medicine-Wichita | Kansas Infant Death and SIDS Network | University of Kansas School of Medicine | University of Kansas School of Medicine

Objective: To investigate parental safe sleep perceptions and practices after receiving a free portable crib

Methods: Parents who received a free portable crib through our health system were invited to participate in an 11-question virtual or telephone interview regarding their safe sleep perceptions and practices. Interviews were transcribed, and the research team conducted thematic analysis. Parents were also offered the opportunity to show researchers their infant's sleep space, which was evaluated with a safe sleep checklist adapted from the American Academy of Pediatrics' safe sleep recommendations.

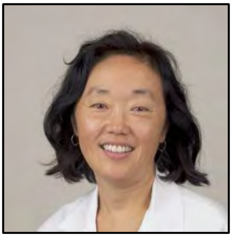
Results: Family interviews (n=11) resulted in six themes: (1) parents remembered receiving safe sleep counseling and often recalled it in detail, (2) many parents planned to have their babies sleep in bed with them prior to receiving the free crib, (3) when describing their infants' sleep practices, parents described many habits that were contrary to the safe sleep recommendations, (4) parents expressed a range of reasons for why they were not following the safe sleep recommendations, (5) parents recommended that the healthcare team continue providing free cribs and counseling all parents on safe sleep recommendations, and (6) overall parents found the free crib to be helpful and sometimes used it in combination with other sleep settings. Parents cited generational family practices, cultural differences, a desire for a softer sleep surface, and caretaker fatigue as reasons they may not adhere to safe sleep guidelines. Visual evaluation of infants' safe sleep spaces (n=5) showed most families were not implementing safe sleep recommendations as they often had blankets and other loose items in the crib.

Conclusion: For many families, the free crib provided a place for their infants to sleep, although study results revealed that few families consistently practiced safe sleep. Further investigation is needed to better overcome this disconnect between knowledge and practice.

ROOM 9 – PARALLEL SESSION 2 – International SUDI Epidemiology

Chairs: Fern Hauck – Charlottesville, Virginia USA & Anna Pease – Bristol UK

O-037 The Importance of Neighborhood Resources for Breastfeeding
Rachel Y Moon – Charlottesville, Virginia USA



O-038 Withdrawn

O-039 Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry: A Model for the Surveillance of Unexpected Infant and Child Deaths
Carri Cottengim – Atlanta, Georgia USA

O-040 Housing Instability among Sudden Unexpected Infant Deaths (SUID) in the SUID and Sudden Death in the Young Case Registry, 2010–2020
Alexa Erck Lambert – New Orleans, Louisiana USA

O-041 Association between the Covid-19 Pandemic and Sudden Infant Deaths: a Study in Colombia

María Luisa Latorre - Bogotà COL

O-042 Sudden Unexpected Infant Death in a Rural Hispanic Population: a Case-Control Study

Zachary Kuhlmann – Kansas City, Kansas USA

This Session available Abstracts

O-037 The Importance of Neighborhood Resources for Breastfeeding

by Rachel Y Moon | Fern R Hauck | Eve Colson | Ann Kellams | Jennifer LoCasale-Crouch | Margaret Wallace | Timothy Heeren | Stephen Kerr | Y. Sophie Yue | G. Deeken | Khara LP Turnbull | Brianna Jaworski | Deiby M Cubides Mateu | Michael J Corwin | University of Virginia School of Medicine | University of Virginia School of Medicine | Washington University in St Louis School of Medicine | University of Virginia School of Medicine | School of Education, Virginia Commonwealth University | School of Education, Virginia Commonwealth University | Boston University | Boston University | School of Education and Human Development, University of Virginia | School of Education and Human Development, University of Virginia | School of Education and Human Development, University of Virginia | School of Education and Human Development, University of Virginia | School of Education and Human Development, University of Virginia | Boston University

Introduction: Breastfeeding protects against SUID. Parental characteristics (e.g., education, race/ethnicity) are associated with breastfeeding initiation and duration. It is unclear how neighborhood resources may impact feeding practices. We aimed to explore the association of neighborhood resources with breastfeeding, and whether this varies based on maternal race/ethnicity and country of birth.

Methods: We analyzed data from the Study of Attitudes and Factors Effecting Infant Care, which surveyed a nationally representative sample of US mothers immediately after birth and at 2-6 months of age, and the Child Opportunity Index (COI) 2.0, a census-tract measure of neighborhood resources (e.g., access/quality of early childhood education, green space). The COI 2.0 tracts are nationally normed and categorized from 1 (very low) to 5 (very high) resourced neighborhoods.

Results: Of 2727 mothers, 59% engaged in any breastfeeding and 28% in exclusive breastfeeding at 2-6 months. Sample distribution across neighborhood resource categories was: very low/low (59%), moderate

(16%), and high/very high (25%). Those living in higher COI neighborhoods were more likely to be >25 years old, white, college educated or higher, and employed. After accounting for individual characteristics, mothers residing in the highest resourced neighborhoods (compared to the lowest) had significantly greater likelihood of any (aOR 1.58 [95% CI 1.08-2.31]) and exclusive (aOR 1.54 [95% CI 1.12-2.10]) breastfeeding. While access to higher resourced neighborhoods differed by race/ethnicity, this did not moderate the association between COI and breastfeeding. Although COI was not related to non-US- born Black and Hispanic mothers' breastfeeding rates, it was with US-born Black and Hispanic mothers.

Conclusion: Health practices often associated with individual choice, such as breastfeeding, are influenced by the extent of resources available within the community within which they occur. Understanding how neighborhood resources influence health practices such as breastfeeding requires examination of contextual and other factors.

O-039 Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry: A Model for the Surveillance of Unexpected Infant and Child Deaths

by Carri Cottengim | Alexa Erck Lambert | Sharyn Parks | Abby Collier | CDC | CDC | CDC | MPHI

Objective: To describe the structure and impact of the United States (US) Centers for Disease Control and Prevention’s Sudden Unexpected Infant Death (SUID) and Sudden Death in the Young (SDY) Case Registry (Registry), a successful surveillance program to inform prevention.

Methods: The Registry is a multi-jurisdictional, population-based surveillance and prevention system employing case inclusion criteria and relying on multi-disciplinary child death review teams to examine each case and enter data into the National Fatality Review Case Reporting System, including medical history, demographic characteristics, death investigation findings, cause of death, caregiver and supervisor information, sleep environment, and prevention recommendations. Review teams also classify cases using Registry algorithms to understand the role of environmental and medical factors in each case. Information about policy and practice changes implemented locally or statewide based on Registry data is also compiled.

Results: The Registry has monitored US SUID cases since 2010 and SDY cases since 2015. It has grown from 5 to 22 awardee sites which include both states and individual counties) and contains 10,609 unexpected infant and child deaths that occurred between 2010–2022. Registry data contribute to the peer-reviewed scientific literature on SUID and SDY, inform refinement of national guidance on safe infant sleep practices, improve understanding about death investigations, and inform data-driven prevention efforts at the local and state level. States also use Registry data to inform changes to jurisdictional policies and practices related to death investigations, safe infant sleep, and systems that engage with families.

Conclusion: The Registry demonstrates a successful SUID and SDY surveillance model, serving as a valuable tool in understanding infant and child death investigation and for developing and implementing prevention strategies. Examples of prevention strategies and practice changes for coroners/medical examiners, child protective services, law enforcement, health care providers, and health offices will be provided.

O-040 Housing Instability among Sudden Unexpected Infant Deaths (SUID) in the SUID and Sudden Death in the Young Case Registry, 2010–2020

by Alexa Erck Lambert | Sharyn Parks | Carri Cottengim | Tiffany Colarusso | Yousra Mohamoud | Carrie Shapiro-Mendoza | Abby Collier | Centers for Disease Control and Prevention, Division of Reproductive Health

Objective: Describe housing instability among sudden unexpected infant deaths (SUID).

Methods: We examined data from the US Centers for Disease Control and Prevention's SUID and Sudden Death in the Young (SDY) Case Registry (Registry), a multi-jurisdictional, population-based surveillance system. We included SUID (<1 year old) that occurred during 2010–2020 among residents of participating states/jurisdictions with a cause of death as: unknown, undetermined, SIDS, SUID, unintentional sleep-related asphyxia/suffocation/strangulation, unspecified suffocation, cardiac or respiratory arrest without other well-defined causes, or ill-defined causes with potentially contributing unsafe sleep factors.

Housing instability was defined by three variables and qualitative review of narratives. Housing instability was affirmative when residence indicated foster/group home, shelter or homeless; or child ever homeless; or child experienced housing instability (i.e., inability to pay rent/mortgage, overcrowding, moving frequently, eviction, staying with relatives/friends, spending the bulk of income on housing); or qualitative review identified these terms describing prenatal or recent family housing instability: “evict/eviction”, “homeless/homelessness”, “shelter”, “housing instability”, “unstable housing”, and “kicked out”. Homelessness was affirmative when residence indicated shelter/homeless; or child ever homeless; or qualitative review identified “homeless/homeliness”. “Crib lost during eviction” and “death within 24 hours of eviction” were quantified through qualitative review. Proportions of housing instability and additional variables described above were calculated.

Results: Among 8,652 SUID, 6.5% infants experienced housing instability, of whom, about half experienced homelessness. Thirty-six (<1%) infants experienced eviction. Fewer than six deaths (number suppressed for confidentiality) occurred in families who lost an infant crib due to eviction; <6 occurred within 24 hours of eviction.

Conclusion: About 1/15 SUID experienced housing instability.

Understanding infants housing instability experiences may inform strategies to support families in providing safe infant sleeping environments.

O-041 Association between the Covid-19 Pandemic and Sudden Infant Deaths: A Study in Colombia

by María Luisa Latorre, Sandra Moreno | Fundación Universitaria Juan N Corpas

Objective: This study aimed to investigate the potential association between the Covid-19 pandemic and Sudden Infant Deaths (SIDs) in Colombia during 2020, along with possible explanations.

Methodology: A retrospective analysis of vital statistics databases was conducted to compare SIDS mortality rates before, during, and after the Covid-19 pandemic in Colombia. The study utilized International Classification of Diseases (ICD-10) codes for the years 2017 to 2021, based on previous research in Colombia.

Results: The study identified 792 deaths potentially associated with SIDS between 2017 and 2021 in Colombia. In 2020, there was a decrease in both the number of SIDS cases (135) and the rate per 1,000 live births (0.21). This represented the lowest rate observed between 1998 (cases = 302, rate = 0.42) and 2021 (cases = 146, rate = 0.24). The percentage of cases with available information on affiliation regime did not show a significant difference between 2017 and 2021. However, the Subsidized Regime, which covers approximately half of the Colombian population living in poverty, consistently exhibited higher rates. No significant differences were found by gender or age. Notably, there was a decrease in SIDS cases during the months of April, May, and June 2020, corresponding to the period of strict quarantine measures in Colombia.

Conclusions: The findings suggest that during the Covid-19 pandemic in Colombia, there was a decline in both total births and infant mortality, reflected in decreased rates of infant mortality for all causes and SIDS. It is possible that the implementation of quarantine measures influenced the reduction in cases of Acute Respiratory Infection and other viral infant diseases. Preliminary data for 2022 indicate a resurgence in the Infant Mortality Rate for all causes in Colombia, reaching levels similar to those observed in 2019.

O-042 Sudden Unexpected Infant Death in a Rural Hispanic Population: A Case-Control Study

by Zachary Kuhlmann | Hayrettin Okut | Lisette Jacobson | Ashley Hervey | Christy Schunn | Maria Torres | Carolyn R. Ahlers-Schmidt | University of Kansas School of Medicine-Wichita Department of Obstetrics and Gynecology | University of Kansas School of Medicine-Wichita Office of Research | University of Kansas School of Medicine-Wichita Department of Population Health | University of Kansas School of Medicine-Wichita Center for Research for Infant Birth and Survival (CRIBS) | Kansas Infant Death and SIDS (KIDS) Network | Kansas Infant Death and SIDS (KIDS) Network | University of Kansas School of Medicine-Wichita Center for Research for Infant Birth and Survival (CRIBS)

Objective: Sudden unexpected infant death (SUID) is the leading cause of death among US infants aged 28 days to 1 year. Between 2005 and 2018 the Kansas Hispanic SUID rate did not change, in contrast to the rates for non-Hispanic Black and White infants which decreased. This study sought to identify characteristics and behaviors of Hispanic women/birthing persons (WBP) related to SUID.

Methods: Linked Kansas birth/death vital statistics data (2005-2018) were used to identify Hispanic WBP with a singleton birth who experienced SUID. To reduce confounding effects, greedy nearest neighbor matching paired each WBP sequentially with the 8 nearest controls based on age, race, payor source and parity. Matching procedures, likelihood-ratio $\chi 2$, Fisher exact test and multiple logistic regression model with Firth's penalized maximum likelihood estimation were computed.

Results: Of 86,792 Hispanic singleton births, 475 involved SUID and were matched with 3,800 controls. No differences were related to marital status, population density of residence, Women Infants and Children program enrollment or language spoken (all p>0.05). SUID was related to lower education and prenatal BMI categorized as obese (all p<0.05), however, multivariable models revealed poor predictive accuracy, with area under the ROC curve=0.574 (95% CI 0.55-0.60). For maternal behaviors, SUID was related to tobacco use during pregnancy, adequate-plus prenatal care, less-than-recommended pregnancy weight gain, not initiating breastfeeding and declining to participate in the state immunization registry (all p<0.05). Behavioral multivariable models revealed better, but still inadequate predictive accuracy with area under the ROC curve=0.682 (95% CI 0.64-0.72).

Conclusion: SUID deaths to Hispanic families are likely multifaceted. Study results can inform education on risk reduction strategies, such as addressing tobacco cessation and breastfeeding initiation. Further research on pre-pregnancy maternal health may also provide insight.

SALA VERDE – PLENARY SESSION 3 – Stillbirth Epidemiology and Prevention

Chairs: Keelin O'Donoghue – Cork IR & Rachel Y Moon – Charlottesville, Virginia USA

Ciao Lapo's epidemiological studies in Italy

Alfredo Vannacci – Florence ITA

Improved estimation of the relationship between birthweight and stillbirth risk using nonlinear modeling

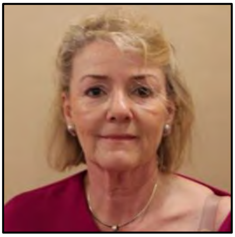
Darren Tanner – Redmond, Washington USA

SALA VERDE – PARALLEL SESSION 3 – Stillbirth Epidemiology

Chairs: John Thompson – Auckland NZ & Sharyn Parks Brown – Atlanta, Georgia USA

O-043 Fetal Growth Restriction and stillbirths in Ireland 2016-2020

Edel Manning – Cork IR



O-044 Association of perinatal mortality with the place of birth in Pakistan: an analysis of Pakistan Demographic and Health Survey 2018

Jamil Ahmed – Manama BHR

O-045 A 6-year, Italian single-institution retrospective study of chromosomal microarray analysis in stillbirths

Edoardo Errichiello – Pavia ITA

O-046 Withdrawn

O-047 Association of Air pollution and Excess Heat with Stillbirth

Marie A Cabiya – Downers Grove, Illinois USA

O-048 Risk of stillbirth in second singleton births by gestational age in first: a population-based cohort study

Yeneabeba Tilahun Sima – Bergen NO

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O-043 Fetal Growth Restriction and stillbirths in Ireland 2016-2020

by Edel Manning | National Perinatal Epidemiology Centre

Objectives: Unlike other developed countries, the rate of stillbirths (SB) in Ireland has remained flat for a number of years. Fetal Growth Restriction (FGR), a common complication of pregnancy, is associated with increased perinatal morbidity and mortality. We aimed to estimate the incidence of FGR among SB nationally and antenatal detection rates.

Methods: We established a national clinical audit and all 19 Irish maternity units have provided anonymised data on perinatal deaths using a validated dataset since 2011. Reportable SB were defined as occurring from 24 weeks gestation or with a birthweight of ≥ 500 grammes. Customised birthweight centiles were calculated for all perinatal deaths using the Gestational Related Optimal Weight (GROW) software.

Results: For the years 2016 - 2020, 1,762 perinatal deaths were reported. SB accounted for 1,184 (67.2%) of all perinatal deaths giving a SB rate of 3.89 per 1,000 births. An increased SB rate was noted in 2020 compared to 2018 (Rate Ratio 1.19). The most common causes of SB were major congenital anomaly (30.6 %) and placental disease (29.5%). Low birthweight was common. Almost one quarter (23.1 %) of SB were below the 3rd customised birthweight centile and nearly half were below the 10th customised birthweight centile (44.0%). Birthweight centiles were significantly lower in SB attributed to major congenital anomaly (MCA); 55.0% were < 3rd centile in SB with a MCA versus 33.7% without a MCA. There was no antenatal diagnosis of FGR in 67.0% of SBs with a birthweight < 3rd centile and this reached 75.0% in 2020.

Conclusions: FGR is highly prevalent in cases of stillbirths in Ireland and for the majority it was not diagnosed antenatally. A care pathway including staff education around risk assessment and surveillance for FGR should be developed using a standard national approach. The use of customised centile growth charts should be considered.

O-044 Association of perinatal mortality with the place of birth in Pakistan: an analysis of Pakistan Demographic and Health Survey 2018

by Jamil Ahmed | Aravind Kumar | Department of Family and Community Medicine, College of Medicine and Medical Sciences, Arabian Gulf University, Bahrain | King Hamad University hospital, Bahrain

Introduction: In Pakistan, too, like other healthcare services, the majority of birth care is provided by private care providers, with about a third of births still occurring in homes. Births in health units with inadequate facilities can increase the risk of perinatal mortality. This study analysed the Pakistan Demographic and Health Survey of 2018 to determine how perinatal mortality is associated with place of birth in Pakistan.

Methods: The analyses are based on the Pakistan Demographic and Health Survey 2017–18 data sets, using STATA version 15, after adjusting for cluster sampling effects. Univariate and bivariate analyses between stillbirths and early neonatal deaths were conducted with independent variables of places of birth and other individual covariates. Multivariate logistic regression models were used to measure the independent effect of variables on the two perinatal mortality outcomes.

Results: According to the survey analysis, during 2017 and 2018, 45% and 25% of births occurred, respectively, at private and public health facilities, while 30% still occurred in homes. Stillbirth rate was 19.1% urban and 25.3% in rural women. The early neonatal mortality rate was 30.7% in urban and 34.6 percent in rural women. The perinatal mortality rate in births in homes, public, and private health facilities, respectively, was 45, 53.1, and 56 per 1000 births.

Conclusion: Pakistan continues to have an extremely high perinatal mortality rate. Private health facilities shared the highest proportion of perinatal mortality; however, it was also high in home births and births occurring in public health facilities. To tackle perinatal mortality in Pakistan, we recommend the provinces must devise a strategy to ensure that private birth providers follow safe birth practices; the women giving birth in their homes need to attend high-quality healthcare units in their catchment areas for births; and the quality of care needs to improve in public health facilities.

O-045 A 6-year, Italian single-institution retrospective study of chromosomal microarray analysis in stillbirths

by Edoardo Errichiello | Giulia Scianaro | Marta Di Biagio | Elena Rossi | Unit of Medical Genetics, Department of Molecular Medicine, University of Pavia, Pavia, Italy; Laboratory of Cytogenomics, IRCCS Mondino Foundation, Pavia, Italy | Laboratory of Cytogenomics, IRCCS Mondino Foundation, Pavia, Italy | Laboratory of Cytogenomics, IRCCS Mondino Foundation, Pavia, Italy | Unit of Medical Genetics, Department of Molecular Medicine, University of Pavia, Pavia, Italy; Laboratory of Cytogenomics, IRCCS Mondino Foundation, Pavia, Italy

Objective: Global stillbirth (SB) rate is estimated 13.9 per 1,000 total births (2.2/1,000 in Italy) and WHO's Every Newborn Action Plan endorses worldwide reduction by 2030. Canonical SB work-up includes fetal autopsy, placental histology, and maternal evaluation. Despite such investigations, a large proportion of cases (up to 60%) remain unexplained. Data regarding the contribution of genetic factors to SB are extremely limited and, according to available literature data, chromosomal anomalies are identifiable by conventional and molecular cytogenetic techniques (karyotyping and array-CGH) in 8-13% cases.

Methods: In the last 6 years (January 2017- December 2022), we extrapolated a cohort of 46 SBs referred to our hospital in which conventional karyotype was negative or failed due to poor cell growth or microbial contamination. On such cases the incremental yield of chromosomal microarray (CMA), consisting of array-CGH or SNP-array, was evaluated.

Results: Mean maternal age was 35.98 (range: 22-44 years), whereas mean week of gestation was 32.57 (range: 22.7-40.7 weeks). Maternal risk factors were identified in 11 out of 46 cases (23.9%): diabetes mellitus (n=4), chronic hypertension (n=2), thyroid dysfunction (n=2), infection (n=2), and venous thromboembolism (n=1). In other 2 cases (4.3%) placental anomalies were recognized. CMA detected chromosomal anomalies in three fetuses. In two cases with failed conventional karyotype, CMA detected two aneuploidies (one trisomy 18 and one trisomy 21), whereas in one case with negative karyotyping test, CMA identified a 655-Kb duplication involving two glycogenes on chromosome 1p31.1 (ST6GALNAC3 and ST6GALNAC5), classified as variant of uncertain significance according to ACMG/ClinGen guidelines.

Conclusion: Detection rate of CMA in our SB cohort was comparable to previous data (8.6% excluding fetuses with other recognizable causes of SB). Our findings support the incorporation of CMA into the routine SB work-up, improving both the test success rate and overcoming some technical challenges of conventional karyotyping.

O-047 Association of Air pollution and Excess Heat with Stillbirth

by Marie A Cabiya | Advocate Aurora Health

Objective: to discuss the effects of environmental exposures (extreme heat and air pollution) on adverse pregnancy outcomes, focusing on stillbirth.

Methods: A PubMed search starting in 2016 was performed to identify articles on stillbirth and environmental exposures such as extreme heat and air pollution.

Results: Although there are limitations to the data due to variable methodology, there is evidence of the association between air pollution and extreme heat on adverse pregnancy outcomes including stillbirth. Both air pollution and extreme heat affect disadvantaged individuals most acutely and worsen health disparities. Among the findings, a U.S. based systematic review showed that 4/5 studies on stillbirth found an association with air pollution

exposure and revealed a 42% increased risk with third trimester exposure to high levels of pollution. The same review found that stillbirth risk increased 6% per 1 °C increase the week before delivery during the warm season.
Beyond literature search results, I share practical ways of counseling pregnant people to minimize environmental exposures during pregnancy.

Conclusion: The adverse effects of air pollution and extreme heat in pregnancy include stillbirth, preterm birth, congenital birth defects, and small for gestational age. There are opportunities for the health community to mitigate these risks at a system and an individual level. Because these health outcomes affect disadvantaged communities first and worst, acting to decrease these exposures is a way to decrease birth inequities.
At a systems level, providers need to advocate for policies that reduce air pollution and decrease carbon emissions. Public health advisories need to target pregnant at times of extreme heat and air pollution events. On an individual level, pregnant people should be informed on how to take personal action to mitigate the obstetric risks of extreme heat and air pollution.

O-048 Risk of stillbirth in second singleton births by gestational age in first: a population-based cohort study

by Yeneabeba Tilahun Sima | Rolv Skjærven | Liv Grimstvedt Kvalvik | Kari Klungsøyr | Linn Marie Sørbye | Nils-Halvdan Morken | University of Bergen, Norway | University of Bergen, Norway | University of Bergen, Norway | University of Bergen and Norwegian Institute of Public Health, Bergen, Norway | University of Bergen and Western Norway University of Applied Sciences, Bergen, Norway | University of Bergen, Norway

Objective: To assess subsequent risk of stillbirth in second pregnancy by gestational age of the first pregnancy and further to examine the impact of obstetric interventions on this association.

Methods: This study used linked data from 274,615 women with first and second singleton births, registered in the Medical Birth Registry of Norway between 1999-2020. Perinatal losses in first pregnancies were excluded. The proportion of stillbirth in second singleton births were described by time periods; 1999-2009 and 2010-2020. Multivariable regression models were used to calculate relative risk (RR) with 95% confidence intervals (CI) of stillbirth by gestational age of first pregnancy (gestational weeks: 20-34, 35-36, 37-38, 39-41 (reference) and ≥ 42+) and adjusted for maternal age, education, and smoking. Additionally, we examined whether these findings differed among women with spontaneous- and iatrogenic (either induced labor or pre-labor caesarean delivery) first deliveries.

Results: Proportions of stillbirth in second pregnancy was 0.30% (373/122870) and 0.28% (425/151745) in 1999-2009 and 2010-2020, respectively. Women who delivered their first baby between 20-34 weeks had a higher risk of subsequent stillbirth compared to those who delivered a first baby at 39-41 weeks. Among women whose first birth occurred at 35-36 weeks, the increased risk of stillbirth was observed only in those who had iatrogenic first births (3.21, 95% 2.05-5.03), while no increased risk was found for those with spontaneous first births (0.77, 95% CI 0.41-1.43).

Conclusions: The overall rate of stillbirth following a first singleton birth surviving the perinatal period remained stable during the study period. Women who delivered their first baby before 37 weeks had higher risk of experiencing stillbirth in a subsequent pregnancy except women with spontaneous labor at 35-36 weeks, where the risk of stillbirth was not increased.

SALA VERDE – PLENARY SESSION 4 – Pathophysiology

Chairs: Robin L. Haynes – Boston, Massachusetts USA & Savannah Lusk – Houston, Texas USA

An overview of what is hot and what is not in pathophysiology of SIDS
Rita Machaalani – Sydney, New South Wales AUS

What can genetics add to the conversation?
Rick Goldstein – Boston, Massachusetts USA

SUDEP and SUDI: shared mechanism of overlapping identity?
George Richerson – Iowa City, Iowa USA

This Session available Abstracts

An overview of what is hot and what is not in athophysiology of SIDS

Rita Machaalani

The hypotheses that have guided pathology and physiology research into SIDS have evolved with result outcomes. This talk will address the main hypotheses that have been under investigation, and summarise the data pertaining to each, identifying the findings that were found to be non-differential and/or of question in the pathophysiology of SIDS, vs those that are 'hot', being reproducible and of merit, thus worthy of further investigation.

What can genetics add to the conversation?

Richard Goldstein

In this presentation, we will look at the major genetic studies in SIDS and other sudden unexpected deaths in the pediatric age range. We will consider the implications of this evidence on our understanding of biological vulnerabilities and on the current mortality plateau. What are the terms of this changing conversation?

SUDEP and SUDI: Shared mechanisms or overlapping identity?

George Richerson

This presentation will discuss data on the mechanisms involved in sudden unexpected death in epilepsy (SUDEP) and the striking similarities with those hypothesized to occur in SUDI. The shared characteristics take on new significance with emerging data indicating that some cases of SUDP have mutations in genes (e.g. SCN1A and DEPDC5) that cause epilepsy and carry a high risk for SUDEP, and have been found to have hippocampal neuropathology seen in epilepsy patients. The real possibility exists that some cases of SUDI/SUDP are actually SUDEP in individuals with undiagnosed epilepsy.

SALA VERDE – PLENARY SESSION 5 – SUDI Physiology

Chairs: Niccolò Nassi – Florence ITA & Robert Darnall – Hanover, New Hampshire USA

The biomechanics of inclined sleep

Erin M. Mannen – Boise, Idaho USA

The physiology underpinning the risk and protective factors for SUDI

Rosemary Horne – Melbourne AUS

Advances in animal models for SUDI research

Russell Scott Ray – Houston, Texas USA

This Session available Abstracts

The biomechanics of safe sleep

Erin Mannen

Here is a brief abstract. I can make it longer if needed:
Biomechanics, the study of movement and mechanics applied to the human body, has been an established field for over 50 years, yet application of biomechanics into safe sleep for infants is a relatively new concept. Understanding how baby product design features and differing mechanical environments influence an infant's body position, muscle activity, and movement can elucidate safety concerns and help explain sleep-related hazards.

The physiology underpinning the risk and protective factors for SUDI

Rosemary Horne – Melbourne AUS

Background: Sudden Unexpected Death in Infancy (SUDI) is believed to be multifactorial in origin. The Triple Risk hypothesis has been proposed to explain this. The model proposes that when a vulnerable infant, such as one born preterm or exposed to maternal smoking, is at a critical but unstable developmental period in homeostatic control (the highest risk period is at ages 2 to 4 months, with 90% of deaths occurring before age 6 months) and is exposed to an exogenous stressor, such as being placed prone for sleep, then death may occur. The model further proposes that infants will die only if all three factors are present, and that the vulnerability lies dormant until the infant enters the critical developmental period and is exposed to an exogenous stressor. The final pathway to SUDI is widely believed to involve some combination of immature cardiorespiratory control and a failure of arousal from sleep.

Methods: Longitudinal physiological studies during sleep can provide important insights into how the risk factors SUDI make an infant more vulnerable by dampening arousal responses and cardiorespiratory control.

Results: These studies have identified that prone sleeping and maternal smoking depress arousal from sleep responses and this is greatest at 2-3 months of age, coinciding with the peak risk period for SUDI. Prone sleeping results in lower blood pressure, cerebral oxygenation and dampened cardiovascular control, and this dampening is also most marked at 2-3 months.

Conclusions: For parents and health professionals to follow safe sleeping advice they need to understand the mechanisms which may increase the risk of death when the advice is not followed. By providing sound physiological evidence for why the safe sleeping recommendations are made we can inform parents and health professionals to help prevent SUDI.

SALA VERDE – PARALLEL SESSION 4 – Thematic Panel 2

Chair: Christy S. Schunn – North Newton, Kansan USA

TP-002 Increasing Safe Sleep Education through Certified Safe Sleep Instructors

Brenda Davis – Wichita, Kansas USA
Stephanie Kuhlmann – Kansas City, Missouri USA
Brenda Salinas – Wichita, Kansas USA
Christy S. Schunn – Wichita, Kansas USA
Maria Torres – Wichita, Kansas USA

Increasing Safe Sleep Education through Certified Safe Sleep Instructors

by Christy S. Schunn, LSCSW | Stephanie Kuhlmann, DO | Ashley M. Hervey, MEd | Maria Torres, BS |Zachary Kuhlmann, DO | Carolyn R. Ahlers-Schmidt, PhD | Brenda Salinas | Daniele Lasseter | Brenda Davis, MSN | Kansas Infant Death and SIDS Network, Inc. | University of Kansas Department of Pediatrics | University of Kansas Department of Pediatrics | Kansas Infant Death and SIDS Network, Inc. | University of Kansas Department of Obstetrics and Gynecology | University of Kansas Department ofPediatrics | Kansas Infant Death and SIDS Network, Inc. | Kansas Department of Children and Families | Wichita Black Nurses Association

The KIDS Network Safe Sleep Instructor (SSI) Certification Project was created to reduce sleep-related infant deaths. The objective is to enhance safe sleep promotion by building capacity to disseminate education strategically to priority audiences, including families, communities, and professionals (e.g., hospitals, maternal/infant clinics). Our central hypothesis is that culturally sensitive education, coupled with easy implementation strategies, can build on the communities' current work to significantly increase the number of parents/caregivers using safe sleep practices.

The SSI Certification Project builds community infrastructure to promote consistent infant safe sleep messages. This in turn, facilitates a safe sleep culture to reduce sleep-related deaths. Instructors attend a 2-day training designed to build the skills necessary to implement established, evidence-supported safe sleep programs. This train-the-trainer model provides the foundation for sustainability and expansion of the Kansas safe sleep campaign and created the vehicle for delivery of the KIDS Network Safe Sleep Community Baby Shower model.

SALA VERDE – PARALLEL SESSION 4 – Thematic Panel 3

Chair: Judith Bannon – Pittsburgh, Pennsylvania USA

TP-003 Cribs for Kids: Changing the Culture of Infant Safe Sleep through Education, Outreach, Products, and Programming

Judith Bannon – Pittsburgh, Pennsylvania USA

Hosted by Cribs for Kids Founder/CEO Judy Bannon and three of the agency's leadership team, the thematic panel will discuss its 25-year evolution and strategic growth from a local non-profit to a nationwide collaborative entity. Founded to provide safe sleep education and safe sleep spaces for at-risk families, Cribs for Kids continues to lead the way, offering nocost community programming, creating accessible safe sleep education, developing safe sleep products, and expanding its presence online as it works to change the culture surrounding infant safe sleep. In addition, the panel will include a focused discussion on its National Infant Safe Sleep Hospital Certification program, featuring its collaboration with Dr. Anat Shatz. The panel will demonstrate how other countries can adopt Cribs for Kids programming to promote infant safe sleep.

ROOM 4 – PARALLEL SESSION 3 – Bereavement SUDI

Chairs: Jennifer Ward - London UK & Barb Himes - Indianapolis, Indiana USA

O-049 The importance of immediate support for sudden and unexpected death in children and young people

Rhian Mannings - Pontypridd UK

O-050 How do newly bereaved parents experience a doll re-enactment shortly after the sudden, unexpected death of their child? A mixed-methods study

Pål Kristensen – Bergen NO

O-051 Sudden Unexplained Death in Childhood (SUDC): Identifying Effective Multi-Agency Approaches for Bereaved Families

Emily Cooper – Preston UK

O-052 Parental guilt and self-blame after infant death, learning from the Folbigg Inquiry

Joanna Garstang – Birmingham UK

O-053 Improving the supports available for healthcare professionals experiencing professional grief and loss in response to neonatal death within the context of a neonatal intensive care unit in a tertiary maternity hospital

Julianna Crowley – Cork IL

O-054 Experiences of Norwegian families attending to online courses of therapeutic writing after the death of a child

Trine Giving Kalstad – Oslo NO
Olga Lehmann – Stavanger NO

O-049 The importance of immediate support for sudden and unexpected death in children and young people

by Rhian Mannings | 2wish

Objective: To ensure anyone affected by the sudden and unexpected death of a child or young person aged 25 and under is supported immediately, and in the longer term.

Method: 2wish was founded in 2012 following the personal experience of our Founder and CEO, Rhian Mannings, who lost her one-year-old son, George, and 5 days after, her husband, consumed with grief, took his own life. Working with professionals in the A&E and Critical Care departments of the University Hospital of Wales in Cardiff, an immediate support pathway was written and cleared through clinical governance and a twelve-month pilot trialled. Following a sudden death, a memory box is offered, the family are referred (with consent) and first contact is made within 24-48 hours. Immediate support lasts whilst risk and/or need is present.

Further support includes counselling, complementary therapy, play therapy, focus groups, monthly events and a respite house.

We support families, friends, witnesses, professionals and individuals and do not put a timeline on grief allowing those bereaved to engage with our service as and when they are ready.

Results: Through partnership working and a consistent approach we embedded our service and work in partnership with every health board, hospital, police force, coroner's office and mental health team across Wales.

We are the leading charity for sudden death in children and young people in Wales and are set to expand into England in Autumn 2023.

Conclusion: We save lives by ensuring those affected by the sudden death of a child have access to immediate support.

We reduce pressure on public and primary care sectors by filling the gap that exists to support those suddenly bereaved of a child through immediate emotional, and practical, support.

We will continue to ensure every individual affected by sudden and unexpected death is offered support.

O-050 How do newly bereaved parents experience a doll reenactment shortly after the sudden, unexpected death of their child? A mixed-methods study

by Pål Kristensen | Richard Goldstein | Center for crisis psychology/University of Bergen | Robert\\\'s Program on Sudden Unexpected Death in Pediatrics, Associate Professor of Pediatrics, Harvard Medical School

Objective. The doll re-enactment is widely considered the standard of care in forensic practice for the death scene investigation (DSI) after sudden and unexpected deaths of infants. In Norway the doll re-enactment is conducted within 48 hours after the infant death. Still, its impact on newly bereaved parents has not been examined.

Methods. A mixed-methods design including both quantitative (self-report questionnaires including posttraumatic stress reactions) and qualitative data (in-depth interviews) were gathered from 45 bereaved parents (23 mothers and 22 fathers) 5-6 weeks after the death. The interviews were transcribed verbatim and thematically analyzed according to Braun & Clark (2006).

Results. Among the parents, 20 (44%) reported that the doll re-enactment had been somewhat or highly distressing. Regression analysis revealed that struggling with posttraumatic intrusions of the death was the only factor associated with experiencing the re-enactment as distressing after controlling for age, gender and finding the child. The indepth interviews revealed five superordinate themes (consent, motivation to participate, appearance of the doll, benefits and ‘finders’ reactions). Although parents were motivated to participate most of them had dreaded the re-enactment procedure and reacted negatively to the appearance of the doll. For many of the ‘finders’ the doll re-enactment triggered the same emotions as finding the child dead. Still, most parents thought they had managed to endure the re-enactments better than anticipated and some also reported benefits, such as reduced worries for causing the child's death.

Conclusion. Investigators should receive additional training before exposing vulnerable parents to the death scene with a child-like doll. Preparing the parents is warranted, including a description of what they can expect and their possible responses to it combined with a follow-up conversation with a mental health specialist.

O-051 Sudden Unexplained Death in Childhood (SUDC): Identifying Effective Multi-Agency Approaches for Bereaved Families

by Dr Emily Cooper | Dr Nikki Speed | Jonathan Holmes | Dr Joanna Garstang | University of Central Lancashire | SUDC UK | University of Central Lancashire | NHS

Objective: This paper will present the findings from a study which captured bereaved families' experiences of the multi-agency response following the unexpected and unexplained death of their child who died aged between 1 and 18 years old. The research identified areas of practice which require improvement and highlights strategies which work well in minimising trauma and supporting families throughout (and beyond) the investigation into their child's death.

Methods: The project uniquely involves researchers with both lived experience of SUDC and investigating SUDI and SUDC deaths. Qualitative methods were employed, involving semi-structured interviews, with bereaved parents from 21 UK-based families. It was crucial that lived experience was centralised and a trauma-informed approach to interviewing was adopted.

Results: The findings demonstrate significant inconsistencies across geographical boundaries and different agencies in the quality and quantity of the communication with families, in the ability and compassion shown from individuals, and in how the investigation is conducted. Families highlighted the significant impacts of the quality of practice on their experiences of trauma and grief, both short and long term. Families feel disempowered in the process of the investigation and feel that their, and their child's, voices and needs are not always heard or respected.

Conclusion: Evidence from SUDC-bereaved families is important to inform guidelines and this is the first study to focus on families affected by SUDC across the UK. We make recommendations for agencies who are involved in the investigation and care of families. These include identifying a knowledgeable, compassionate single point of contact appointed on day one who can provide swift, appropriate recommendations for local emotional and peer support, explain the investigative process, advocate for families' needs and be visible and responsive. Policy should seek to empower families by giving them a voice in official processes such as the child death review panel.

O-052 Parental guilt and self-blame after infant death, learning from the Folbigg Inquiry

by Dr Joanna Garstang | University of Birmingham

Objectives: Kathleen Folbigg was recently pardoned and released from jail, after serving 20 years. She was found guilty of murder in 2003 following the deaths of her 4 children during 1989-99.

Ms Folbigg wrote diaries expressing her feelings of guilt and self-blame, these were treated as admissions of guilt at trial.

The objectives are to review research on bereaved parents' feelings of guilt, relating this to grief theories and the Folbigg case.

Methods: Databases were systematically searched for papers with primary data on parental guilt, selfblame and grief following child death, results were screened, critically appraised and findings narratively synthesised.

Results: 22 of 1466 identified papers were included.

Clinical depression following infant death was reported in 17-57% of mothers, persisting for many years. Complex or Prolonged Grief Disorder

(PGD) occurred in 40-57% of SIDS mothers, PGD is associated with sudden deaths, and parents with anxious, insecure or avoidant attachment styles. Post-traumatic Stress Disorder (PTSD) occurs in up to 39% of parents following infant death.

Maternal feelings of guilt or self-blame were common and associated with depression, anxiety or PTSD. These feelings persisted despite reassurance from professionals that they were not responsible and were not related to cause or circumstances of death.

Murray-Parkes (1972) describes self-blame as normal in grieving, by blaming one-self death is no longer a random, unpredictable, and unexplained event, but becomes controlled creating some order which is easier to bear. Irving (2008) explains that bereaved parents may feel guilty as their role as parents is to nurture their children; when children die parents have failed in their primary responsibility.

Conclusions: The self-blame and guilt in Ms Folbigg diary entries reflected her grief for which she needed professional support. These feelings are common in bereaved parents and should not have been misconstrued as evidence of guilt.

O-053 Improving the supports available for healthcare professionals experiencing professional grief and loss in response to neonatal death within the context of a neonatal intensive care unit in a tertiary maternity hospital

by Julianna Crowley | Cork University Maternity Hospital

Crowley J [1,2,], McAteer M[4] , O'Donoghue K[1,2,3,]

1. Pregnancy Loss Research Group, Department of Obstetrics and Gynecology, University College Cork, Ireland
2. Cork University Maternity Hospital, Cork, Ireland
3. INFANT Research Centre, University College Cork, College Road, Cork, Ireland
4. Collaborative Action Research Network Co-Lead coordinator: Adjunct Lecturer, NUI Galway, Supervisor, RCSI/Irish Hospice Foundation

Background: Healthcare professionals experiencing loss and grief in response to neonatal death is a subject overlooked within healthcare systems and research. Neonatal intensive care unit (NICU) healthcare professionals regularly contend with neonatal death, and this often involves strong emotional involvement as they aim to provide high quality bereavement care to bereaved parents and families. The aim of this study was to improve supports available for staff experiencing grief and loss by exploring the experiences of NICU nurses and consultant neonatologists providing end of life care and perinatal bereavement care.

Methods: Data collection utilised a qualitative approach using a semi-structured interview guide. Ten healthcare professionals participated: seven neonatal nurses and three consultant neonatologists. Interviews took place between February and May 2023. Results generated were thematically analysed.

Results: Four main themes were generated: healthcare professionals experience of professional loss and bereavement when a baby they have cared for dies; the need for structured debriefing that meets the emotional needs of staff; the expression of professional grief in the workplace and the need for ongoing bereavement education. When the experience of loss and grief goes unacknowledged in the workplace, this may lead to maladaptive coping strategies and impact on staff wellbeing.

Conclusion: This professional experience of loss and grief and its impact needs to be acknowledged and supported by healthcare systems so that professionals can be supported when providing end of life care. The knowledge generated from this research can now inform how best to improve support for staff experiencing professional loss and grief in the workplace.

O-054 Experiences of Norwegian families attending to online courses of therapeutic writing after the death of a child

by Olga Lehmann | University of Stavanger

How can bereaved parents receive effective forms of support that promote their health and wellbeing if there is limited knowledge about the nature of their needs, and how to meet them?

Since 2020, and thanks financing from the DAM foundation and the LUB Research Fund, I have collaborated with The Norwegian SIDS [sudden infant death syndrome] and Stillbirth Association (LUB), and have set the basis for user-involvement and piloted 5 online courses on therapeutic writing (females n=49; males n=15) in Norway.

The objectives of this project have been to,

a) gain knowledge about the experiences and needs of mothers and fathers as they grieve the death of their children;
b) develop an empirically-based intervention that is sustainable for volunteer organisations over time.

We have integrated phenomenological and existential methodologies from anthropology and psychology, as well as narrative theories and methodologies, to we work with these families as they write. Our data is based on fieldwork notes, qualitative surveys, and writings that the parents donated to us after attending to our courses.

Our results suggest that online low-threshold interventions alike are attractive and inclusive, easing the access to peer-support and specialized grief support independently of geographical location, gender, or diagnosis. The sense of community crafted in these groups, in addition to the benefits of writing practices that increased emotional literacy and meaning-making, helped bereaved parents to process difficult emotions such as anger and shame in addition to melancholia. A sense of compassion and self-compassion was also fostered. We will present examples of the practices and writings in this talk to exemplify our low-threshold intervention.

ROOM 4 – PARALLEL SESSION 4 – SUDI Pathology Symposium

Betty McEntire - Naples, Florida USA

- Introductions and Goals of Workshop
- Sponsored by America SIDS Institute
- History of ISPID Pathology Symposia
- The Role of Pathology in Solving SIDS

Betty McEntire - Naples, Florida USA

Betty L McEntire, PhD
CEO, American SIDS Institute
Naples, Florida USA

Brain
Rita Machaalani - Sydney, New South Wales AUS

Genes and Molecular Autopsy
Laura Heathfield - Cape Town ZA

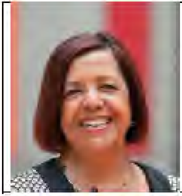
Biomarkers
Robin L. Haynes - Boston, Massachusetts USA

Forensic Perspective & Issues
Roger Byard - Adelaide, South Australia AUS

Panel Discussion
Moderator:
Betty McEntire - Naples, Florida USA

Panelists:
Roger Byard - Adelaide, South Australia AUS
Marta C Cohen - Sheffield UK
Robin L. Haynes - Boston, Massachusetts USA
Laura Heathfield - Cape Town ZA
Rita Machaalani - Sydney, New South Wales AUS

Wrap-up & a Look into the Future
Roger Byard - Adelaide, South Australia AUS
Rita Machaalani - Sydney, New South Wales AUS

	**Roger Byard, PhD, MD, DSc** Marks Chair of Pathology Discipline of Anatomy and Pathology The University of Adelaide Adelaide, South Australia Australia
	**Rita Machaalani, PhD** Associate Professor, SIDS & Sleep Apnea Laboratory Faculty of Medicine and Health University of Sydney Sydney, NSW Australia
	**Robin L Haynes, PhD** Principal Research Associate Pathology Boston Children's Hospital Boston, MA USA
	**Laura Heathfield, PhD** Univ. of Cape Town Cape Town, South Africa
	**Torleiv Ole Rognum, MD, PhD, MHA** Professor, Department of Forensic Medicine University of Oslo and Oslo University Hospital Oslo, Norway
	**Marta C Cohen, MD** Professor of Paediatric and Perinatal Pathology Department of Metabolism and Oncology, University of Sheffield Consultant.

This Session available Abstracts

1 The Brain in Sudden Infant Death Syndrome (SIDS)

Rita Machaalani, The University of Sydney, New South Wales, Australia
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Background: Brain research in SIDS has been rewarding in identifying that abnormalities exist in the SIDS brain, ranging from alterations in brain neurotransmitter and receptor expression levels, changes in cell type numbers and function, and architectural morphologies. Yet it has been challenging to reproduce the findings, with reasons including heterogeneity of study populations, contribution of the presence of the risk factors, inconsistent diagnostic classification, and difference in study methodologies.

Methods: Summary analysis of SIDS brain research to date to highlight the major brain findings of impact, with particular focus on data obtained from our laboratory over the past 2 decades.

Results: Abnormalities identified include alterations in markers of processes such as apoptosis, inflammation, water and cellular ion channel homeostasis, protein regulation, and of neurotransmitter, growth and receptor systems. Architectural morphological changes are reported in the hippocampus and brainstem medulla. Changes affected all cell types of the brain including neurons, astrocytes and microglia, the latter two indicative of inflammatory processes. Risk factors of a history of cigarette smoke exposure, a recent upper respiratory tract infection, and bedsharing are associated with several of these findings.

Conclusions: The brain of babies classified as SIDS have abnormalities compared to non-SIDS, and they seem to be widespread, indicating the importance of continued brain research to help piece together the exact mechanism(s) contributing to the final demise of these babies.

2 Genes and Molecular Autopsies

Laura J Heathfield, PhD, Division of Forensic Medicine and Toxicology, Department of Pathology, University of Cape Town, Cape Town, South Africa
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Objectives: To highlight the importance of population-specific research to develop a molecular autopsy that is locally relevant.

Methods: Two hundred South African infants who experienced sudden and unexpected death and whose cause of death was undetermined after post-mortem investigation were included in this study. Parents provided informed consent to participate. Mutations and genes that are typically sequenced in molecular autopsies were assessed. This was followed by the targeted analysis of mutations that have high carrier frequencies in South Africa. A combination of Sanger sequencing and massively parallel sequencing were used.

Results: None of the typical mutations that are normally analyzed during molecular autopsies were found in the South African infants. Out of the four most commonly studied genes relating to cardiac arrythmia, KCNQ1, KCNH2, SCN5A and RYR2, only KCNQ1 was informative: a likely pathogenic variant previously associated with severe congenital long QT syndrome in South African patients was observed in almost 15% of the infant cases. For metabolic disorders, the common mutations in ACADM were not observed at all. However, a founder mutation in GALT was observed in a homozygous state in an infant, explaining her demise. Upon delivery of this result to her mother, it was discovered the infant's twin had also demised.

Conclusions: These findings represent new candidate mutations to assess, and directly inform a molecular autopsy which is locally relevant. Considerations of which genes to include in a molecular autopsy are crucial to improving diagnostic yield. This research also advocates that molecular autopsies should be prioritized for identical twins, as it holds potential to save lives.

3 Biomarkers Of SIDS: Identifying SIDS Risk and Understanding Pathological Mechanisms

RL Haynes, PhD, Department of Pathology, Boston Children's Hospital and Harvard Medical School, Boston, MA, USA
robin.haynes@childrens.harvard.edu

Background: An important goal in sudden infant death (SIDS) research is to identify specific biomarkers. Biomarkers, defined as objective indicators of a pathologic process, medical condition, or medical state, can be presented in many different forms or types of measurements (e.g., biochemical, physiological, or genetic). Biomarkers of SIDS risk can help to identify infants at risk prior to death and allow interventions. Biomarkers of SIDS pathogenesis can be used by medical examiners to distinguish a SIDS death from other sudden and unexpected deaths in infancy. For researchers, biomarkers can be used to identify pathological processes related to death, including those processes occurring within difficult to obtain tissues (e.g., brain).

Methods: Our laboratory and others have utilized different methodologies in blood taken from neonates who have died of SIDS to identify potential biomarkers of SIDS risk. Recent work in this area has focused on biomarkers related to neurochemicals. Postmortem studies have utilized blood taken at autopsy to identify biomarkers related to peripheral neurochemical abnormalities and platelet function. Specificity and sensitivity of biomarker data has been accessed statistically.

Results: Recent biomarker data will be discussed within the context of known pathological findings in SIDS and general challenges related to biomarker discovery.

Conclusions: Given the heterogenous nature of SIDS pathogenesis, difficulty arises when attempting to identify singular biomarkers of all SIDS infants. Rather, biomarkers of risk and/or pathogenesis can be utilized to begin to identify subsets of SIDS infants with unique profiles of abnormalities, risks, and ultimately strategies to prevent death.

4 Forensic Perspectives and Issues

Roger W. Byard PhD, MD, DSc, Forensic Science SA and The University of Adelaide, Adelaide, South Australia, Australia
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Objectives: To explore major developments in recent years in pathophysiological mechanisms for SIDS and to examine trends in pathological assessments.

Methods: Examination of relevant recent literature.

Results: There are both epidemiological and neuropathological differences between infants who die alone (classical SIDS) and those who die in shared sleeping situations (co-sleeping). Deficiencies in brainstem substance P could also explain vulnerabilities of certain infants to the prone position. However, it unfortunately appears that applications of the standard international definitions of SIDS are declining. There has been a 12% fall in the number of published peer-reviewed papers on SIDS listed on PubMed that correctly cited standard definitions (56% compared to 68% in 2012). Almost two thirds of studies between 2019-2021 had no, or non-standard, definitions. Although infant death rates in South Australia between 1994-98 and 2014-18 have shown a marked decline in SIDS cases (55 to 12), this has been accompanied by a corresponding increase in the numbers of cases classified as “undetermined” (5 to 18). When the two groups are merged (60/80vs30/56) no significant changes occurred (p=0.26).

Conclusions: Failure to use standard definitions and changing diagnostic terminology may, therefore, have markedly influenced recent apparent changes in infant mortality. Research papers are also being published where cases have been classified as SIDS without even an autopsy being performed. Given these two trends, important questions to ask are: 1) How can we correctly interpret conclusions relating to SIDS research if studied cases do not fulfil standard criteria and, 2) How can we accurately monitor trends in SIDS mortality if there is diagnostic shift.

ROOM 5 – PARALLEL SESSION 3 – Workshop 3

Chair: John Waldron - London UK

W-003 Tackling smoking during pregnancy: the English experience

John Waldron - London UK

NHS England's tobacco dependency treatment pathway for pregnant women

Heidi Croucher - London UK

Supporting pregnant smokers to quit with financial incentives

Rebecca Scott - London UK

Preventing relapse to smoking postnatally

Caitlin Notley - London UK

Nicotine and vaping during pregnancy

Peter Hajek - London UK

W-003 Tackling smoking during pregnancy: the English experience

by John Waldron | Action on Smoking and Health (ASH) UK

Smoking during pregnancy is a leading preventable risk factor for stillbirth and SIDS, increasing the risk of stillbirth by 47% and tripling the risk of SIDS. England has introduced several measures to reduce rates of maternal smoking, including opt-out stop smoking support for all pregnant smokers accessing NHS maternity services and, more recently, a national financial incentive scheme for pregnant smokers. These have contributed to the proportion of women who were smokers at the time of delivery in England declining by over a third between 2010/11 and 2022/23, from 13.6% to 8.8%.

This workshop will seek to:

- Highlight the importance of tackling maternal smoking for reducing rates of stillbirth and SIDS.
- Provide an overview of the English approach to addressing maternal smoking, including a summary of the key interventions and areas for future research.
- Set out the English approach to nicotine use for smoking cessation during pregnancy, including e-cigarettes.

Further information about the workshop structure is set out in the attached document.

ROOM 5 – PARALLEL SESSION 4 – Communication/Social Media

Chairs: Trina Salm-Ward – Milwaukee, Wisconsin USA & Anat Shatz – Ganey Tikva IL

O-055 The perils and pearls of SUDI risk assessment at point-of-care - Part 1

Christine McIntosh – Auckland NZ

O-056 The perils and pearls of SUDI risk assessment; why proactive systematic early pregnancy care is now the focus – Part 2

Christine McIntosh – Auckland NZ

O-057 The importance of listening to families when communicating SIDS reduction advice: co-sleeping case study

Jennifer Ward – London UK

O-058 The Impact of Social Media on Safer Sleep Choices

Stella Parkin – London UK
Jennifer Ward – London UK

O-059 Expectant and New Mothers’ Use of Facebook Private Groups to Learn about Safe Sleep, Breastfeeding and Infant Care Practices

Rebecca Carlin – New York USA

O-060 Translating research into a SUDI education and prevention programme in AOTEAROA New Zealand

Melanie Christensen MacFarlane – Auckland NZ

This Session available Abstracts

O-055 Part 1. The perils and pearls of SUDI risk assessment at point-of-care

by Christine McIntosh | John Thompson | Dept. Paediatrics; Child and Youth Health, The University ofnAuckland, and Te Whatu Ora Health New Zealand | Dept. Paediatrics; Child and Youth Health, ThenUniversity of Auckland

Background: The Safe Sleep Calculator SUDI risk assessment tool was developed to be used at the point of care to enable individualized SUDI protection advice and targeted support. The SUDI rate for Māori and Pacific people's communities in Aotearoa, New Zealand (NZ) is higher than for other populations. These communities expressed concern about using risk assessment in SUDI education because of the risk of stigma and judgment.

Objective: To explore the causes of stigma and judgment when taking a risk assessment approach to SUDI prevention and consider how to use SUDI risk assessment constructively.

Methods: A mixed methodology translational research program led to the development, implementation, and evaluation of the Safe Sleep Calculator SUDI risk assessment tool.

Qualitative research relating to the experience of both giving and receiving SUDI risk assessment in the context of the Safe Sleep Calculator has been explored, as well as the relationship to the wider context of maternity and early life healthcare provision.

Results: Healthcare worker and consumer focus groups have identified reasons why Māori and Pacific people experience stigma and judgment when accessing healthcare. Healthcare practitioners' cultural safety, sufficient time, and the right attitude for a SUDI protection conversation and pathways for support for the pregnant person and their family were identified as critical for effective care.

Conclusion: SUDI risk assessment needs to be situated within adequately resourced and accessible care with practitioners who are culturally safe and trained in behavior change conversations in order to have an impact when working with populations most in need of SUDI protection care and avoid further stigma or judgment.

O-056 Part 2. The perils and pearls of SUDI risk assessment; why proactive systematic early pregnancy care is now the focus.

by Christine McIntosh | Dept. Paediatric; Child and Youth Health, The University of Auckland, New Zealand, Te Whatu Ora Health New Zealand Counties Manukau, Auckland, New Zealand

Background: The Safe Sleep Calculator SUDI risk assessment tool was developed to enable individualized advice and targeted support. It was recognized during piloting that the Safe Sleep Calculator should be nested within wider assessment tools and should start early in pregnancy.

Objective: To describe how the Safe Sleep Calculator risk assessment tool has evolved into holistic pregnancy and infancy assessment tools and why we believe this approach is necessary to achieve health provider impact on SUDI rates in Aotearoa, New Zealand (NZ).

Methods: The Best Start Kōwae assessment modules for early pregnancy, early infancy, and postnatal assessments have been developed as integrated digital tools in the primary care patient record. They incorporate best practice guidelines-based decision support and care pathways, including SUDI risk assessment. The Best Start Kōwae are being developed and implemented by the National Hauora Coalition, a Māori Primary Healthcare Organization, under the guidance of a Senior Advisory Group of Māori practitioners and researchers.

Results: Around half of all primary care practices in NZ have access to the Best Start Kōwae for clinical use. A Health Quality Safety Commission dashboard reports Best Start Kōwae aggregate data with specific equity measurement for Māori compared to non-Māori for assessment areas, e.g., maternal mental health, smoking, and preeclampsia risk. The tools continue to evolve through an ongoing and collaborative approach, including healthcare consumers, providers, and research groups.

Conclusion: Population groups with high SUDI rates experience inequitable access to quality early pregnancy care and, therefore, lost opportunities for improved pregnancy outcomes and SUDI risk reduction. Taking a systematic approach using the Best Start Kōwae has demonstrated how to identify and tackle inequities and address early pregnancy drivers of SUDI risk

O-057 The importance of listening to families when communicating SIDS reduction advice: co-sleeping case study

by Jenny Ward | Kate Holmes

Background: The Lullaby Trust works with public health and families to promote safer sleep advice to reduce infant mortality in the UK. With mortality reductions slowing, research was undertaken to understand what advice families are searching for, and ensuring this links with known prevention advice.

Methods: Online surveys with families were undertaken in 2021 and 2022, compared to social media post interactions and website page clicks. These are compared to data available from the National Child Mortality database on deaths in England. Engagement with online advice and direct information contacts was analyzed to identify where high traffic might indicate gaps in advice to families.

Results: Co-sleeping advice is greatly sought-after. Families engage with content that discusses co-sleeping.
Most families admit to co-sleeping at some point (87%) but the majority did not plan to do so before their baby was born (73%). Half of babies who die of SIDS in England die in a high-risk co-sleeping situation, and the majority of these did not plan to co-sleep. Yet 44% of respondents had no conversation

about co-sleeping with a health professional. ‘Cosleeping’ takes 3 of the top 5 search terms for leading people to the Lullaby Trust’s website in 2023 and 16% of all website users enter at the co-sleeping page.

Conclusions: We need listen to families and understand their situation, decisions, and actions, particularly online, to direct safer sleep messages to the most at risk. Discussions about cosleeping need to take place antenatally and postnatally and acknowledge that co-sleeping can happen accidentally to help prevent high risk situations. Working with families is an essential part of public health messaging. Families need to be directed from the most popular entry point for advice (co-sleeping) to get all the safer sleep advice.

O-058 The Impact of Social Media on Safer Sleep Choices

by Jenny Ward | Lullaby Trust

Objective: To understand the importance of social media in determining parents’ and carers’ infant care practices with regards to safer sleep.

Methods: A survey from The Lullaby Trust to parents’ and carers’ in conjunction with Bounty – an organisation supporting new parents - promoted on The Lullaby Trust’s social media channels with a £100 Voucher incentive. This was in conjunction with analysis of engagement with The Lullaby Trust’s social media content and enquiries regarding product advice.

Results: The Lullaby Trust found that social media was having a significant impact on parenting decisions. Of those surveyed, 51% of respondents stated they follow influencers for parenting tips and/or baby product recommendations. Worryingly, 37% of those surveyed had bought a baby sleep product that doesn’t conform to safer sleep advice after seeing them on their Instagram and Facebook feeds. Nearly all (94%) of those surveyed stated that they understood that sleep surfaces that aren’t firm or flat can increase the risk of SIDS. However, the survey also showed that 40% have a positive view of baby sleep pods and nests after seeing them online, despite there being no British Standard for them as a sleeping space for babies. This interest in products via social media was reflected in analysis of our social media content, with product posts having above average engagement.

Conclusions: Anecdotal evidence from engagement with families had suggested that parents' and carers' use of social media sites, such as Instagram and Facebook, was having an impact on their parenting choices. This was confirmed by our survey and internal research. As some popular baby sleeping products promoted on social media by influencers, celebrities and content creators do not conform to safer sleep advice, this could potentially put babies at risk.

O-059 Expectant and New Mothers' Use of Facebook Private Groups to Learn about Safe Sleep, Breastfeeding and Infant Care Practices

by Rebecca Carlin | Rachel Moon | Ann Kellams | Fern Hauck | Eve Coulson | Katherine Boguszewski | Emma Shaw | Columbia University Medical Center | University of Virginia | University of Virginia | University of Virginia | Washington University St. Louis | University of Virginia | Boston University

Objective: Facebook groups are widely used by parents as sources of information and advice, and are potentially a powerful tool to alter attitudes and practices regarding safe sleep and breastfeeding. This study aimed to explore expectant and new mothers' perspectives about using Facebook private groups (FPGs) for parenting support, in order to inform the development and implementation of an intervention to address SUID risk behaviors.

Methods: We conducted and analyzed fifteen in-depth, semi-structured interviews with a purposeful sample of expectant or new mothers. We asked participants about their perspectives on using FPGs for parenting support including information about safe sleep and breastfeeding. Themes and subthemes were developed iteratively from coded data using the constant comparative approach with multiple coders from different backgrounds.

Results: Mothers identified 3 main drivers for using FPGs for parenting advice: 1) Information seeking, 2) Experience when using Facebook, and 3)

Social connectedness. The quality, trustworthiness and accessibility of information were often cited as important to mothers. Mothers frequently sought product information, including about sleep-related devices, breastfeeding support, and parenting tips. Women described a variety of ways in which they engaged with FPGs and both the positive and negative feelings they experienced while using the platform. Most appreciated the easy access and immediacy of answers.

Women who used the platform often sought to expand their social network and build a supportive community of people they could trust and easily reach.

Conclusions: FPGs are generally a valued tool for expectant and new parents seeking information and advice, even those who do not otherwise use Facebook, due to the quality and accessibility of information and the social supports they receive from participating.

While engagement and the feelings around using such groups are mixed, they remain a potentially powerful way to alter social norms regarding safe sleep behaviors and breastfeeding.

O-060 Translating research into a sudi education and prevention programme in Aotearoa New Zealand

by Melanie MacFarlane-Christensen | University of Auckland

Objective: Aotearoa-New Zealand (NZ) has one of the highest SUDI rates among developed countries, and indigenous Maaori infants are most affected. Bed-sharing is associated with more than half of all SUDI cases in NZ. This research has informed the development of a locality specific SUDI prevention programme in Counties-Manukau - an urban Auckland area with a large Maaori population, and which experiences the greatest number of SUDI deaths nationwide. The programme is commissioned by NZs government-run health and disability funder, Te Whatu Ora, as part of a nationwide suite of community- and family-led solutions to improve hauora [health and wellbeing] outcomes.

Methods: The qualitative research was underpinned by a Maaori cultural framework and gathered data via in-depth face-to-face interviews in the homes of mothers with young infants born in Counties-Manukau. Interview transcripts were analysed using general purpose thematic analysis. The resulting research-based programme, “Kua Ao te Raa”, comprises a community-, workforce- and whole-of-family approach to infant safe sleep and SUDI prevention. The programme engages with families, communities, and the SUDI prevention workforce, and is supported by an outcomes-focused programme evaluation.

Results: Thirty mothers participated in the research, including 17 Maaori. Two-thirds of mothers reported previous or current bed sharing. All mothers had some knowledge about SUDI and SUDI prevention; however, some knowledge was inaccurate, and extreme tiredness and/or the practices and preferences of close family and friends sometimes interfered with mothers’ safe sleep intentions. Based on mothers’ suggestions, the programme includes safe sleep education and the development of personalised safe sleep plans in conjunction with the people (family and friends) directly involved in the infant’s sleep.

Conclusion: This programme builds on research, and responds to the lived experiences and cultural realities, values, and beliefs of mothers through the design and delivery of effective, culturally appropriate, and innovative SUDI prevention interventions.

ROOM 6 – PARALLEL SESSION 3 – Pathophysiology

Chairs: Rick Goldstein - Boston, Massachusetts USA & Monica H Wojcik - Boston, Massachusetts USA

O-061 Defining Potential Vulnerable Networks in the Medulla Oblongata in SIDS
Robin L. Haynes - Boston, Massachusetts USA

O-062 Astrogliosis in the sudden infant death syndrome (SIDS) medulla- a comparison across 2 separate research cohorts
Lauren Luijerink - Sydney, New South Wales AUS

O-063 A potassium channel subdomain regulates gene transcription and channel function in the developing heart
David K. Jones - Ann Arbor, Michigan USA

O-064 Involvement of the Superior Colliculus in SIDS Pathogenesis
Riffat Mehboob - Lahore PK

O-065 Manipulation of the serotonergic and noradrenergic systems in mice to inform roles in autoresuscitation
Savannah Lusk - Houston, Texas USA

O-066 Expression of Reelin in the Human Infant Hippocampus and Changes Attributed to SIDS
Vanessa Despotovski - Sydney, New South Wales AUS

This Session available Abstracts

O-061 Defining Potential Vulnerable Networks in the Medulla Oblongata in SIDS

by Robin L. Haynes | Felicia Trachtenberg | Kevin J. Cummings | Benjamin W. Okaty | Ronald M. Harper | James C. Leiter | Richard D. Goldstein | Robert A. Darnall | Gene E. Nattie | Hannah C. Kinney | CJ Murphy Laboratory for SIDS Research; Department of Pathology, Boston Children's Hospital and Harvard Medical School, Boston, Massachusetts, USA; Robert's Program on Sudden Unexpected Death in Pediatrics, Division of General Pediatrics, Department of Pediatrics, Boston Children's Hospital, Boston, MA, USA | Carelon Research, Newton, Massachusetts, USA | Department of Biomedical Sciences College of Veterinary Medicine. Dalton Cardiovascular Research Center, University of Missouri, Columbia, MO, USA | Department of Genetics, Harvard Medical School, Boston, MA, USA | Department of Neurobiology and the Brain Research Institute, University of California at Los Angeles, Los Angeles, CA, USA | White River Junction VAHC, White River Junction, VT, USA | Boston Children's Hospital | Emeritus Professor of Molecular and Systems Biology and of Pediatrics, Geisel School of Medicine at Dartmouth, Hanover, NH | Emeritus Professor of Molecular and Systems Biology, Geisel School of Medicine at Dartmouth, Hanover, NH, USA | Boston Children's Hospital

Objective: A leading hypothesis is that a subset of sudden infant death (SIDS) results from a failure of brainstem networks critical for arousal from sleep or autoresuscitation in response to asphyxia. Serotonergic abnormalities, including altered 5-HT1A receptor binding, appear in the medulla of SIDS cases. Research in rodents however, has supported an important role for 5-HT2A/C receptors in protective responses, particularly arousal and autoresuscitation. Here, we hypothesize that 5-HT2A/C receptor binding is altered in medullary cardiorespiratory- and/or arousal-related nuclei in SIDS cases versus controls.

Methods: We used receptor autoradiography in 58 SIDS and 12 controls to measure binding to 125I-DOI, a 5-HT receptor agonist, in key medullary nuclei. Analysis of covariance controlling for postconceptional age compared SIDS vs. controls, and 95% confidence intervals of regression curves based on binding data from controls were used to statistically define “abnormal” binding.

Results: Significant binding alterations emerged in 7 of the 10 nuclei sampled in SIDS cases compared with controls, with differences occurring in two patterns: 1) a significant reduction in binding in SIDS; and 2) a significant age-vs-diagnosis interaction with age- related increased binding in the controls, compared to unchanged binding in SIDS. We identified a subset (~ 80%) of SIDS cases with abnormal 5-HT2A/C binding in at least one medullary nucleus. Medullary nuclei were differently affected in SIDS, with the medial accessory olive (MAO) and nucleus tractus solitarius (NTS) being the most prevalent abnormality in ~ 65% of SIDS.

Conclusions: Our data support the hypothesis that abnormalities in the 5-HT2A/C receptor, potentially combined with abnormalities in 5-HT1A receptors, result in faulty 5-HT signaling in critical homeostatic medullary networks. Since the MAO and NTS are critical components of an olivocerebellar subnetwork important for its role in cardiorespiratory control under stress, an increased focus on functions and networks involving olivocerebellar subnetworks is suggested.

O-062 Astrogliosis in the sudden infant death syndrome (SIDS) medulla-a comparison across 2 separate research cohorts

by Lauren Luijerink | Marta Cohen | Rita Machaalani | The University of Sydney | Sheffield Children's NHS Foundation Trust | The University of Sydney

Objective: Astrogliosis is visualised immunohistochemically via an upregulation of glial fibrillary acidic protein (GFAP). Astrogliosis has been investigated in the sudden infant death syndrome (SIDS) brain previously, with particular focus on brainstem nuclei.

Vast contradictions have been reported as to whether astrogliosis is in fact a feature of SIDS, likely due to inconsistencies in experimental method. This includes the method of assessing astrogliosis, given that its definition remains highly subjective.

Our laboratory previously introduced a novel method for GFAP quantification, termed 'R score', which aims to standardise observer judgement by taking into account the proportion of GFAP-positive cells stained at each level of pathological severity, ranging from healthy to severe.

Methods: The current study aimed to investigate astrogliosis via GFAP immunohistochemistry in SIDS versus non-SIDS infants in 9 sub-regions of the medulla, across 2 separate research cohorts in the UK (non-SIDS = 9, SIDS = 21) and Australia (non-SIDS = 7, SIDS = 21). The experimental and quantification method was standardised to determine whether the results were consistent between cohorts. Further analyses were run according to the presence of major SIDS risk factors including bed-sharing, prone sleeping, upper respiratory tract infection, cigarette smoke exposure and male gender.

Results: There were no significant differences in GFAP-expression between SIDS and non-SIDS in any of the nuclei studied for either cohort, nor for any of the risk factors in the UK cohort. In the Australian cohort, higher GFAP expression occurred in female infants in the cuneate nucleus ($p = 0.009$) and for infants found in the non-prone sleep position in the arcuate nucleus ($p = 0.002$).

Conclusion: To our knowledge, this is the first study to analyse GFAP expression across 2 separate SIDS cohorts applying the same experimental method. Application of this method to other relevant brain regions will be the next step.

O-063 A potassium channel subdomain regulates gene transcription and channel function in the developing heart

by David K. Jones | Abhilasha Jain | Eric N. Jimenez-Vazquez | University of Michigan | University of Michigan | University of Michigan

Objective: KCNH2 encodes hERG1, a developmentally-regulated potassium channel that mediates function in cardiac and neuronal tissue. hERG1 variants are associated with intrauterine fetal death, sudden infant death syndrome, and sudden unexplained death in epilepsy, but how KCNH2 variants trigger sudden death in the young is unclear.

Methods: We completed immunocytochemistry and patch clamp electrophysiology from CRISPR gene-edited human stem cell-derived cardiomyocytes, native heart tissue, and human embryonic kidney cells (HEK293) to identify a new mechanism by which hERG1 regulates cardiac function.

Results: We identified a novel KCNH2-encoded hERG1 polypeptide (hERG1NP) that is targeted to the nuclei of immature cardiomyocytes. The hERG1NP immunofluorescent signal is dramatically downregulated in matured cardiomyocytes. Antibodies targeting distinct hERG1 channel epitopes demonstrated that the hERG1NP immunofluorescent signal maps to the hERG1 channel's distal C-terminal domain. KCNH2 deletion using CRISPR abolished hERG1 currents and the hERG1NP signal in stem cell-derived cardiomyocytes. We also identified a nuclear localization sequence (NLS) within the distal hERG1 C-terminus. Accordingly, the distal C-terminal domain was targeted almost exclusively to the nuclei when overexpressed HEK293 cells. Deleting the NLS from the distal polypeptide abolished nuclear targeting. RNAseq analysis demonstrated that the putative hERG1NP alters expression of gene transcripts associated with cell differentiation and proliferation. Additionally, overexpressing the putative hERG1NP polypeptide significantly reduced hERG1 current density, compared to cells expressing the NLS-deficient hERG1NP or GFP. Finally, inserting a SIDS-associated variant, R885C or R1047L, disrupted hERG1NP nuclear targeting, transcriptional regulation, and modulation of hERG1 currents.

Conclusion: These data demonstrate that hERG1NP regulates gene transcription and thereby indirectly modulates hERG1 current at the membrane. These data also suggest that hERG1NP dysfunction likely represents a novel mechanism of sudden death in the young.

O-064 Involvement of the Superior Colliculus in SIDS Pathogenesis

by Anna Maria Lavezzi | Riffat Mehboob | Francesco Piscioli | Teresa Pusiol | University of Milan, Milan, Italy | Lahore Medical Research Center, Lahore, Pakistan | Provincial Health Care Services, Institute of Pathology, Santa Maria del Carmine Hospital, 38068

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The aim of this study was to investigate the involvement of the mesencephalic superior colliculus (SC) in the pathogenetic mechanism of SIDS, a syndrome frequently ascribed to arousal failure from sleep.
We analyzed the brains of 44 infants who died suddenly within the first 7 months of life, among which were 26 infants with SIDS and 18 controls.
In-depth neuropathological investigations of serial sections of the midbrain showed the SC layered cytoarchitectural organization already well known in animals, as made up of seven distinct layers, but so far never highlighted in humans, albeit with some differences.
In 69% of SIDS cases but never in the controls, we observed alterations of the laminar arrangement of the SC deep layers (precisely, an increased number of polygonal cells invading the superficial layers and an increased presence of intensely stained myelinated fibers).
Since it has been demonstrated in experimental studies that the deep layers of the SC exert motor control including that of the head, their developmental disorder could lead to the failure of newborns who are in a prone position to resume regular breathing by moving their heads in the sleep arousal phase. The SC anomalies highlighted here represent a new step in understanding the pathogenetic process that leads to SIDS.

O-065 Manipulation of the serotonergic and noradrenergic systems in mice to inform roles in autoresuscitation

by Savannah Lusk | Javi Hernandez | Russell Ray | Baylor College of Medicine | Baylor College of Medicine | Baylor College of Medicine

Objective: Investigate the independent and combinatorial roles of the serotonergic and noradrenergic systems in autoresuscitation.

Methods: The serotonergic and noradrenergic systems have been implicated in postmortem studies of SIDS infants. We developed a novel series of conditionally expressed inhibitory and excitatory receptors that allow for singular excitation or inhibition of either the whole serotonergic or noradrenergic systems as defined by Pet1 or dopamine-beta-hydroxylase expression, respectively. When combined, we can specifically activate or inhibit the serotonergic and/ or noradrenergic systems for a total of 8 distinct combinations of perturbations. Upon activation and/ or inhibition at 7-8 postnatal days of age, we challenge the mice in a high-face-value assay that quantifies their ability to autoresuscitate, a commonly proposed endpoint for SIDS. The number of episodes of autoresuscitation survived is the reported outcome in this study.

Results: In >170 mouse pups (~17 pups per group), we found that singular activation or inhibition of the noradrenergic system results in decreased survival. In contrast to previous studies, we found that serotonergic inhibition does not impact survival when neonates are challenged until failure. We also show that survival is restored to control levels when noradrenergic inhibition is combined with serotonergic inhibition. However, decreased survival when the noradrenergic system is activated is not rescued by serotonergic inhibition. We injected controls with saline or clozapine-N-oxide (CNO, ligand that activates the receptors) and found a significant effect of CNO on survival.

Conclusions: As the underlying genetic and environmental mechanisms driving SIDS are likely to have pleiotropic effects across multiple neural systems, our first-of-its-kind dual serotonergic and noradrenergic system modulations sets the stage to more comprehensively model key aspects of SIDS neuropathology that reveal a previously uncharacterized dynamic functional interplay between the noradrenergic and serotonergic systems in protective respiratory reflexes.

O-066 Expression of Reelin in the Human Infant Hippocampus and Changes Attributed to SIDS

by Vanessa Despotovski | Karen Waters | Rita Machaalani | 1. Faculty of Science, Charles Perkins Centre, The University of Sydney, NSW 2006, Australia | 2. Faculty of Medicine and Health, Medical Foundation Building, K25, The University of Sydney, NSW 2006, *Australia 3. The Children's' Hospital, Westmead, NSW 2145, Australia | 2. Faculty of Medicine and Health, Medical Foundation Building, K25, The University of Sydney, NSW 2006, Australia 3. The Children's' Hospital, Westmead, NSW 2145, Australia*

Objective: Morphological differences in the Dentate Gyrus (DG) of the SIDS hippocampus have been reported and thought to be due to abnormal neuronal migration. Reelin is an extracellular matrix protein known to be critically involved in neuronal migration during human development. This study examined reelin expression within the human infant hippocampus, and evaluated whether its expression is altered in SIDS per se, or with SIDS risk factors. Further analysis evaluated whether morphological features of the DG such as bilamination, granule cell dispersion, thinning, ectopic cells, gaps and blood vessels separating the granule cells, are associated with altered reelin expression.

Methods: Immunohistochemical staining for reelin was applied on hippocampal tissue from infants diagnosed with SIDS I (n=9), SIDS II (n=30) and e-SUDI (n=6). Expression within the layers of the DG, CA4/Hilus and CA3-CA1 were quantified.

Results: Reelin expression significantly decreased within the whole CA1 (p=0.01) and more specifically the Stratum Pyramidal layer (p=0.02) in SIDS II when compared to e-SUDI.

Reelin expression was not significantly altered in the DG of SIDS infants. SIDS infants reported to bed-share had higher reelin expression (p= 0.05) in the sub-granular zone (SGZ) of the DG while infants with a recent upper respiratory tract infection (URTI) had lower reelin in the molecular layer (ML) of the DG (p=0.05). Reelin expressing cells were increased in proximity to the feature(s) of bilamination, thinning and blood vessels, yet decreased in granule cell dispersion, ectopic cells and gaps in the DG.

Conclusions: Reelin is decreased within the CA1 of the SIDS infant hippocampus, while for the DG, reelin was altered by the risk factors of bed-sharing and an URTI, as well as morphological features.

ROOM 6 – PARALLEL SESSION 4 – Thematic Panel 4

Chair: Raffaele Piumelli - Florence ITA

TP-004 Italian SUDI Summary

Preventing sudden infant death syndrome (SIDS) with good parental practices: the results of a survey in Sicily (Italy) for new perspectives for studies on local inequality differences
Achille Cernigliaro - Palermo ITA

Effectiveness of Sudden Infant Death Syndrome (SIDS) Prevention Campaigns in Lombardy: Trends in SIDS, SUDI, and Infant Mortality Rates from 2007 to 2022
Luana Nosetti - Varese ITA

Epidemiological Surveillance for Sudden Unexpected Infants Death (SUID) in Piedmont Region: since 2004 a useful tool for prevention and for national and international comparisons
Silvia Noce - Turin ITA

Sudden Unexpected Infant Death: The "Tuscany Model"
Vincenzo Nardini - Pisa ITA

TP-004 (1) Preventing sudden infant death syndrome (SIDS) with good parental practices: the results of a survey in Sicily (Italy) for new perspectives for studies on local inequality difference

by Raffaele Pomo | Achille Cernigliaro | Pediatrics, Neonatology and NICU Complex Hospital Unit, Buccheri La Ferla Fatebenefratelli Hospital, Palermo, Sicily, Italy and Center for prevention of SIDS risk, Palermo, Sicily, Italy | Clinical Pathology Complex Hospital Unit, Health Authority Trapani Province, Trapani, Sicily, Italy and Health Activities and Epidemiological Observatory Department, Health Authority Sicily Region, Palermo, Sicily, Italy

Objective: Describe the prevalence of SIDS determinants. Estimate the association between infants' supine position during sleep as main prevention factor for SIDS and parental, infant, and pre-intra-postpartum characteristics to focusing new studies to evaluate local inequality differences in parental care.

Methods: using a regional cohort survey to select representative samples of women in local territories to focusing new studies. Data were collected at 1 month postpartum through a telephone questionnaire. The prevalence of risk factors for SIDS was calculated and a multivariate logistic model was applied to estimate the associations (OR-95%CI) between supine position during sleep and exclusive breastfeeding, pre-natal courses, rooming-in, formula prescription, pacifier use, and age, marital status, nationality, work, education, economic level and smoking of the mothers.

Results: 1055 women were studied. 62% place their babies in supine position, 84% practice rooming-in, 11% of mothers smoke, 38% of the babies were exclusively breastfed and 34% used the pacifier. The supine position was positively associated with exclusive breastfeeding (OR=1.82 95%CI 1.34-2.48), maternal age>35 (OR=2.43 95%CI 1.52-3.88), high education (OR=1.80 95%CI 1.30-2.49), and high socioeconomic status (OR=1.50 95%CI 1.13-1.99). Negatively associated with postpartum smoking (OR=0.61 95%CI 0.39-0.95).

Conclusion: The study confirmed that exclusive breastfeeding can be considered a good SIDS prevention practice, while unhealthy behaviors like smoke are predictive of greater use of the prone or lateral position. Further ongoing investigations will highlight the effect of individual and local context inequalities on the good parental practices and other determinants of SIDS, allowing for the recalibration and strengthening of intervention policies to promote safe sleep and other good childcare practices in those territories that show greater fragility. Inequality is a priori risk factor for health, including SIDS, and must be consider when promote heath in maternal infant care areas where the health gain is higher.

TP-004 (2) Effectiveness of Sudden Infant Death Syndrome (SIDS) Prevention Campaigns in Lombardy: Trends in SIDS, SUDI, and Infant Mortality Rates from 2007 to 2022

by Luana Nosetti | Elena Radrizzani | Massimo Agosti | Olivia Leoni | Pediatric Unit Insubria University Varese Italy | Pediatric Unit Insubria UniversityVarese Italy | Pediatric Unit Insubria University Varese Italy | Epidemiological Observatory Lombardy Region Milano Italy

Objectives: The SIDS mortality rate has decreased overall after the introduction of the Safe to Sleep campaign. In Lombardy, the SIDS mortality rate hasn't been known since 2000. The objective of the study is to estimate the mortality rate for SIDS, SUID, and infant mortality in the period between 2007 and 2022, analyzing the reduction that occurred following the introduction of campaigns in 2001 to reduce the risk of SIDS and evaluate their effectiveness.

Methods: We analyzed the available official ISTAT data on infant and newborn deaths in the first year of life, are residents and registered in the mortality registries of the health districts in which the Lombardy region is divided. The analysis covers the years 2007 to 2022.

Results: Between 2007 and 2022, the mortality rate for SIDS was found to be 0.03‰ live births, the mortality rate for SUID was found to be 0.34‰ live births, and the average infant mortality rate was found to be 1.49‰ live births over the period. Compared with previous data in the literature from the decade between 1990 and 2000, there has been a significant reduction in the SIDS mortality rate (-76.92%; $p < 0.0001$), as well as a reduction in the infant mortality rate(-63.66%; $p < 0.0001$).A significant change in the number of SUID cases was observed during the analyzed period ($p < 0.005$). For the first time, a higher incidence of SIDS was observed in females than in males (23F, 15M, 1 unknown). SIDS is still more frequent after the first month of life.

Conclusions: These results confirm the effectiveness of the campaigns to reduce the risk of SIDS carried out in Lombardy, which have led to a reduction in SIDS cases by minimizing infants' exposure to risk factors. The reduction in infant mortality is associated with improved perinatal care, care during labor and delivery, and neonatal care.

TP-004 (3) Epidemiological Surveillance for Sudden Unexpected Infants Death (SUID) in Piedmont Region: since 2004 a useful tool for prevention and for national and international comparisons

by Silvia Noce | Alessandro Vigo | Giulia Costagliola | Giovanni Botta | Marco Forni | Daniela Palladin | Roberto Testi | Annamaria Baldelli | Silvana Malaspina | Centre for Pediatric Sleep Medicine and for SIDS, Ospedale Infantile Regina Margherita, Città della Salute e della Scienza di Torino | Dipartimento Materno Infantile, ASL CN2, Ospedale Pietro e Michele Ferrero di Verduno | S.C. Pediatria, ASL TO4, Ospedale di Chivasso | SUID/SIDS Multidisciplinary Committee, Piedmont Region | SUID/SIDS Multidisciplinary Committee, Piedmont Region | S.C. Anatomia Patologica, ASL Città di Torino | Dipartimento di Prevenzione, ASL Città di Torino | SUID/SIDS Multidisciplinary Committee, Piedmont Region | S.C. Distretto Sud Est, ASL Città di Torino

Introduction and Objective: Since 2004 Piedmont has activated an epidemiological surveillance of Sudden Unexplained Infant Death (SUID) thanks to the close collaboration between the SIDS (Sudden Infant Death Syndrome) Hospital Centre and the Local Health Units. Protocol and results obtained in the period 2004-2020 are here described.

Methods: All deaths of children aged 0-24 months undergo a standardized evaluation process, applied to cases identified through death certificates and those managed in real time. If the cause of death is unclear on the certificate, it is considered as SUID and investigated. In SUID cases, local SIDS reference person gather clinical, coroner's and autopsy records, which are sent to the epidemiological coordinator in Turin. The collected data are reviewed by a multidisciplinary committee and classified using Krous' criteria and, since

2016, the CDC's criteria. All SUID follow the same diagnostic process, aligned with the Avon system.

Results: In the considered period 1610 deaths occurred (corresponding mortality rate 2.72 ‰ live births). Among the cases analyzed, 431 (27%) had poorly defined diagnoses on death certificates, but 70% of them were later reclassified as specific causes of death. The remaining 127 cases were classified as SUID (mortality rate of 0.21 ‰). Using Krous criteria we identified 25 cases of SIDS 1B and 25 cases of SIDS 2; no SIDS 1 A were found. 57 cases (45%) resulted to be explained sudden deaths. CDC classification was applied to 38 SUID occurred between 2016-2020 :14 cases (37%) occurred in unsafe sleep environment; 4 out of 14 deaths were attributed to suffocation. Non-Italian populations experienced almost double mortality and SUID rate.

Conclusion: This surveillance, utilizing retrospective and real-time investigation, enabled an accurate assessment of SUID cases at manageable costs, integrating major classification systems for comparisons with national and international registries. The data provided valuable insights for targeted prevention measures.

TP-004 (4) Sudden Unexpected Infant Death: The “Tuscany Model”

by Vincenzo Nardini | Raffaele Piumelli | Niccolò Nassi | Anna Maria Buccoliero | Maria Elena filice | Rossella Occhini | Cristina Salvatori | Marta Peruzzi | Cinzia Arzilli | IInd Pathology Unit -Pisa University Hospital - Pisa- Italy | Scientific Consultant Seeds for SIDS Parents Association | Sleep Breathing Disorders and SIDS Centre, Meyer Children’s Hospital, Florence, Italy | Pathology Unit, Meyer Children’s Hospital, Florence, Italy | IInd Pathology Unit -Pisa University Hospital - Pisa- Italy | Pathology Unit, S.Donato Hospital, Arezzo, Italy | Scientific Consultant Seeds for SIDS Parents Association | Scientific Consultant Seeds for SIDS Parents Association | Scientific Consultant Seeds for SIDS Parents Association

Introduction: Sudden Unexpected Infant Death (SUID) is a general definition for all sudden and unexpected deaths in infancy. Traditionally all SUID of an infant aged 1 to 12 months were wrongly labelled Sudden Infant Death Syndrome (SIDS), even without performing a thorough post-mortem examination and/or a collecting information about the scene and circumstances of the death.

In Tuscany, a SIDS reduction campaign has been carried out since 2002 by the the Regional SIDS Centre of the Meyer Children's Hospital and, in order to better understand and classify the entire phenomenon, in collaboration with the Tuscany Region Health department, a project aimed at implementing the multiagency management of SUID cases was started.

In 2008, a multiagency group was created aiming to establish an algorithm for the management of SUID cases.

A shared intervention protocol of the task force was drawn up for each case in which a SUID occurs, even alerting the Court (in order to not exclude crime suspected cases). The SIDS Centre Staff contact the families as soon as possible directly or through the family paediatrician to take charge the family, answering the parents' questions about what happened and providing information about SUID and collecting information about the death circumstances.

The referral pathologist (always on call) carry out, preferably within 24 hours from the death, a complete and useful autopsy, according with the shared regional protocol and the findings of the autopsy are disclosed to the families about 2 months later in a multiagency meeting (the pathologist, a paediatrician from the Regional SIDS Centre, a psychologist and a sub-specialist when required.

Conclusions: The Tuscany model SUID structured multiagency approach ensures both the care of the bereaved families and sensitive classification of the cause of death even improving prevention strategies to ensure a greater reduction of sudden infant deaths in the future.

ROOM 9 – PARALLEL SESSION 3 – Families and Health Professional Strategies /Social Media

Chairs: Kathleen Anne Boyd – Glasgow, Scotland UK & Christine McIntosh – Auckland NZ

O-067 Perspectives of Nutrition Program Staff Serving Women from Low-Income Families about Improving Breastfeeding Rates
Eve Colson – St. Louis, Missouri USA

O-068 The Challenge of Screening Out Scam Responses to Online Recruitment for Safe Sleep Research
Rebecca F Carlin – New York USA

O-069 Listening to Parent Voices: Considering the Impact of Anti-Black Racism on Sudden Unexpected Infant Death (SUID)
Eve Colson – St. Louis, Missouri USA

O-070 Celebrities of Instagram: Influencers of unsafe sleep?
Craig Bragg – Birmingham UK

O-071 The value of collaborating with members of target population groups to co-design and deliver prevention messages and resources

Keren Ludski – Melbourne AUS

O-072 Developing and implementing a program to reduce stillbirths, SIDS and SUID: an overview of the impact of an initiative in rural Jordan

Shereen Hamadneh – Al-Mafraq JO

O-067 Perspectives of Nutrition Program Staff Serving Women from Low-Income Families about Improving Breastfeeding Rates

by Bryanne N Colvin | Eve R Colson | Mackenzie Cunningham | Chanel Peguero | Rachel Moon | Marc T Kiviniemi | Ann L Kellams | Katherine E Boguszewski | Fern R Hauck | Emma Forbes | Washington University School of Medicine | Washington University School of Medicine | Washington University School of Medicine | Boston University School of Medicine | University of Virginia School of Medicine | University of Kentucky | University of Virginia School of Medicine | University of Virginia School of Medicine | University of Virginia School of Medicine | Boston University School of Medicine

Objective: In the U.S., the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides supplemental foods and nutrition education to low-income pregnant/new mothers and infants. Although breastfeeding education and support are primary WIC tenets, WIC clients have lower rates of any and exclusive breastfeeding. WIC staff are trusted resources for WIC clients, and have unique insights about needed components for interventions to increase breastfeeding in this high-risk population. To support the development of an effective intervention for WIC clients, we aimed, through qualitative methods, to understand facilitators and barriers to breastfeeding from the WIC staff perspective and learn their strategies to improve breastfeeding rates.

Methods: We conducted focus groups with WIC staff in Massachusetts and Virginia, U.S. to explore their experiences with facilitators and barriers to initiating and continuing breastfeeding for WIC clients, and their suggestions for interventions aimed at improving breastfeeding rates. Data collection and analysis followed an iterative process using constant comparison by multiple, diverse researchers with expertise in qualitative methods.
Thematic saturation was reached.

Results: 51 WIC staff members participated in 7 focus groups. Themes related to staff experience included client beliefs about breast- and formula-feeding (including beliefs about milk supply), breastfeeding experiences

(including difficulty with pain and latch), social supports, sociocultural influences, self-efficacy and competing priorities (including employment, care of other children). Themes related to strategies used to promote breastfeeding included providing education (including specifics about content, format, and timing), relationship building, and engaging the clients' support systems.

Conclusions: WIC staff identified the importance of providing specific, concrete information about breastfeeding, strategies to breastfeed while working and caring for other children, and increasing social support for breastfeeding parents. This study exemplifies how to ensure that important voices, in this case WIC staff, inform the development of interventions to change health-related behaviors.

O-068 The Challenge of Screening Out Scam Responses to Online Recruitment for Safe Sleep Research

by Rebecca Carlin | Rachel Moon | Columbia University Vagelos College of Physicians and Surgeons | University of Virginia

Objective: Online recruitment using targeted advertisements is increasingly used for safe sleep studies because of its vast reach and cost-effectiveness compared to in person recruitment. However, it is difficult to identify scam responses to ads (individuals or computer bots repeatedly enrolling with aliases), which affects data validity. We aimed to assess the proportion of likely scam responses to online recruitment for a safe sleep study.

Methods: Online advertisements were placed on Facebook, Craigslist, and Reddit, seeking pregnant persons to participate in an online safe sleep intervention. Interested participants completed an eligibility form (Qualtrics) and were contacted via telephone for consent. Data provided by participants and Qualtrics were searched for duplicate entries, which were then analyzed for consistency in other response fields. Responses were coded as either likely legitimate (consistent responses in key fields) or likely scam (discordant responses in key fields). Cost per enrolled participant was also tracked.

Results: Between November 2021 and June 2023, 854 eligibility surveys were completed. 304 (35.5%) were identified as likely scam responses. Of these 72 and 278 had identical IP addresses and latitude and longitude (L&L) points respectively, but discordant contact information, date of birth or due date. No respondents were flagged as suspicious/scam by Qualtrics or the advertising platforms. Despite iterative changes to advertisement targeting, the most recent advertisements on Facebook from March-June 2023 resulted in 331 responses, with 113 (34.1%) identified as likely spam. The cost per enrolled participant during this latest period was $13.30.

Conclusions: Although online advertising is an effective way to recruit pregnant persons for safe sleep research, a large proportion of responses may not be legitimate. Identifying duplicate IP addresses and L&L is an effective initial screening tool, but further work is needed to better identify scam responses. Researchers using online recruitment should disclose the methods used to identify scam respondents.

O-069 Listening to Parent Voices: Considering the Impact of Anti-Black Racism on Sudden Unexpected Infant Death (SUID)

by Mia Malcolm | Bryanne Colvin | Fern R. Hauck | Rachel Y Moon | Margaret G Parker | Rachel Witt | BJC HealthCare | Washington University School of Medicine | University of Virginia School of Medicine | University of Virginia School of Medicine | UMass Chan Medical School | University of Minnesota School of Medicine

Objective: In the United States (US), Black infants are more likely to die from SUID than white infants.

Much research has been conducted to understand the factors associated with these disparities and educational interventions have been studied to promote health equity. Also in the US, researchers have identified that anti-Black racism can impact patient outcomes.

To date, no studies have examined the impact of anti-Black racism on SUID or SUID-related infant care practices. The objective of our session is to discuss the potential connection between anti-Black racism and SUID by presenting our published research examining parental experience of anti-Black racism in the neonatal intensive care unit (NICU) and then how these finding can inform our work to prevent SUID and the disparities that exist.

Methods Used for the Study of Anti-Black Racism: Using qualitative research methods, we conducted in-depth, semi-structured interviews with 20 Black mothers of preterm infants in a single NICU 6-18 months after hospital discharge regarding experiences related to NICU care and anti-Black racism. We iteratively developed codes and then themes using the constant comparative method with team members from different backgrounds.

Results from the Study of Anti-Black Racism: Mothers experienced anti-Black racism at the interpersonal, institutional, and structural levels that impacted them and the care of their infants. They provided potential solutions that included improving staff education and training, increasing representation from the Black community among healthcare providers, and strengthening peer supports.

Conclusions and Connection to SUID: Black mothers in our study experienced interpersonal, institutional, and structural anti-Black racism. We posit that such experiences of racism may directly impact SUID outcomes and could explain in part the disparities in SUID seen in the US and elsewhere. We will present how using the lens provided by these participants could inform and improve our current strategies to prevent SUID.

O-070 Celebrities of Instagram: Influencers of unsafe sleep?

by Dr Craig Bragg | Dr Elizabeth Venables | Dr Joanna Garstang | Birmingham Community Healthcare Trust | Birmingham Community Healthcare Trust | University of Birmingham

Objective: To establish if influencers and celebrities on Instagram are using safe sleep environments and promoting safe sleep practices to their followers.

Methods: We searched Instagram for influencers who were pregnant or had a baby under 1 year old between October 2021 and January 2023.We created a safe sleep score from 0-10, based on guidance from the Lullaby Trust. We reviewed influencer Instagram feeds to analyse photos posted of babies sleeping, nursery environments or sleep spaces with or without the baby. We gave each photo a safe sleep score. We recorded number of followers for each influencer.

Results: We reviewed 30 photos from 22 influencers. Mean score for photos with a sleeping baby (n=22) was 7.2 (range 4-10). Only four photos showed baby in their own sleep space, the rest were on carpeted floors, sofas or co-sleeping on their parents' bed. Mean score for photos without a sleeping baby (n=8) was 8.5 (range 7-10). The most common areas of bad practice were the sleeping environment not being clear (typically of cuddly toys or freefloating, ruched or thick, fleecy blankets) (n=11) , the use of soft-sided sleeping nests, bumpers and quilts (n=4), and wearing hats or bows (n=3). Influencers had a mean of 28 million followers each (range 14,900-581 million). In total potentially 594,874,300 people could have seen these photos of unsafe sleep environments.

Conclusion: Social media is normalising unsafe sleeping practices, with celebrity baby photos potentially viewed by vast populations. The general public look to influencers to emulate their lifestyles and nursery choices, however influencers are not experts in safe sleep. Unsafe sleep photos can be posted without repercussions or recrimination. We should work with new celebrity parents to post photos promoting safe sleep.

O-071 The value of collaborating with members of target population groups to co-design and deliver prevention messages and resources

by Keren Ludski | CEO Red Nose Australia

Objective: It is essential that Stillbirth and SUDI prevention messages and resources are targeted to the populations they are trying to reach. This presentation will explore what true co-design looks like, its importance in ensuring prevention messaging gets cut through to targeted populations; methods to encourage community members to lead, take part and encourage change and strategies to ensure community members feel heard, respected and know their contributions are appreciated whilst they are in the advocating role.

Methods: Co design is about capturing different perspectives and experiences to work together towards better solutions to ensure prevention messaging is getting cut through. Over the last 18 months Red Nose has worked collaboratively with people from a diverse range of backgrounds, Aboriginal and Torres Strait Islander people and people who are culturally and linguistically diverse. We have captured their experiences through surveys, working groups, phone and email consultations.

Results: People can add huge value through their lived experience. Tapping into existing networks and connections allowed us to empower participants to see the value in their contribution. Through fostering a safe space and developing relationships with community members we built trust. Preparing participants allowed them to process their own experience and begin to think about what they would like to share. This resulted in a suite of resources that met the needs of diverse communities.

Conclusions: Lived experience and community voice are critical components in ensuring high quality, sensitive, culturally safe messaging and resources. True co-design happens over a period of time with many touch points and opportunities to give feedback. From this process we are able to begin the process of developing and delivering prevention messages and resources to better support a broader community.

O-072 Developing and implementing a program to reduce stillbirths, SIDS and SUID: an overview of the impact of an initiative in rural Jordan

by Shereen Hamadneh | Al al-Bayt University, Jordan ; Happy Baby and Family Association

Objectives: This paper explores the implications of an education program on stillbirths, SIDS, and SUID and strategies that can be used to educate parents in rural of Jordan. It also evaluates healthcare providers' experiences of participating in this educational program.

Methods: This action research approach was conducted among a purposive sample of hospital/community healthcare providers, key stakeholders, and parents in Irbid Governorate, Jordan. Data were collected using focus group sessions, interviews, feedback, field notes, and a questionnaire to assess the impact of developing and implementing intervention package about stillbirths, SIDS, and SUID. This intervention tutorial is an update of an earlier version developed by Hamdanah (2014). The researcher also used the recent updated materials of the American Academy of Pediatrics, CDC, Red Nose Australia, and Safe to Sleep Canada.

Result: Health workers in rural and remote areas were identified as an effective education and training group on health promotion programs in their communities. However, reinforcement was recommended to continue their professional development.
The use of online education technology and social media has been identified as a less cost strategy, supporting accurate and timely professional education. However, several challenges were noted, such as staff shortages. Furthermore, the low socio-economic status, poor lifestyle, low level of education, low expectations about marriage, high rates of teenagers marriages, gender issues, male dominances, domestic violence, and high rates of smoking were play as barriers of implementing prevention strategies for stillbirth, SIDS and SUCD.

Conclusions: Government and political stakeholders need to put in place policies and procedures that will enhance the role of healthcare providers as educators among their communities. Especially since crises and disasters increased the demographic changes of the population, which pushed them to leave their homes and live in remote and isolated areas. Bedouins, refugees and villagers were identified as high-risk groups.

SALA VERDE – PARALLEL SESSION 5 – Workshop 4

Chair: Rosemary Horne – Melbourne AUS

W-004 How immaturity of control of the cardiorespiratory and thermoregulation systems increase the risk for SUDI in preterm infants

Veronique Bach – Amiens, FR
Rosemary Horne – Melbourne AUS
Hugues Patural – Saint-Etienne, FR

SALA VERDE – PARALLEL SESSION 6 – Genetics and Metabolomics

Chairs: Rita Machaalani - Sydney, New South Wales, AUS & Vanessa Despotovski - Primbee, New South Wales AUS

O-073 Brainstem anomalies in stillbirth: a neuropathological and genetic preliminary study
Edoardo Errichiello - Pavia ITA

O-074 Metabolomics analyses identify novel associations with Sudden Infant Death Syndrome
Keith L. Keene - Charlottesville, Virginia USA

O-075 A Genomic Investigation of Sudden Unexpected Postnatal Collapse in Hospitalized Neonates
Monica H Wojcik - Boston, Massachusetts USA

O-076 The Tygerberg Medico-legal Mortuary SUDI Experience. A 15-year overview

Corena de Beer – Stellenbosch ZA

This Session available Abstracts

O-073 Brainstem anomalies in stillbirth: a neuropathological and genetic preliminary study

by Edoardo Errichiello | Agnese Spennacchio | Mauro Lecca | Graziella Alfonsi | Patrizia Leonardi | Giulia Ottaviani | Unit of Medical Genetics, Department of Molecular Medicine, University of Pavia, Pavia, Italy; Laboratory of Cytogenomics, IRCCS Mondino Foundation, Pavia, Italy; SUID and SIDS Italia Onlus, Turin, Italy | Medical Genetics Unit, Department of Molecular Medicine, University of Pavia, Pavia, Italy | Medical Genetics Unit, Department of Molecular Medicine, University of Pavia, Pavia, Italy | Lino Rossi Research Center, Anatomic Pathology, Department of Biomedical, Surgical and Dental Sciences, Università degli Studi di Milano, Milan, Italy | Lino Rossi Research Center, Anatomic Pathology, Department of Biomedical, Surgical and Dental Sciences, Università degli Studi di Milano, Milan, Italy | Lino Rossi Research Center, Anatomic Pathology, Department of Biomedical, Surgical and Dental Sciences, Università degli Studi di Milano, Milan, Italy

Objective: Central nervous system (CNS) abnormalities represent a common cause of stillbirth (SB), especially in the third trimester of pregnancy, being detected in more than 1/3 cases subjected to fetal autopsy and post-mortem, or in utero, brain magnetic resonance imaging (MRI). Brainstem nuclei are implicated in the control of crucial physiological functions during fetal life such as swallowing, breathing movements, heart rate, and blood pressure.
The "brainstem hypothesis" implies that dysfunction of such anatomical regions may increase vulnerability to sudden infant death syndrome (SIDS)/sudden unexplained death in childhood (SUDC). This preliminary study combines neuropathological and genetic investigations, under the hypothesis that SIDS/SUDC and SB may represent distinct etiological entities although in a genotypic and phenotypic continuum from fetal life to childhood.

Methods: We investigated a subset of 29 stillbirths (18 males and 11 females) showing prominent brainstem anomalies, such as arcuate nucleus and pre-Botzinger complex hypoplasia, by whole-exome sequencing (WES). Samples were part of archival material collected from the Lino Rossi Research Center between 2008 and 2022. Histopathological analysis was performed on serial sections. All but one fetal loss occurred after 28 gestational weeks (mean: 38.05; range: 27-41.7). Genomic DNA was extracted from postmortem formalin-fixed paraffin-embedded brain tissues and matched normal tissues as controls (thymus or thyroid). After deep sample quality evaluation, DNA samples underwent WES by using the Human Core Exome kit with Mitochondrial Panel (Twist Bioscience) on a Novaseq6000 platform (Illumina).

Results: The bioinformatic analysis, still ongoing, was focused on genetic variants with a minor allele frequency below 5%, located within exonic and splicing regions and related to abnormal brainstem morphology according to the Human Phenotype Ontology (HPO) and related interactome data.

Conclusion: This study will help to identify the correlation of neuropathological anomalies with genetic bases and their intriguing overlaps in SIDS/SUDC.

O-074 Metabolomics analyses identify novel associations with Sudden Infant Death Syndrome

by Keith L. Keene, PhD | Cornelius Normeshie, MD, MBA, MPH | Xiangqing Sun, PhD, MS | Josyf C. Mychaleckyj, DPhil | Fern R. Hauck, MD, MS | University of Virginia | University of Virginia | University of Virginia | University of Virginia | University of Virginia

Objective: Sudden infant death syndrome (SIDS) is characterized as a SUID that remains unexplained after autopsy, investigation of the death scene, and review of the medical history. SIDS often occurs unexpectedly, and few biomarkers exist for the prediction or diagnosis of SIDS. Metabolites are sensitive indicators of homeostatic changes (whether induced by genetics, epigenetics, or environment), and are excellent candidates for biomarkers of disease.

Methods: To identify potential biomarkers for SIDS, we have performed a comprehensive global metabolomics study quantitating more than 1,200 serum metabolites (1,015 named and 222 unnamed) in 302 infants from the

Chicago Infant Mortality Study (CIMS) and NIH NeuroBioBank biospecimen repository, utilizing Metabolon's DiscoveryHD4™platform.

Results: Following quality control measures, we were able to detect 756 metabolites present in ≥90% of samples, 841 metabolites present in ≥80% of samples, and more than 900 metabolites present in ≥70% of samples. To identify SIDS associated biomarkers, we performed SIDS versus non-SIDS (Welch's t-test) as well as logistic regression analyses, identifying 42 and 68 associations reaching or exceeding Bonferroni-corrected significance (0.05/1,000= 5 x 10-5) for non-transformed and log-transformed values, respectively. Thirtynine of those metabolites were significant in both non- and log-transformed analyses.
Logistic regression analyses, including race, sex, and cohort as covariates, identified 80 Bonferroni significant associations for log-transformed values. Seven of the top ten associations were significant in all three analyses, with the most significant associations observed for 5-hydroxylysine (P= 2.08x10-11 non-transformed Welch's t-test) and N1- Methyl-2-pyridone-5-carboxamide (P=3.8x10-10 log transformed Welch's t-test; P=3.6x10-10 log transformed logistic regression). Other consistent associations included ribitol, a novel compound (X-23639), sedoheptulose, 2-hydroxyoctanoate, and 1,2-dilinoleoyl-GPC (18:2/18:2).

Conclusion: Metabolomics offers promise for identifying disease biomarkers in SIDS. Our efforts identified N1-Methyl-2-pyridone-5-carboxamide, uremic toxin and 5-hydroxylysine, a type 1 collagen isolated from the heart, that may be important in SIDS.

O-075 A Genomic Investigation of Sudden Unexpected Postnatal Collapse in Hospitalized Neonates

by Monica H Wojcik | Jill A Madden | Casie A Genetti | Alan H Beggs | Ingrid A Holm | Richard D Goldstein | Boston Children's Hospital | Boston Children's Hospital | Boston Children's Hospital | Boston Children's Hospital | Boston Children's Hospital | Boston Children's Hospital

Objective: Genetic and genomic contributions to sudden unexpected early neonatal death (SUEND) remain incompletely understood. Furthermore, the phenotypic spectrum underlying these deaths is broad. Although many deaths occur unwitnessed in the community, a subset of these deaths occur after witnessed, unexpected cardiovascular collapse either immediately after birth, in the newborn nursery, or in the neonatal intensive care unit. Genomic insights into these cases may illuminate the phenotypic and molecular underpinnings of the broader spectrum of SUEND/SUDI. We therefore undertook a genetic evaluation of a cohort of cases of sudden unexpected postnatal collapse occurring in the hospital setting.

Methods: Prospective cohort study of sudden unexpected postnatal collapse of neonatal and infant hospital inpatients under one year of age. Exome sequencing (preferably as a trio) and analysis was performed using DNA extracted from blood or frozen tissue.

Results: Ten cases were enrolled, comprising four preterm and six full term infants. Four deaths occurred immediately after delivery, four in the first 24 hours of life and two within the first week of life. Two had minor structural anomalies noted on pre- or postmortem examination. Four had unexplained metabolic acidosis (one with concomitant hyperammonemia) identified around the time of cardiac arrest. Of six cases whose genomic data has been fully analyzed, a potential explanation has been identified in one infant: a stop gain variant in MCM10, a gene previously associated with an autosomal recessive lethal cardiomyopathy. Subsequent RNA sequencing and long read genome sequencing are underway to evaluate for evidence of a functional impact and/or a second variant in this gene. Genomic analysis of the remaining cases is ongoing.

Conclusion: The phenomenon of sudden cardiorespiratory collapse in a highly monitored setting, such as a neonatal intensive care unit, warrants further evaluation as a window into genomic contributions underlying SUEND/SUDI.

O-076 The Tygerberg Medico-legal Mortuary SUDI Experience. A 15-year overview

by Prof Corena de Beer | Stellenbosch University, South Africa

Sudden Unexpected Death in Infancy (SUDI) cases at Tygerberg Hospital, Cape Town, South Africa, are admitted to the Tygerberg Medico-legal Mortuary and investigated according to the SA Inquests Act (58 of 1959) to identify possible causes of death. Between 150 and 300 SUDI cases between 1 week and 1 year of age are admitted per year.

The routine SUDI investigation protocol in South Africa is determined by the National Health budget and only includes macroscopic and microscopic evaluation, collection of samples for special laboratory investigations and liver and lung tissue for histology. In 2009, additional investigations were introduced as ancillary tests to assess viral and bacterial infections in different organs of the body, and this is dependent on research funding.

To date, a total of 783 infants with a male-to-female ratio of 1:0.9 were included in different research projects. Sociodemographic information was collected and compared to the SUDI risk factors published in the literature. The mean age of the infants was 12.4±10.7 weeks, with a mean birthweight of 2483±826g. Most cases occurred in colder months, the vast majority co-slept and were placed to sleep on their sides or stomachs.

The most common pathogens detected were RSV, HRV, enteroviruses, HHV-6, Neisseria meningitidis and E.coli. Increased immune markers suggesting infection at the time of death included IL-6, CRP and IL1-alpha and can be used as cost-effective alternative to expensive molecular tests to confirm infection. Our research continue to explore more cost-effective alternatives for the diagnosis of various infectious diseases in SUDI cases.

Final causes of death assigned at our institution, include Infection, SIDS or Other (confirmed at autopsy). Histological changes can be suggestive of infection, but if supported by laboratory tests confirming specific pathogens or increased biomarkers of infection, more cases can be assigned a final cause of death of Infection instead of unknown / SIDS

SALA VERDE – PLENARY SESSION 6 – Prevention Programs

Chairs: Carri Cottengim - Suwanee, Georgia USA & Jeanine Young - Herston, Queensland AUS

Risk Perception and Sudden Unexpected Infant Death

Kyran Quinlan - Chicago, Illinois USA

Health economics of SUID research: strengthening the evidence and informing policy

Kathleen Anne Boyd - Glasgow, Scotland UK

Interventions to Reduce Risk of Sleep-Related Infant Deaths: Progress and future opportunities

Trina Salm Ward - Milwaukee, Wisconsin USA

This Session available Abstracts

Health Economics of SUID research: strengthening the evidence and informing policy

Kathleen A Boyd, PhD, MSc

A recent systematic review into the economic burden of SUID highlighted the direct cost of stillbirth to range from $6934 to $9220 (USD; 2020) per stillbirth but this excludes indirect costs and the intangible costs on the parents in terms of psychological effects, which have wide reaching adverse impacts and further economic implications. Economic evidence in the area of neonatal death, still birth and perinatal and infant death is limited, and many studies on preventative interventions which have found them to be beneficial and clinically effective, still remain to be implemented in practice.

Local and national policymakers and health technology assessment agencies around the world use both clinical and cost effectiveness evidence to support decisions about health service commissioning. Where public health budgets are limited, economic evidence is vital for supporting investment in interventions which offer the best value for money, e.g. by demonstrating the greatest benefit /gain for the required investment. This session will highlight how health economic evidence can strengthening SUID research, and be used to demonstrate value for money enabling decision makers to make evidence informed, value based decisions for intervention/policy adoption. This presentation will describe some of the economic evidence on SUID prevention interventions, highlight how economic considerations can be better incorporated into such studies to capture and value the wide range of outcomes , and give an example from the UK CPIT II and III trials to demonstrate how convincing clinical and economic evidence enabled swift government policy updates (NI CE 2021 NG209; and the Khan 2022 report) to implement financial incentives for smoking cessation during pregnancy.

Interventions to Reduce Risk of Sleep-Related Infant Deaths: Progress and future opportunities

Trina C. Salm Ward, PhD, MSW

Sudden Unexpected Infant Death (SUID)/Sudden Unexpected Death in Infancy (SUDI) is a leading cause of postneonatal mortality in many developed countries. Many of these deaths include modifiable risk factors, such as infant sleep position, surface, and environment, and as a result, risk reduction efforts often focus on changing infant caregiver sleep practices. This presentation will describe theoretical frameworks that have been helpful in examining infant caregiver sleep practices. This presentation will describe the current state of interventions to reduce risk of SUID, including successes as well as challenges in further reducing risk and SUID rates. Applying the theoretical frameworks, additional opportunities for intervention will be explored.

ROOM 4 – PARALLEL SESSION 6 – Trends/Pot Pouri SUID Epidemiology

Chairs: Margaret G. Parker - Boston, Massachusetts USA & Carrie Shapiro-Mendoza - Atlanta, Georgia USA

O-077 Infant deaths from Accidental Suffocation in England & Wales; rare events or unrecognised by professionals?

Joanna Garstang - Henley-in-Arden UK

O-078 Sudden Unexplained Death in Childhood (SUDC) in England and Wales: frequency and classification of deaths

Joanna Garstang - Henley-in-Arden UK

O-079 Sudden infant death syndrome (SIDS) risk factors identification: a systematic review of the methodological approaches used and their evolution

Sophie de Visme - Nantes FRA

O-080 Understanding Sudden Unexpected Death in Children Over 1 Year of Age

Peter Fleming - Okehampton UK

This Session available Abstracts

O-077 Infant deaths from Accidental Suffocation in England & Wales; rare events or unrecognised by professionals?

by Dr Joanna Garstang | Ms Marivjena Menka | University of Birmingham | University of Birmingham

Objectives: The objective is to determine whether detailed infant death investigation has led to diagnostic shift away from SIDS or greater recognition of deaths due to Accidental Suffocation or Strangulation in Bed.

Methods: In England, since 2008 all sudden unexpected child deaths have mandatory joint police and healthcare investigation, including death scene examination. Cause of death should be determined by multi-professional case conference.

We obtained official mortality data based on death certification ICD10 codes for infants aged 28 -364 days for 2000-2020, for Sudden Infant Death Syndrome (SIDS -R95), unspecified causes of mortality (R96, R98, R99) and Accidental Suffocation and Strangulation in Bed (ASSB-W75). We calculated death rates based on annual population of children aged under 1 year.

Results: Unexplained infant deaths (R95-99) decreased from 265 in 2001 to 161 in 2020, with the mortality rate falling from 0.45 to 0.26 per 1000 infants. SIDS accounted for 66% of unexplained infant death in 2001 falling to 53% in 2020 with a corresponding increase unspecified deaths (R99).

Few deaths are recorded as ASSB, ranging between 2 in 2017 and 17 in 2001, accounting for 1-6% of total SUDI (W75 plus R95-99). The rate for ASSB ranged from 0.003 to 0.029 per 1000 infants. There was no relationship between changes in rates of unexplained infant death and ASSB.

Conclusions: There is a diagnostic shift away from SIDS towards unspecified causes of death, particularly in the last 5 years. In contrast to other countries, improved investigation has not led to increased recognition of deaths from ASSB, despite greater understanding of risks particularly of infants co-sleeping with adults who have used alcohol or drugs. There needs to be clear guidelines on classifying deaths from ASSB to improve recognition and understanding of risks, while avoiding over-interpreting risk factors such as bed sharing as directly causal.

O-078 Sudden Unexplained Death in Childhood (SUDC) in England and Wales: frequency and classification of deaths

by Dr Joanna Garstang | Ms Marivjena Menka | University of Birmingham | University of Birmingham

Objective: To determine frequency of Sudden Unexplained Death in Childhood (SUDC) in children aged 1-14 years in England and Wales.

Methods: SUDC is the sudden and unexpected death of a child, aged 1 to 17 years, which remains unexplained after a thorough case investigation including death scene examination, postmortem examination, and medical history evaluation. There is no ICD-10 code for SUDC and deaths are coded as unspecified causes of death (R96, R98, R99) or SIDS (R95).

We obtained official mortality data from death certificates for 2001-2020 for children aged 1-14 years, and data on total child population aged 1-14 years. We determined the total number of SUDC based on the ICD-10 codes R95-R99, the annual mortality rates for SUDC and compared these with total child mortality in this time-period. We compared SUDC rates with rates of sudden unexplained infant deaths.

Results: The number of SUDC cases remained constant with a mean of 28 SUDC/year (range 20-38), with the rate between 0.002 – 0.04 per 1000 children (1-14 years) each year. In the same period, total child mortality decreased significantly from 1420 deaths in 2001 to 703 in 2020, and the child mortality rate (1-14 years) from 0.154 per 1000 to 0.070. SUDC accounted for 2% of all child deaths in 2001 and 3.5% in 2020. There was no relationship between SUDC rates and rates of sudden unexplained infant deaths which decreased throughout this time period.

Conclusions: SUDC is a poorly understood condition. The rate of SUDC has remained static over the last 20 years despite overall child mortality falling. SUDC now accounts for a greater proportion of child deaths although the numbers overall are low. The lack of ICD code makes surveillance difficult and hinders research efforts.

O-079 Sudden infant death syndrome (SIDS) risk factors identification: a systematic review of the methodological approaches used and their evolution

by Sophie de Visme | Gabrielle Dupuy | Jérémie F. Cohen | Sabine Plancoulaine | Yacine Refes | Loïc de Pontual | Inge Harrewijn | Christèle Gras-Le Guen | CHU de Nantes, Inserm, UIC FEA, CIC1413 | AP-HP, Hôpital Necker Enfants Malades | Université Paris Cité and Université Sorbonne Paris Nord, Inserm, CRESS | Université Paris Cité and Université Sorbonne Paris Nord, Inserm, INRAE, CRESS | Université Paris Cité and Université Sorbonne Paris Nord, Inserm, INRAE, CRESS | AP-HP, Hôpital Jean Verdier | CHU de Montpellier | CHU de Nantes, Inserm, UIC FEA, CIC1413

Objective: Sudden infant death syndrome (SIDS) rates remain high in countries with advanced economies. Deciphering current risk factors for SIDS requires well-designed epidemiological studies. We aimed to systematically review the methods used in studies assessing SIDS risk factors.

Methods: Two review authors independently and systematically searched on PubMed and Google Scholar for case-control studies published between 1965 and 2021 reporting SIDS risk factors, selected relevant studies, and extracted data. We described study designs and used univariate analysis to assess their evolution over the study period.

Results: We included 185 articles, reporting 114 different designs of case-control studies, published between 1965 and 2021 and conducted in 28 countries. Most studies were conducted at a regional level and used systematic (94%) and incident (73%) case recruitment methods. SIDS cases were mostly recruited through death certificates (73%), coroners (56%), and hospitals (50%). Controls were mostly recruited through birth certificates (70%), hospitals (40%), and maternities (30%). The median number of cases per study was 244 (min/max: 4/21,126; inter-quartile range: 107-398).

Controls were selected randomly (56%) – with (30%) or without (70%) a described method – or consecutively to each case (53%). Most studies selected controls without applying exclusion criteria (74%) and controls were frequently matched with cases (86%), mostly on age (83%). Throughout the study period, methods shifted towards national recruitment, with incident cases, and recruitment of controls through birth certificates ($p < 0.05$ for all comparisons).

Conclusion: Methods used in case-control studies to identify SIDS risk factors exhibited substantial variability and evolved towards larger population-based design. These findings provide methodological insights to inform future research in the field.

O-080 Understanding Sudden Unexpected Death in Children Over 1 Year of Age

by Vicky Sleap | University of Bristol

Objectives: To identify unexpected deaths of children (1 to 17 years) and investigate similarities and differences in social, medical, developmental, and environmental factors between those that are explained and those that remain unexplained.

Methods: The National Child Mortality Database (NCMD) collects information on all child deaths in England, with statutory notification within 48 hours. NCMD paediatricians review notifications daily. All sudden unexpected deaths of children (SUDC) undergo a full child death review process. SUDC deaths in the calendar year of 2020 were analysed in detail.

Results: Of the 255 SUDC aged 1-17 years in 2020, child death reviews had been completed for 204 (80%) (66 children aged 1-4; 138 aged 5-17). For unexpected child deaths aged 1-4 years, 22 (33%) remained unexplained, whilst for children aged 5-17 years, 10 (7%) remained unexplained. For both explained and unexplained deaths, there was an excess of children of non-white ethnicity and more deprived neighborhoods. The male excess in the explained deaths was not seen in the unexplained deaths. Parental smoking, drug and alcohol use were not different between the two groups, but for both around half the families were known to social care; 21% of the explained deaths and 31% of the unexplained deaths had a history of parental violence. Of the children whose deaths remained unexplained, 27% had a history of convulsions, compared to 32% of those whose deaths were explained.

Conclusion: SUDC is a rare event. The link with febrile convulsions has been previously reported for the unexplained sudden deaths in childhood. Our research demonstrates that this link is as strong for the explained deaths. The association with socioeconomic deprivation is less clear than for unexplained infant deaths, and the evidence base around other potentially contributory factors is weak. Research to investigate the potential importance of febrile convulsions in unexpected child deaths is urgently needed.

P01 Epidemiology of SUID and Stillbirth

P01-1 The Baby Sleep Planner: process evaluation of a UK assessment and planning tool for families with infants at increased risk of sudden and unexpected death in infancy

Jenny Ingram[1], Anna S Pease[1], Peter Fleming[1], Karen Patrick[2], Kieren Pitts[3], Becky Ali[1], Nicholas Turner[1] and Peter S Blair[1] and The Baby Sleep Project Family Advisory Group

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Objective: Successful national campaigns have lowered sudden and unexpected infant death rates over the past 3 decades, but deaths persist in socio-economically deprived families in the UK. The majority of sleep related deaths occur in an unsafe sleep environment suggesting that improvements to support for some families to follow this advice more consistently could save lives. We report on the evaluation of a risk assessment and planning tool that aims to improve the uptake of safer sleep advice in families with infants at increased risk of SUDI.

Methods: An individualised SUDI risk assessment and tool to plan for safe sleep during times of disruption (the Baby Sleep Planner) was evaluated using qualitative methodology. Advice within the tool was concordant with UK guidance from The Lullaby Trust[1] and NICE[2]. User testing of the tool was conducted by health visitors, midwives and family nurses. Qualitative interviews with health professionals and families allowed for iterative changes to the tool and for insights into its function and influence on parental behaviour.

Results: Twenty-two health professionals enrolled in the evaluation, of which 20 were interviewed. Twenty parents were interviewed about their experiences with the tool. Health professionals reported appreciating the functionality of the tool, allowing them to identify at risk families for further support. They suggested expanding use to include relevance in the antenatal period, and versions available in languages other than English. Parents were positive about the tool, feeling that it was useful and appropriate and that the plans would be of benefit to them and other family members.

Conclusions: Minor refinements to the tool based on these findings have ensured that the tool is now ready for testing in a larger study. In depth evaluation of how the tool works will support successful implementation.

References:

1. The Lullaby Trust [online] Available at: https://www.lullabytrust.org.uk
2. NICE. (2022). Postnatal Care [NG194]. [online] Available at: http://www.nice.org.uk

P01-2 SUDI in child-care setting in the Netherlands

Kanits F, L'Hoir MP , Semmekrot B, Engelberts AC, Feskens

Objective: In the Netherlands, the number of children attending formal childcare increased over the past decades. In 2021, 540,410 children aged 0 to 3 years attended formal day care, for an average of 790 hours. About a quarter of the 0 year old attended formal day care in 2015 (± 40,000 children), and about 45% of 1 year olds (± 81,000 children). H igher SUDI rates in childcare settings than expected have previously been found. The aim of this study was to compare the SUDI incidence in and out of childcare setting s and describe the prevalence of risk factors in both groups.

Method: The Dutch SUDI Expert Group collected data of 317 SUDI cases aged 0 - 12 months from 1996 2023. Included for analysis where those aged 3 12 months, that died on a weekday between 8am and 6pm (N=98). The expected number of SUDI cases in childcare settings was calculated given the number of children attending childcare in the Netherlands and the average time per week spend there. SUDI cases from 2010 2023 in childcare homes and centres (n= 18) were compared to SUDI cases out of childcare settings, e.g., at home (n=16).

Results: A 2. 6 times higher SUDI incidence than expected was observed in childcare settings compared to the incidence outside the childcare setting (p<.001). Among SUDI cases between 2010 2023, cases in childcare settings were more often female (55% vs. 25%), first born 25 % vs. 13 %), and parental education level was higher. In childcare children more often were placed supine (72 vs 50%), in a sleeping sack (73 vs. 42%), last sleep without a pacifier (75% vs 50%), breastfed (29% vs. 8%) and had parents who did not smoke (89% vs. 64%).

Conclusion: Generally, childcare centres in the Netherlands strictly adhere to the Dutch national SUDI prevention guidelines, and the data on risk and preventive factors support this notion.

P01-3 Dutch safe sleep survey

Floortje Kanits, Monique L'Hoir, Magda Boere-Boonekamp, Adèle Engelberts, Edith Feskens

Objective: The aim of this study is to describe to what extent Dutch parents of infants aged 0-11 months comply with the Dutch safe sleep recommendations, and to explore reasons to deviate from these recommendations.

Methods: A cross sectional study with an online questionnaire was distributed through Youth Healthcare organizations. A total of 2870 responses were included for analysis.

Results: The prevalence of adherence to safe sleep recommendations was relatively high. The majority of infants were usually placed to sleep in the supine position, with a higher prevalence in younger infants. Room-sharing practices showed a significant increase compared to the last survey in 2017, particularly among infants aged 0-6 months. The use of sleep sacks, and avoidance of duvets and large soft toys in infant beds also showed positive trends. It was observed that parents extensively used internet and social media for information on safe sleep practices. Parental perception of infant sleep quality was associated with both sleeping position and place.

Conclusion: The findings of this study indicate an improvement in adherence to safe sleep recommendations compared to the previous survey conducted in 2017. The increase in room-sharing practices and the use of sleep sacks are positive developments. However, there are still areas that require attention, such as bed-sharing with young infants. The extensive use of internet and social media for information-seeking suggests the importance of monitoring online information about safe sleep practices. Parental perception of infant sleep quality and its association with sleeping position and place highlight the need for further research and possible interventions to support parents in promoting safe sleep. Despite certain limitations, this study provides valuable insights into the current state of safe sleep practices in the Netherlands and serves as a basis for future improvements in infant care. Besides, it provides implications for SUDI prevention in other countries.

P01-4 Spatial analysis of Sleep-Related Infant Deaths in Argentina (1997-2019)

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Objective: Our objective was to analyze the spatial and temporal variation of sleep-related infant deaths (SID) and its causes in Argentina between 1997-2019. Differences in the prevalence of supine positioning and other sleep environment conditions among different ethnic populations may contribute to these disparities multidimensional.

Methods: Data on SID were obtained from the Ministry of Health of Argentina. The rate of SID (SIDR) and the percentages of causes of deaths (R95, R96, R98, R99, W75, W78 + W79, classified according to ICD-10 diagnostic codes) were calculated geographically at the level of regions and departments and for periods of three years. Argentina can be grouped into five geographical regions based on environmental similarities: North-West (NWA), North-East (NEA), Cuyo, Centre and Patagonia. Moran index and Local Indicators of Spatial Association (LISA) were used to describe temporal and spatial variation.

Results: There is a negative secular trend in SIDR, which is more pronounced and significant in the more developed regions of the country. The SIDR by triennium and region are highest in all the country at the beginning of the time series and during the first fifteen years, followed by a progressive and consistent reduction. However, it continues to rise persistently in Cuyo, NWA, NEA and Centre.

Conclusions: The investigation study presented three main areas: 1) Addressing the potential impact of structural racism; 2) Recognizing the lack of access to economic, social and educational resources as a risk factor for sleep-related infant deaths; 3) It is essential to create a SID National Registry standardizing data collection throughout the territory. In this way, this federal registry would allow real-time knowledge of the factors that contribute to the risk of SID and optimize preventive recommendations taking into account the georeferencing of cases to know the areas in which actions should be focused and efforts concentrated.

P01-5 Prevalence of SIDS risk factors in England: National data collected in 2020 compared to population controls collected in 2016/17

by Peter Blair | Anna S Pease | Nicholas Turner | Tom Williams | Becky Ali | Jenny Ingram | Karen Patrick | Karen Luyt | Vicky Sleap | Peter Fleming | University of Bristol | University of Bristol | University of Bristol | University of Bristol | University of Bristol | University of Bristol | Royal United Hospitals, Bath | University of Bristol | University of Bristol | University of Bristol

Objective: Given the welcome decline in Sudden Infant Death Syndrome (SIDS) rates, few case-control studies are conducted internationally to measure the current prevalence of risk factors in the infant sleeping environment. The National Child Mortality Database (NCMD), based in Bristol, collects detailed data on all child deaths in England. The aim of this investigation was to identify any changes in previously reported SIDS risk factors.

Methods: SIDS deaths reviewed by a Child Death Overview Panel (CDOP) including a full post-mortem in 2020 were compared to control infants recruited in two hospitals (Bristol and Birmingham) from June 2016 to August 2017. A control infant sleep was chosen in the 24-hours prior to interview to reflect both the age distribution of SIDS infants and whether a day-time/night-time sleep.

Results:

Of the 361 unexpected infant deaths that occurred in England during 2020, 75% (n=270) had been reviewed by a CDOP by September 2022. Of these, 138 were classified as SIDS.

The 133 SIDS thought to occur during sleep were compared with 194 recruited controls.

The SIDS infants (median age=67 days [iqr:34-119 days]) were slightly younger than the controls (median age=77 days [iqr:44-114 days]) with a higher male preponderance (61.7% vs 46.4% controls). Infants placed prone

(17.3% vs 1.6% controls, OR=15.2 [95% CI:4.3-54.0]) or on their side (16.3% vs 7.3% controls, OR=3.1 [95% CI: 1.4 to 6.7]) were still significant risk factors. Infants found in hazardous co-sleeping environments (on sofa, with parents consuming alcohol or drugs, parents who smoked or pre-term infants <3 months old) was highly significant (45.5% vs 3.1% controls, OR=27.1 [95% CI:11.2-65.9]) whilst co-sleeping in the absence of these hazards was not (6.8% vs 8.7% controls, [OR=1.4 [95% CI:0.6-3.4].

Conclusion: Previous risk factors surrounding sleep position and hazardous bed-sharing are still present suggesting targeted intervention of these vulnerable families is needed.

P01-6 Unexplained infant death in Houston, TX: A 17-year retrospective

by Savannah Lusk | Melissa Blessing | Andersen Chang | Angela Bachim | Christopher Greeley | Jennifer Ross | Russell Ray | Baylor College of Medicine | Texas Children\'s Hospital | Baylor College of Medicine | Baylor College of Medicine | Baylor College of Medicine | Harris County Institute of Forensic Sciences | Baylor College of Medicine

Objective: Objective: To understand the epidemiological trends of SUID in Harris County from 2004-2021.

Methods: Using data from Child Fatality Review Team (CFRT) of Harris County, the Medical Examiner’s Office, and the Texas Department of State Health Services, we performed a retrospective analysis of 17-years of SUID cases in Harris County, Texas. We applied a novel birth rate correction for SUID rates over the first year of life. Associations were tested using a Tukey HSD and linear regression models with co-linear factors considered.

Results: To focus on biologically and environmentally unexplained SUID cases, we subsetted our dataset into two groups: Group 1) SIDS and Undetermined causes of death (COD) and Group 2) SIDS only COD. Our preliminary data includes 1,094 (Group 1) and 406 (Group 2) cases. Across all cases, is comprised of ~43% black, ~32% Hispanic, ~20% white, ~3% Asian, and ~0.4% unknown and 57% male infants. Distribution of death across the first 12 months of life shows a peak of death around 2 months of age. We do not see an association with month or season in the raw SUID data nor using our correction for birth rates. When we apply the standard per 1,000 live births normalization, we see a significant increase in Spring and Winter only for Group 1. We also report race-dependent significant differences in yearly and monthly trends, male-to-female ratios, and age at death and race dependent significant associations between SUID cases and adults diagnosed with asthma, income level, and overcrowding based on Zip Code.

Conclusions: This dataset represents one of the most racially and socio-economically diverse in the United States. We show that standard trends may be driven by majority white datasets and that response to socioeconomic stress varies by race/ ethnicity, which leads to differences in risk between classically described minority groups.

P01-7 Comparing explained vs unexplained SUDI in England

by Vicky Sleap | University of Bristol

Objective: To identify sudden unexpected deaths of infants (SUDI) and compare background characteristics between those that are explained and those that remain unexplained.

Methods: The National Child Mortality Database (NCMD) collects information on all child deaths in England, with statutory notification within 48 hours. NCMD paediatricians review notifications daily. All sudden unexpected deaths of infants (SUDI) undergo a full child death review process. SUDI deaths in the calendar year of 2020 were analysed in detail.

Results: Of the 361 SUDI during 2020, child death reviews had been completed for 249 (69%) (73 infants aged 0-27 days; 176 aged 28-364 days). Of SUDI aged 0-27 days 26 (20%) remained unexplained; for those aged 28-364 days 103 (80%) remained unexplained. For unexplained deaths, 64%

were male and 36% female compared to 49% male and 51% female for explained deaths. A significantly larger proportion of unexplained deaths were of infants living in the most deprived neighbourhoods (42%) than those in the least deprived neighbourhoods (8%). This was also true of the explained deaths – 34% in most deprived and 10% in the least deprived. The unexplained deaths were strongly associated with low birthweight (29%), prematurity (28%), multiple births (8%), larger families (44%), admission to a neonatal unit (28%), maternal smoking during pregnancy (50%), young maternal age (36%), parental smoking (69%) and parental drug misuse (35%). The profile of vulnerability surrounding the birth characteristics was even more marked among the explained deaths.

Conclusion: SUDI is a rare event. For unexplained sudden deaths in infants the link with socioeconomic deprivation is clear as is the evidence base around other potentially contributory factors such as prematurity and admission to a neonatal unit. However, the same factors are even more significant for those deaths that were eventually explained, and further research is needed to investigate the reasons for this.

P02 International trends in SUID

P02-1 Whole genome sequencing analysis: a project to identify genetic determinants of unexplained Sudden Unexpected Infant Death

by Eleonora Dicesare | Sonia Scopelliti | Edoardo Errichiello | SUID&SIDS Italia | SUID&SIDS Italia | SUID&SIDS Italia

Introduction: Recent scientific studies aimed to investigate the genetic basis underlying SIDS ethiopathogenesis. These studies were focused on specific subset of genes involved in the regulation of serotonin transport and its precursors in the brainstem, genes associated with epileptiform conditions, cardiomyopathies, arrhythmic syndromes, and metabolic disorders. The Piedmontese Reference Center for Pediatric Sleep Medicine and SIDS, in collaboration with the University of Pavia, intends to promote a pilot project based on the retrospective analysis of a homogenous and single-center cohort of SIDS.

Methods: The preliminary cohort is composed of 20 unexplained SIDS selected from a wider cohort of cases identified as SIDS 1B according to Klaus classification (mean age 98 days), collected in the Regina Margherita Children's Hospital (Turin) from year 2004 to 2020, of whom detailed clinical records and archival dried blood spot specimens are available.
Samples will undergo DNA extraction and after quality check, whole-genome sequencing (WGS) analysis.

Results: A specific aim of the project, although performed on a small sample size, will be to compare the detection yield of WGS (presumably higher) to existing literature data, which are mainly based on gene panels or whole-exome sequencing (WES). Furthermore, WGS approach may allow characterizing in more detail the genetic architecture of SIDS by looking at both coding and non-coding regions of the genome.

Conclusion: In February 2023, SUID&SIDS Italia provided funding for an ongoing project, leaded by the University of Pavia in collaboration with the

Lino Rossi Research Center (Milan), focusing on the genetic causes of stillbirths. Furthermore, the organization aims to foster research endeavors pertaining to the genetic underpinnings of unexplained SUID.

This particular domain of study continues to suffer from a dearth of scientific evidence, necessitating heightened efforts to address this knowledge gap, hoping to be able to provide answers to families and prevent tragic events in the future.

P02-2 When connection protects against SIDS: the telematic network of the Piedmont region for the diagnostic assessment of at-risk infants.

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Introduction: In 1994 in Turin Children Hospital Regina Margherita (Piedmont region, Italy) a Reference Center for the surveillance and prevention of SIDS was founded and in 2004 a protocol for the epidemiological surveillance of sudden deaths from 0 to 24 months was started in collaboration with the Public Health Department. In order to offer the clinical-diagnostic competence of the Reference Center to the whole territory in a uniform way, a telematic network was created. Twenty pediatric and neonatal units were equipped with the same cardiorespiratory monitor, which allows infants admitted to different regional facilities to undergo 24 hour recordings subsequently sent to the regional Reference Center for analysis and evaluation.

Therefore, in 2013 a pediatric regional board on ALTE was founded and a technical document was produced to standardize the management of ALTE cases throughout the regional network. The aim of this study is to verify the effectiveness of the network regarding a homogeneous approach to infants affected by ALTE through an epidemiological surveillance from January 2019 to August 2021.

Methods: a database analyzing 563 cases of ALTE was created to assess the management of the ALTE phenomenon. The authors chose the execution of the following exams as markers of adherence to the new regional recommendations: electrocardiogram, blood gas analysis and 24 hour recording cardiorespiratory monitoring.

Results: over the total of the patients considered the blood gas analysis was performed in 81% of the cases, electrocardiogram in 79%, while cardiorespiratory monitoring in 80%.

Conclusion: the management appears reasonably consistent across most participating centers, assuring an homogeneous treatment of infants with ALTE all over the regional territory. These results acquire particular value considering the elusive and difficult clinical framework of the ALTE phenomenon.

P02-3 Skin-to-skin contact and delivery room practices in Piedmont and Aosta Valley Italian Regions: 2020-2022 update

by Silvia Noce | Michelangelo Barbaglia | Eleonora Dicesare | Andrea Guala | Alessandro Vigo | Maria Chiara Russo | Centre for Pediatric Sleep Medicine and for SIDS, Ospedale Infantile Regina Margherita, Città della Salute e della Scienza di Torino | S.C. Pediatria, Ospedale Castelli, Azienda Sanitaria Locale VCO, Verbania, Italy | SUID&SIDS Italia | S.C. Pediatria, Ospedale Castelli, Azienda Sanitaria Locale VCO, Verbania, Italy | Dipartimento Materno Infantile, ASL CN2, Ospedale Pietro e Michele Ferrero di Verduno | S.C. NICU, Ospedale Maria Vittoria, Torino

Background: Sudden unexpected postnatal collapse of presumably healthy neonates during early skin-to-skin contact is a rare, yet recognized occurrence, associated with a high risk of mortality and morbidity. A survey was conducted in 2012 and again in 2016 throughout almost the whole Piedmont and the Aosta Valley Northern Italian regions, to evaluate the environmental and logistical aspects that could be linked to SUPC in delivery wards. The authors were interested to verify the evolution of the management of skin-to-skin according to the Italian society of neonatology recommendations, through a new surveillance with preliminary results.

Methods: the same questionnaire created in 2012, about the management of the early skinto-skin practice in neonatal units, has been proposed again in May 2023 to all the delivery wards, after an integration including questions about application of safe sleep rules and about the count of SUPC cases occurred. The collected data were elaborated anonymously. At the time of data analysis, 20 completed questionnaire out of 30 units were collected.

Results: in the present surveillance 45509 newborns from 2020, 2021, 2022 were considered. Early skin-to-skin contact was proposed in all the delivery rooms and took place immediately. No significant differences were found regarding newborns safety supervision. Compared to the past the following differences were highlighted: early skin-to-skin lasted at least 2 hours in 14/20; routine newborn care was given maximum after 2 hours in 16/20. Vital parameters monitoring with biomedical devices was performed in 4/20 wards during skin-to-skin.

Conclusion: this update demonstrates how attention to the safety of the newborn during skin-to-skin contact has remained constant after 7 years, with the introduction of previously unavailable data from biomedical instruments (pulse oximeter and cardiac frequency monitoring).

P02-4 Knowledge and Recommendations for Sudden Infant Death Syndrome Prevention: Insights from Latin America

by María Luisa Latorre, Laura Castro | Fundación Universitaria Juan N Corpas

Objective: The objective of this study is to assess knowledge about sudden infant death syndrome (SIDS) and the recommendations provided by pediatricians and other healthcare professionals to families for its prevention. The study aims to identify areas for targeted educational campaigns and interventions to reduce the incidence of SIDS and home deaths in Latin America.

Methodology: This cross-sectional cohort study was conducted in collaboration with the Sudden Infant Death Prevention Committee of the Latin American Pediatric Association (ALAPE). A survey based on the 2022 American Academy of Pediatrics (AAP) recommendations was utilized, consisting of 11 questions to evaluate knowledge about safe sleep practices for SIDS prevention. The survey underwent rigorous content validation (Coefficient = 0.88) and internal reliability validation (KR20 = 1). A total of 774 participants from 17 Latin American countries were included, including 547 pediatricians, 45 other healthcare professionals, and 190 students.

Results: The survey received the highest number of responses from pediatricians in Uruguay (223) and Colombia (202). Among pediatricians, 98.1% acknowledged the preventability of SIDS. Recommendations included placing infants on their backs for sleep (86.27%), using pacifiers (29.3%), using pillows (6.49%), and using a soft mattress (3.34%). Furthermore, 66% believed that complete age-appropriate vaccination reduces the risk. Among students, 73% of medical and public health students recommended the back sleep position, while only 21% of nursing assistant students did so.

Conclusions: The study highlights the need to extend research to other Latin American countries, particularly those with lower rates of recommending the back sleep position, such as Guatemala and Paraguay (around 60%). Additionally, nursing assistant students demonstrated lower knowledge regarding safe sleep practices. These findings emphasize the importance of targeted campaigns and educational interventions to enhance awareness and knowledge regarding SIDS prevention in the region.

P03 Pathophysiology

P03-1 The toxic duo for high SIDS rates: prone sleeping with a stuffy nose

by Henning Wulbrand | Pediatric Neurology

Parallel to spreading the prone sleep position for infants after medical recommendation in books (Baby and Infant Child Care, Benjamin Spock, see Ruth Gilbert 2005) since 1943-88 the incidence of Sudden Death in infants increased up to 60.000 victims worldwide turning out to be the most tragic mistake in the history of Pediatrics. In 50-70% of these cases an upper airway infection coincided. The hypothesis is, that an exacerbation of O2-desaturations occurs during rebreathing air with low fiO2.

In 40 infants (age 1-49 weeks) O2-saturation recordings during mild rhinitis. Supine sleeping infants spent 1,7% of total sleep time <95% O2-saturation in contrast to 22,9% sleeping prone skin to skin on mother´s chest and 57,5% in a prone/side sleeping infant. Mean O2-saturation and number of O2-desaturations >4% in supine sleeping infants was 98,7% and 7,7/hour compared to 95,2% and 22,1/hour in the skin to skin sleeping infant and 93,2% and 28,2/hour in the side/prone sleeping infant. The initial O2-saturation correlated to the number and extent of O2-desaturations.

This could be explained by a O2-saturation shift to the steeper part of the sigmoid O2-Hemoglobin-Dissociation curve. The prone/side sleeping infant showed no O2-desaturation during strict supine sleep, but several prolonged periods of low O2 saturation <70% up to 15 sec while rebreathing. This infant was found in prone face down position 6 weeks before and successfully resuscitated by the mother. The low O2-saturation could have been associated with a collapse of muscle tone and consciousness leading to rolling over to prone face down position issuing to suffocation as described by pathologists and coroners already in 1944.

In conclusion rebreathing with a stuffy nose is leading to an exacerbation of number and intensity of O2-desaturations potentially issuing in suffocation in face down position in a subset of SIDS victims.

P03-2 Cardiorespiratory Arousal from Obstructive Apneas in infants with Bronchopulmonary Dysplasia and mechanisms of failure

by Henning Wulbrand | Pediatric Neurology

Ex preterm infants particularly with Bronchopulmonary Dysplasia have an increased risk for SIDS. The hypothesis was that the balance of diaphragmatic and submental muscle activity can be disturbed during oxygen decrease leading to upper airway obstruction and to life threatening events. Apnea termination is performed by an augmented breath, submental EMG activation and heart rate increase without cortical arousal activation.

Polygraphic recordings, including surface EMG (EMGsub, EMGdia), EEG, ECG, and transcutaneous PO2/PCO2 (tcpO2/tcpCO2) were performed on 10 preterm infants at 36, 40, 44, and 52 weeks of conceptional age. EMGsub increased initially, then decreased in 28 of 33 non-rapid eye movement (N-REM) sleep apneas (REM: 35 of 69 events). This correlated
with a decrease of tcpO2 during N-REM sleep ($p < 0.05$). A parallel decrease of EMGsub and EMGdia was correlated with the occurrence of bradycardia (REM and N-REM: $p < 0.01$). Concomitant termination of apnea and bradycardia ($n = 22$), occurred in the presence of a phasic, simultaneous activation of EMGsub and EMGdia in 64% of REM sleep and in 79% of N-REM sleep-related event, was characterized by a deep inspiration, and correlated
with the extent of tcpO2-decline during REM sleep apneas ($p < 0.05$) without occurrence of cortical EEG arousal. EEG activity decreased during the begin of apneas in REM and NONREM sleep reflecting an aroused state due to EEG desynchronization. Apnea termination was achieved by a "Cardiorespiratory Arousal" activation: an augmented breath, increase of submental EMG activity and heart rate without the occurrence of EEG arousal activation.
During extreme O2 decrease this mechanism failed with occurrence of bradycardia issuing in asystole due to increased vagal tone.

In conclusion termination of obstructive apneas is performed by subcortical brainstem related activation, "Cardiorespiratory Arousal" without cortical EEG arousal while O2 levels remain above a critical minimum.

P03-3 Biomarker-based risk stratification for Sudden Infant Death Syndrome (SIDS): a study protocol of the BIOMINRISK project

by Mathilde Ducloyer | Patricia Franco | Alban-Elouen Baruteau | Vincent Sapin | Loïc de Pontual | Aurore Guyon | Frédéric Savall | Pauline Scherdel | Léa Ferrand | Bérengère Jarry | Sophie de Visme | Christèle Gras-Le Guen | Fleur Lorton | Nantes Université, CHU de Nantes | Université de Lyon1, Hospices civiles de Lyon, Inserm | Nantes Université, CHU de Nantes, Inserm, CIC 1413 | Université Clermont Auvergne | Université Paris-Cité, Hôpital Jean Verdier, AP-HP, | Université de Lyon1, Hospices civiles de Lyon, Inserm | Université de Toulouse, Hôpital Rangueil | Nantes Université, CHU de Nantes, Inserm, CIC 1413 | Nantes Université, CHU de Nantes, Inserm, CIC 1413 | Nantes Université, CHU de Nantes, Inserm, CIC 1413 | Nantes Université, CHU de Nantes, Inserm, CIC 1413 | Nantes Université, CHU de Nantes, Inserm, CIC 1413 | Nantes Université, CHU de Nantes, Inserm, CIC 1413

Objective: The overall aim of the BIOMINRISK project is to identify new biomarkers involved in the pathophysiological mechanisms of sudden infant death syndrome (SIDS) along three axes: (i) genetic: to identify new genetic variants associated with sudden unexpected infant death (SUDI); (ii) neurobiological: to understand the involvement of different neuromodulators in the physiopathology of arousal deficits in infants who have died of SUDI; (iii) radio-anatomical: to map the upper airways of infants who have died of SUDI using computed tomography.

Methods: We will analyze data from 250 cases of SUDI included in the French SUDI registry between 2020 and 2024 for which biological samples and medical imaging were collected. We will conduct 3 parallel studies in these SUDI cases: 1) Genetics: a trio analysis by whole genome sequencing of SUDI cases and their two parents; 2) Neurobiological: a case-control study of concentrations of neuromodulators involved in the sleep/waking regulation system (butyrylcholinesterase, serotonin in serum and orexin in cerebrospinal fluid). Living controls (450 infants) with a blood test and a lumbar puncture as part of their routine care will be recruited prospectively in the 15 participating French hospitals between 2023 and 2024 and will be matched to SUDI cases on age and sex; 3) Radio-anatomical: a case-control study of anatomical variations in the upper airways (nasomaxillary complex, oral cavity) using the principle of geometric morphometry based on landmarks. Living controls (250 infants) will be recruited by selecting infants who have had a brain CT scan including the facial bones and will be matched to SUDI cases on age and sex.

Dissemination: Our multidisciplinary approach will enable us to identify new biomarkers involved in SIDS. Their integration into a SIDS risk stratification algorithm should help to personalize prevention and reduce the SIDS incidence rate.

P03-4 Screening for inherited cardiac conditions after stillbirth or SIDS: by family screening and/or genetics? A literature search

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Background: Causes of stillbirth and sudden infant death syndrome (SIDS) often remains unknown. Several studies have identified inherited cardiac conditions (ICC) as an underlying cause in some. Establishing a diagnosis of ICC is essential to lower recurrence risk in families. After sudden death in pediatric patients (age 1-18 years) a combined approach of genetic testing and cardiological screening in first-degree relatives has proven beneficial in identifying ICC.

Objective: To establish the diagnostic yield of genetic testing and/or family screening for ICC in stillbirth/SIDS.

Methods: A PubMed literature search was performed on genetic testing/family screening/ICC in stillbirths and SIDS. Genetic outcome was evaluated to determine the prevalence of (likely) pathogenic variants and variants of unknown significance (VUS) in genes associated with ICC.

Results: 9 (retrospective) cohort studies on the genetic yield of ICC were included (n=421 stillbirths and n=751 SIDS cases in total). In 1 % of stillbirth cases and 10% of SIDS cases a (likely) pathogenic variant was reported in: TRPM4 and SCN5A (both 0,8 %), KCNH2 (0,5%), ANK2 (0,3%), KCNE1 and KCNE2 (both 0,2%). VUS were identified in 16% of the stillbirths and 36% of the SIDS cases. Data on segregation of variants were absent. No relevant studies on diagnosing ICC by cardiological screening in families following stillbirth or SIDS were found.

Conclusions: This literature survey indicated that: 1) ~ in 1:100 cases of stillbirths and 1:10 cases of SIDS (likely) pathogenic variants were identified in genes associated with inherited cardiac arrhythmia syndromes, 2) no studies on cardiological screening in first-degree relatives in these specific groups have been performed (so far). This, combined with the relatively high percentage of VUS found, indicates that further studies are needed to evaluate the role of genetic testing versus detailed family evaluation (family history and/or cardiological screening) in cases of stillbirths and SIDS.

P03-5 Immunological protein profile in sudden infant death syndrome (SIDS)

by Linda Ferrante | Siri H. Opdal | Roger W. Byard | Oslo University Hospital, Oslo, Norway | Oslo University Hospital, Oslo, Norway | Oslo University Hospital, Oslo, Norway/The University of Adelaide

Objective: The aim of this study was to investigate a panel of immune proteins in cases of sudden infant death syndrome (SIDS). Our hypothesis is that, in at least a subset of SIDS cases, a dysregulated immune response is a contributing factor leading to death.

Methods: The subjects in this study included 46 SIDS cases (median age 16.3 weeks, range 1.5-47 weeks) and 41 controls (median age 58 weeks, range 0-215 weeks), all autopsied at the Department of Forensic Sciences, Oslo University Hospital. The causes of death in the controls were accidents/trauma. Samples of cerebrospinal fluid (CSF) were analyzed quantitatively by Proximity Extension Assay (PEA) technology developed by Olink, using the Immune Response PEA panel from Olink® Proteomics.

Results: The initial results revealed that normalized protein expression differed between SIDS cases and controls for 28 of the proteins. This abstract will focus on five proteins that are involved in immune system regulation. IFNLR1 ($p=0.003$), IL10 ($p=0.007$), IRAK4 ($p<0.001$) and IL6 ($p=0.035$) all had lower protein concentrations in SIDS cases compared to controls, while for CD28 ($p=0.024$) higher protein concentrations were found in SIDS cases compared to controls.

Conclusion: The results from this study confirm previous research indicating that a dysregulation of the immune system may be a predisposing factor for SIDS. We found that the CSF concentration of several immune proteins, including IL6, IL10 and IFNLR1 (the latter being an interleukin receptor associated kinase) was significantly different in SIDS cases compared to controls. The results indicate that these aberrant protein concentrations may point to a cytokine storm and uncontrolled defense mechanisms toward the common cold or other non-fatal infections. This may be lethal if the infant at the same time is at a vulnerable developmental stage, and is exposed to external risk factors such as maternal smoking or prone sleeping.

P04 Prevention

P04-1 The Baby Sleep Planner: involving families in designing an intervention to reduce the risk of sudden infant death syndrome

By Anna S Pease1, Jenny Ingram1, Peter Fleming1, Karen Patrick2, Kieren Pitts3, Becky Ali1, Nicholas Turner1 and Peter S Blair1 and The Baby Sleep Project Family Advisory Group

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Objective: Reductions in sudden infant deaths have stalled for families in more socially deprived groups, and new approaches are needed. Involving families in the design of new ways of communicating safer sleep messages may hold the key to successful engagement with this group. We describe the development of a risk assessment and planning tool that aims to improve the uptake of safer sleep advice in families with infants at increased risk of SIDS.

Methods: Online workshops, email and one-to-one meetings between fifteen family advisors and two members of the research team provided a safe and productive environment to develop a web-based tool with two parts: an individualised SIDS risk assessment and a tool to plan for safe sleep during times of disruption. This collaboration between researchers and family members also sought to develop a model for how risk communication can be improved.

Results: A final model for risk communication about safer sleep with families with infants at risk included six stages of communication: 1) Be honest, 2) Give a rationale, 3) Provide practical steps, 4) Learn from other's experiences, 5) Ask about a plan, 6) Share with wider support. This model was employed throughout the development of the Baby Sleep Planner, with continual refinements as discussions between families and the research team progressed. Family involvement further strengthened the development of the tool by keeping wording and images accessible, inclusive of people who don't live in standard housing, and families with more than one baby.

Discussion: Our collaboration between the research team and family members sought to uphold the principles of coproduction: valuing different forms of knowledge and sharing power. Family involvement in the coproduction of resources for infant safety is a powerful way to make those resources more effective and protect more infants from sudden and unexpected death.

P04-2 Understanding Sudden Unexpected Death in Infants: Insights from Pacific mothers and grandmothers living in Aotearoa New Zealand.

by Amio Matenga Ikihele1,, Kalesita Pole1, Ane Fa'aui1, Maryann Heather2, Fiona Langridge3, Janine Paynter2 Teuila Percival, 1,2 Vili Nosa2*
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Background: Sudden Unexpected Death in Infancy (SUDI) is the leading cause of post-neonatal mortality in Aotearoa New Zealand. It is an important equity issue, affecting Māori and Pacific Island families disproportionately, including those who live in socioeconomically disadvantaged regions. Māori infants are nearly nine times more likely (RR of 8.96), and Pacific infants, are six times more likely (RR of 5.85) to experience SUDI compared to non-Māori and non-Pacific infants. The aim of this study was to explore the knowledge, awareness and understanding of SUDI among Samoan, Tongan, Cook Island and Niue mothers and grandmothers living in Aotearoa, New Zealand.

Methods: This study utilised the Kakala framework underpinned by the Talanoa method, allowing authentic insights reflective of real-life experiences by mothers and grandmothers to be shared. The Kakala framework describes the Tongan process of making a garland of flowers using four steps: teu (to prepare); toli (to collect); tui (to string together the flowers); and luva (gifting of the garland).

Mothers and grandmothers identifying with Samoan, Tongan, Cook Island, or Niue heritage, with a child or grandchild under two years, and living in Aotearoa New Zealand, were invited to participate in the talanoa. Two in person and six online talanoa using the platform Zoom were facilitated in 2022, each lasting approximately one to two hours. Data was analysed using a general inductive approach.

Results: Four themes were identified: (1) Knowledge and awareness; (2) Sleep practices; (3) Sources of information; and (4) Cultural and generational differences.

Conclusion: The insights from this study provide an important foundation to understand how Samoan, Tongan, Cook Island and Niue concepts can be used for culturally appropriate SUDI prevention campaigns. Importantly, it also highlights areas that can optimise the health and wellbeing of Pacific infants and families living in Aotearoa New Zealand.

References:

1. Tipene-Leach D, Fidow JF. 2022. Sudden Unexpected Death in Infancy Prevention in New Zealand: The Case for Hauora – a wellbeing approach. Wellington: Ministry of Health.
2. Ministry of Health. (2022). Sudden Unexpected Death in Infancy: An analysis of coronial SUDI Liaison Reports from Sept 2018 to June 2020 with subsequent recommendations. Wellington: Ministry of Health.
3. Rutter, C., Walker, S. Infant mortality inequities for Māori in New Zealand: a tale of three policies. Int J Equity Health 20, 10 (2021). https://doi.org/10.1186/s12939-020-01340-y

P04-3 The importance of culturally grounded SUDI prevention approaches when connecting with Pacific families in Aotearoa New Zealand

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Background: A consistently higher rate of Sudden Unexpected Death in Infancy (SUDI) is reported among Pacific infants compared to non Māori and non Pacific infants, 1,2 leading to a demand for new approaches to infant care and maternal and family wellbeing that are culturally grounded, family and Pacific values centered. My Baby's Village flagship programme was established in 2021 in response to a need to support the New Zealand Police in leading a Pacific approach to preventing SUDI . With funding from the Ministry for Social Development through Pasefika Proud pathways, a Pacific infant safety initiative/campaign My Baby's Village (MBV) was established.

Aims/Purpose: My Baby's Village utilises cultural practices to engage with mothers and families, to prevent SUDI. An important element of MBV involves highlighting the diverse Pacific Cultural Care systems as a culturally affirming wellbeing approach. 3 In collaboration with Community Cultural knowledge holders, MBV facilitates free workshops and talanoas (open discussions) where mothers and families can participate and learn traditions such as sewing a baby Ie Pili (Niue baby blanket), Fala pepe (Samoan baby mat), Ei Katu Cook Island flower crown) and Infant fofo traditional baby massage). While there is no one single solution, it is acknowledged that it is necessary for new approaches to safe sleep messaging that is Pacific led, culturally anchored, and fanau family centred.

Methods: My Baby's Village, hosted through Moana Connect works alongside Pacific ethnic specific Community Cultural knowledge holders. Each cultural session incorporate s SUDI prevention education and provide s culturally affirming spaces for mothers , grandmothers and communities to connect and talanoa (photos Through a MBV community fund, we have also funded 30x community grassroots initiatives across Aotearoa New Zealand.

Results: Since early 2022, Since early 2022, MBV has delivered 14x cultural workshops in Auckland, Rotorua, and delivered 14x cultural workshops in Auckland, Rotorua, and Hamilton. We have also worked alongside 150 mothers, Hamilton. We have also worked alongside 150 mothers, fathers and families in person with an and families in person with an increasing demand to go nationally through the promotion on our increasing demand to go nationally through the promotion on our MBV social media channels. social media channels. Feedback from those who have attended our workshops including those who have attended our workshops include: "Being comfortable in the in the space we were in, thein, the knowledge passed on to us to help us with our babies. Just providing a safe space for us to be ourselves."

"It's a need for our families and communities, some our matua's [elders] pass away and take the knowledge with them so it's amazing to learn with them all this and be able to share our experiences with others."

"Good to learn what our mothers and grandmothers have done and can continue it for the younger generations."

P05 SUDI and Stillbirth education, intervention

P05-1 The Memory Box web-based training program: a tool to improve perinatal bereavement care skills and knowledge among healthcare professionals in Italy

by Claudia Ravaldi | Laura Mosconi | Roberto Bonaiuti | Alfredo Vannacci | PeaRL - Perinatal ResearchLab oratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | PeaRL - Perinatal Research Laboratory, CiaoLapo Foundation, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy

Objective: Bereavement care after perinatal loss plays a pivotal role to facilitate the grieving process.

In Italy, more than 50% healthcare professionals (HCPs) felt inadequate to provide support after perinatal loss and almost all reported the need for training. To address this need, CiaoLapo charity, active in improving bereavement care for all losses during pregnancy and after birth, has promoted the Memory Box training program since 2012, reaching 3000 HCPs. In April 2022, CiaoLapo launched a web-based course to increase the number of HCPs involved.

Methods: The Memory Box web-based training program lasts 8 hours and includes: an introduction to the course, 9 lessons about peculiar topics of bereavement care (definition of perinatal loss, trauma oriented care, communication of diagnosis, inpatient management, shared decision making, respectful care, meeting with the baby, memory box, follow-up), each one followed by a test, and a final lesson with “take home” messages. Each participant completed a satisfaction survey at the end of the course about the quality of course contents, teachers and tests.

Results: 2048 HCPs, from all over Italy, concluded the course from May 2022 to June 2023. Quality of course content, teachers and tests received a mean score of 4.76 (SD 0.52) on a scale from 0 to 5. About the quality of contents, on a scale from 0 to 100, the usefulness of the course in clinical practice was the aspect that received the highest mean score (96.14, SD 9.2) followed by the acquisition of new skills (95.59, SD 9.18). About the quality of teaching, “skilled and competent” was the major aspect highlighted by HCPs.

Conclusion: Formal training about bereavement care is paramount to guarantee respectful care after perinatal loss. A web-based course is an easy to use method that allows to reach several HCPs keeping training costs down.

P05-2 Let's Talk Community Chats

by Barb Himes | First Candle

Introduction: Approximately 3,500 babies die annually in the United States from sleep related deaths including Sudden Infant Death Syndrome (SIDS), accidental suffocation and strangulation in bed. The introduction in 1994 of the Safe Sleep Guidelines developed by the American Academy of Pediatrics (AAP) led to a 50% reduction in SIDS rates, which remains level while SUID rates have gone up and are twice as high among Black and Native American infants than white.

Method: Let's Talk Community Chat is a community partner program that ensures families lived experiences about safe sleep practices are heard and respected. Most importantly, the information families are provided is not only accurate but relevant to them, free of bias and judgement. This is a grassroots program led by trusted community care providers with training from First Candle on AAP safe sleep guidelines, breastfeeding support and education on the proper and safe use of infant products. Trained community facilitators who are paid a stipend include doulas, lactation consultants, dads and grandparents engage with families in the same community location on a monthly basis at places families frequently gather - churches, gyms, etc.

Goals & Objectives: The goal is to give the family and other caregivers - clear information about safe sleep practices, the reasoning behind the AAP safe sleep guidelines, and talk with them about the challenges, obstacles, and choices they make about where and how their baby sleeps. Unlike traditional health fairs, Let's Talk gives families time for in-depth one-on-one conversations about their unique situations.

Results: *226 people participated. *Less than 20% received information at the hospital. *61% learned something new. *100% would recommend Let's Talk Chats to a friend.

Conclusion: Let's Talk was piloted in Harlem with additional locations scheduled in Atlanta and Philadelphia. Continue to expand Let's Talk Community Chats in other sites.

P05-3 Bereavement care after stillbirth in Italy and parents psychological well-being: results from CLASS Study

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Objective: Stillbirth is a global health issue affecting millions of parents around the world. Respectful care after this event is crucial for improving parents' psychological well-being. Official national guidelines about bereavement care are essential to aid healthcare professionals to guarantee such care. However, Italy does not have official guidelines and, only recently, recommendations have been published. The aim of this study is to explore Italian bereaved parents' perspective of the application of the international guidelines and to validate such guidelines in the Italian context.

Methods: The CLASS study is a web-based cross-sectional study. The sample consisted of 261 women who answered to: a socio-demographic section; the CLASS checklist, involving all items common to the main international guidelines about bereavement care (six areas were identified: respect for the baby and parents, information and communication, birth options, hospital stay, creating memories, aftercare); the Perinatal Grief Scale (PGS); the National Stressful Events Survey PTSD Short Scale (NSESSS) and the CLASH STILLBIRTH questionnaire regarding obstetric violence.

Results: The mean score of mothers' perception about compliance to guidelines was 1.96 (scale from 0 to 4). Categories of the CLASS checklist with the lower score were: respect towards the baby; communication about funeral and autopsy; creating memories and aftercare. Compliance with ≥40 CLASS checklist items was related to greater satisfaction of care (OR 2.02 CI 1.07-3.83), perceived respectful care (OR 3.81 CI 1.99-7.30) and to reduce grief (OR 0.09 CI 0.04-0.19) and PTSD symptoms (OR 0.22 CI 0.09-0.49).

Conclusion: The CLASS study shows that women who received respectful care, according to the international stillbirth guidelines, had lower levels of grief and posttraumatic stress symptoms. This study also highlights the need for official national guidelines and adequate training and support for healthcare professionals in countries where they are lacking.

P05-4 Knowledge of infant safe sleep practice and awareness of infant safe sleep resources of amongst Indigenous parents in Alberta: a case study to understand infant safe sleep reality

by Delshani Peiris | University of Calgary

Authors: D. Peiris, S. Bouchal, L. Crowshoe, R. Henderson, I. Mitchell

Objective: The purpose of this case study was to determine if currently used infant safe sleep education and resources in Alberta are useful for Indigenous peoples by determining what is known about infant safe sleep and SIDS, the source of safe sleep information, and how safe sleep information is shared.

Methods: The case study design was chosen to learn and understand the infant sleep reality of Indigenous peoples in Alberta through inquiring the knowledge and understanding of infant safe sleep from Indigenous parents and caregivers who care for a child born between 2010-2020. Broad questions were determined to allow the participants to speculate and construct their own subjective meaning to their infant safe sleep reality. Individual participant interviews were conducted over Zoom Meetings in Alberta during December 2020. Participants were recruited purposively through existing networks, including snowball sampling. Nine participants were deemed eligible for this study, and seven participants completed the individual interview.

Results: All participants in the case study demonstrated a familiarity with infant safe sleep and SIDS.
Participant connection of infant safe sleep with SIDS, indicates that participant understanding of infant safe sleep is linked to their knowledge of SIDS.

Conclusion: Infant-adult bed-sharing was described as the dominant method of infant sleep practice by participants in this study. Participants who practiced bed-sharing described practicing either direct bed-sharing, bed-sharing with an infant sleep device, or bed-sharing with creating a physical barrier between infant and adult. The results of this study are consistent with practice of infant-adult bed-sharing observed in Indigenous communities in New Zealand and Australia.

P05-5 The relationship between health promotion, harm reduction, and risk reduction activities for infant safe sleep: a policy exploration

by Delshani Peiris | University of Calgary
Authors: D. Peiris, S. Bouchal, L. Crowshoe, R. Henderson, I. Mitchell

Background: In Canada, infant safe sleep messaging advises against infant-adult bed-sharing. Based on the national and regional recommendations for infant safe sleep, healthcare providers would not promote or educate on bed-sharing practice. The goal of health promotion is to enable individuals control over improving their own health. Health is defined as a state of complete physical, mental and social well-being, and for individuals to achieve this state, they require the knowledge, skills, and resources to identify, realize and achieve their health needs. The goal of health promotion can only be achieved through advocating for health equity, research action to investigate health disparities experienced by vulnerable populations, public health activities that address inequities, and creating policy that responsive to research and advocacy efforts.

Discussion: Disease and injury prevention are the public health activities aimed to preventing disease, injury, and mortality from occurring through policy and risk reduction activities. Current infant safe sleep messaging and SIDS prevention activities are focused on reducing risk associated with SIDS, and not providing individuals with knowledge, skills, and resources to realize and actualize their health needs.

Conclusion: In order to successfully engage in effective health promotion, infant safe sleep activities in Canada must represent the goals of health promotion, and include a harm reduction approach for infant-adult bed-sharing for both Indigenous and non-Indigenous peoples. A harm-reduction approach is especially vital as evidence shows that bed-sharing is prevalent in Indigenous and non-Indigenous peoples.

P05-6 New Baseline Sleep in Flanders (Belgium): Sleep safety as part of the comprehensive recommendations on sleep: "Safe, Connected and Skillful”

by Greet Wissels | Yves Debaut | Tine Vandamme | Child and Familiy, Flemish Government | Child andFamiliy, Flemish Government | Child and Familiy, Flemish Government

Kind en Gezin (Child and Family), the Flemish governmental agency responsible for child welfare, places great emphasis on efforts to increase parents' awareness and knowledge about the importance of safe sleep. We saw a significant decrease in the number of cot deaths. Therefore we remain committed to the 7 preventative measures to keep the rate low.

Today a shift occurs in parents' questions concerning their child's sleep. Questions about their baby falling asleep and staying asleep, about bedsharing in relation to breastfeeding or bonding. Focussing only on sleep safety means parents look elsewhere for satisfactory answers. They tend to take uninformed risks. They seek refuge on the commercial market, where the aim is often a quick fix for the child's problem, with the risk of accidents and sleep problems in the long run.

This observation forces us to take a broader approach to our recommendations. Therefor we wrote the “Baseline Sleep: "Safe, Connected and Skillful" (in Dutch: 3 V's: Veilig Verbonden en Vaardig). The poster will show a visual, which summarizes the text.
The approach to sleep is an interplay between 4 pillars:

1. Sleep is an individual growth process.
2. Sleeping is tuning into what the child needs.
3. Safe, connected and skillful sleep
4. Resilient parent

Our strengths

We recognize the fact that our recommendations are no longer in line with the broader view on sleep parents are asking for.
With the baseline sleep, which approaches sleep from a comprehensive context, sleep safety is but one aspect.
Starting from the baseline, we offer families with young children sustainable and safe support, which is also free and accessible to all families.
In this way we as a government distinguish ourselves from commercial services and products.

P05-7 ShaDeS (Shared Decision-making in Stillbirth) study: Communication and Shared Decision-making after Stillbirth

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Objective: Shared decision-making (SDM) plays a pivotal role in care after stillbirth, as highlighted by international guidelines, having the power to positively impact parents' psychological wellbeing.

Italy doesn't have formal national guidelines about bereavement care and, only recently, recommendations have been published. The ShaDeS study aims to investigate how Italian women perceive their own centrality in decision-making processes and how this might impact satisfaction of care.

Methods: The ShaDeS study is a cross-sectional web-based study divided in four sections: sociodemographic information, communication of bad news and bereavement care, decisions about childbirth (SDM-Q-9, SHARED, and DCS), and decisions and communication about autopsy (CPS). A satisfaction index was calculated using the mean of four items of the DCS and three items of the SHARED. Negative aspects of care identified by means of qualitative analysis were coded using the CLASS checklist for stillbirth care.

Results: 187 women completed the survey. Women who didn’t have an emergency childbirth reported a median score of 66.6 (0-100 range) at the SDM-Q-9, and a median score of 3.5(1-5 range) at the SHARED. Only 29.4% of participants reached the cutoff of 37.5 in the DCS (0-100 range) suggesting a difficulty in reaching decisions. Mothers who reported such difficulty had a lower score at the composite satisfaction index (p<0.0001) than the other responders. Of the 64.5% of women that discussed autopsy, only 28.3% were involved in an SDM approach, despite this being associated with higher levels of satisfaction of care (p=0.001).

Conclusion: The ShaDeS study represents a first attempt to investigate SDM approach within bereavement care in Italy. This approach is only moderately widespread among mothers, despite its association with higher levels of satisfaction of care. Further studies should investigate how to improve an SDM approach in bereavement care around stillbirth.

P05-8 Women’s experience of care around stillbirth during COVID-19 pandemic: an Italian cross-sectional mixed methods study

by Francesca Roper | Ronja Sturm | Nanna Maaløe | Claudia Ravaldi | Laura Mosconi | Alfredo Vannacci | 1-CiaoLapo Foundation for Perinatal Health, Prato, Italy 2-University of Copenhagen - Faculty of Health and Medical Sciences | University of Copenhagen - Faculty of Health and Medical Sciences | University of Copenhagen - Faculty of Health and Medical Sciences | 1-CiaoLapo Foundation for Perinatal Health, Prato, Italy 2-PeaRL - Perinatal Research Laboratory, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | 1-CiaoLapo Foundation for Perinatal Health, Prato, Italy 2-PeaRL - Perinatal Research Laboratory, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | 1-CiaoLapo Foundation for Perinatal Health, Prato, Italy 2-PeaRL - Perinatal Research Laboratory, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy

Objective: In Italy, around three out of 1,000 pregnancies end in a stillbirth. Previous research highlighted the lack of knowledge about the quality of bereavement care and the healthcare professionals’ difficulties in providing respectful care after stillbirth, even before the COVID-19 pandemic. The aim of this study is to explore to what extent bereavement care in Italy has been prioritized during the pandemic.

Methods: This study is embedded in the "Continuing care in Covid-19 Outbreak: A global survey of New and expectant parent experiences" (COCOON) research project and is a cross-sectional mixed methods web-based study. The sample included mothers who suffered a stillbirth in Italy between 30th January 2020 and 31st October 2021. The survey included questions about care received after the diagnosis of stillbirth during intrapartum period, hospitalization and follow-up. Qualitative results were analyzed using a thematic content analysis and descriptive statistics was used for quantitative data.

Results: 208 women (mean age 34.5, SD 4.8), answered the survey. Care experiences ranged from very positive to extremely negative. The most lacking aspects of care were: 1) absence of partner (39% of mothers were alone during labor and birth); 2) loneliness and being neglected ; 3) physical, but not emotional care (65% of women did not receive information about grieving process and what to expect); 4) missed opportunities for memories and meeting the baby (42% of mothers didn't have the opportunity to collect mementos); and 5) lack of information and guidance (21% of women were not counseled about post-mortem examination).

Conclusion: This study highlighted that perinatal care wasn't perceived as a priority during the COVID-19 pandemic in Italy. It is necessary to further promote respectful bereavement care after stillbirth which is essential to protect women's right to respectful reproductive healthcare and to promote their wellbeing.

P05-9 Lessons learnt from a charity campaigning for Sudden Unexplained Death in Childhood (SUDC) - SUDC UK

by Nikki Speed | SUDC UK

Objective: This presentation will share the journey and lessons learned from three mothers who founded and established a charity to raise awareness and create a united, impactful voice for all those affected by SUDC in the UK (www.sudc.org.uk).

Methods: It will share the environment, opportunities, and challenges when SUDC UK was founded in 2017 and the significant milestones since. It will share the quantitative and qualitative impact, moments of success and failure and the many lessons learned.

Results: SUDC UK used previous knowledge, skills, personal experience and volunteer spirit to capitalise on opportunities to collaborate and effectively advocate for change. It has worked with national and international organisations and influencers to give a new voice to families in the UK who are affected by the unexpected and unexplained death of a child between 1 and 18. It has influenced policy, medical care and bereavement care for families, engaged the scientific community and, for the first time, the UK Government and the British press. This was only possible through collaboration, considered timing, being bold, seeking external expertise and most importantly, by enabling families to share their stories.

Conclusion: Many parents and professionals are curious about founding a charitable organisation; the emotional toil and risks, the impact on grief and the potential to achieve their mission. SUDC UK is a small charity and rather than claim to be ‘best practice’, this presentation simply charts the journey of the charity, the bereaved mothers who founded it and those families we serve. With tangible results to share such as publications, groundbreaking national reports, key events like climbing a mountain as a community and the 2023 Parliamentary debate on SUDC, we hope it will inspire others to learn about Sudden Unexplained Death in Childhood and also feel hopeful that progress is possible.

P05-10 The targeted prevention of unexpected infant death (SUID): an experience from Piedmont Region, Italy

by Silvana Malaspina | Alessandro Vigo | Sonia Scopelliti | Silvia Noce | S.C. Distretto Sud Est, ASL Città di Torino | Paediatric Unit,Michele and Pietro Ferrero Hospital,Verduno, ASL Cuneo 2 | SUID&SIDS Italy Association | Centre for Pediatric Sleep Medicine and for SIDS, Ospedale Infantile Regina Margherita, Città della Salute e della Scienza di Torino

Introduction and objective: Since 2004, the Piedmont Region has activated an epidemiological surveillance of SUID, carried out through the regional Reference Center for SIDS in Regina Margherita Children Hospital of Turin and the regional Public Health Services. The surveillance activity has shown that situations such as prematurity, familiarity for SIDS, social disadvantage and isolation (such as foreign family in poverty) expose newborns at a higher risk of developing SUID. Therefore, an intervention was designed with the aim of identifying and reporting such situations.

Method: The neonatology departments and the SIDS Center of the Children Hospital identify and report newborns at risk to the SUID reference persons of the local public health services. Subsequently, contact with the family takes place, home visits are organized to evaluate the context of life and interventions are prepared to remove the SUID risk conditions, for example through the activation of social services and through the support offered by SUID-SIDS parents association.

Results: Interventions carried out on cases of familiarity for SIDS and other situations of fragility were 66 and the average of cases followed per year has gradually increased over time.

Conclusions: The preventive intervention conducted in the limited number of cases has yielded positive outcomes. However, it is evident that further observations are essential to gather substantial insights from this ongoing preventive activity.

P05-11 Prevention is a weapon, let's not underestimate the risk!

by Sonia Scopelliti | Floriana Diviccaro | Rosalba Fazio | Monica Diviccaro | SUID & SIDS Italia | SUID & SIDS Italia | SUID & SIDS Italia | SUID & SIDS Italia

Introduction: In 2022, with the aim of assessing the level of knowledge regarding SUDI/SIDS prevention strategies and identifying any critical issues, a survey was conducted. The collected data highlighted significant shortcomings both in terms of knowledge of accurate and comprehensive information and in the dissemination of messages by professionals.

Objective: The uncertainty as to whether the condition was due to the COVID emergency context or significant communication gaps unrelated to the context emphasized the need for further investigation.

Materials and Methods: Between May and June 2023, the same questionnaire distributed in 2022 was disseminated among parents with children aged 0-24 months. The questionnaire was promoted through association channels, healthcare providers, and other professionals. The data were recorded in an Excel spreadsheet.

Results: By the end of June, 233 questionnaires were collected.
96% of the children had been vaccinated.
42% of caregivers were or had been smokers.
14% of parents had not received any information on safe sleep in any circumstance.
Upon postpartum hospital discharge, 30% of parents received insufficient or incomplete information, while 45% received no information.
Over 70% of respondents never discussed issues related to risks from overheating, sleep environment, bed sharing, or the dangers of seating devices with their family pediatrician.
63% of respondents shared the same sleep surface.

Conclusions: Based on the collected data, it was found that the lack of information among parents continues to be widespread. Parents do not have access to clear, comprehensive, and exhaustive information. The high percentage of parents who unknowingly share sleep surfaces, unaware of the risks, should prompt us to reflect on effective communication.

P06 Support for families and bereavement

P06-1 Objectives and Tools of Naître et Vivre parental association

by Christine Tran Quang | Christine Tran Quang to represent Naître et Vivre

Naître et Vivre is an association officially recognized in France and has been in existence since 1979. It has 3 aims:

1. Accompanying parents in their bereavement process
2. Preventing unexpected infant death
3. Support for research

Naître et Vivre offers support and accompaniment to parents undergoing the ordeal of unexpected infant death or perinatal bereavement. It puts its volunteer parents and doctors at the service of suffering families and loved ones. This support takes the form of face-to-face meetings between bereaved parents, but also more recently remote meetings thanks to the development of new tools and interfaces (Zoom Meeting), always supervised by psychologists or volunteers trained in listening. In addition, parents can obtain personalized welcome from the association's medical advisor to help them better understand the circumstances surrounding their child's death.

As part of this support, the association has produced 2 books to help families and children deal with the theme of a baby's death, using appropriate words and illustrations.

The Association is involved in training young parents and healthcare professionals, sharing experience and collecting data at major professional and scientific events. As such, we recently obtained the "Qualiopi" label, which means it is now officially recognized in France as a Training Center. We have developed several tools (different prevention media, video), which will be presented, promoting optimal sleeping conditions for babies. The association has translated these posters into 14 languages in an attempt to target the most socially underprivileged public, the latest version of which will be presented is in Ukrainian.

As a long-standing partner of the public authorities, Naître et Vivre takes concrete action to promote the development of research, participating for instance to the “OMIN”, French repertoire of SIDS. Its presence at congresses such as ISPID enables the association to forge links with other parenting associations and enhance the scientific knowledge of its members.

P06-2 The Ethics of Fetal Autopsy and Its Implication for Bereavement Support

by Elisa Groff | Ulm University Hospital, Institute of the History, Philosophy and Ethics of Medicine

Objective: Clinical fetal autopsy (CFA) often informs the mother’s decision-making and medical care for subsequent pregnancies. Indeed, CFA and the examination of the placenta provides information which is of great importance also for the reproductive medicine team, as they can identify unexpected congenital malformations or the cause of repeated miscarriage or stillbirth. This raises ethical issues which have not been thoroughly studied yet in the literature, such as those of extensions and limitations of the process of informed consent and data protection, since post-mortem biological samples can be used e.g. for genetic counselling and precision fertility treatments.

Method: By applying a comparative approach, the research aims to:
(1) examine current practices for seeking consent for CFA at German departments of obstetrics and gynecology;
(2) investigate whether there are guidelines for the clinical care of the mother after stillbirth, e.g. lactation health information, or for bereaved parents after stillbirth and infant death;
(3) identify evidence gaps in doctor - patient / bereaved parents communication.

Results: This paper will briefly discuss current scenarios of normative and care ethics in clinical perinatal autopsy in Germany. It will do so by reflecting on the preliminary outcomes of the research project “The Ethics of Fetal

Autopsy and its Impact on Reproductive Medicine", which is funded by the Hertha Nathorff Programme at the Ulm University Hospital.

Conclusion: The present paper will attempt to:
(1) formulate ethical recommendations for CFAs that meet current standards of care ethics,
(2) develop awareness on the value of fetal autopsy for subsequent pregnancies, and
(3) pave the pathway to collaborative action to provide appropriate respectful care for all agents affected in the context of perinatal death.

P06-3 Rebuilding bereaved parents support services during pandemic: CiaoLapo telehealth experience

by Claudia Ravaldi | Cristina Petrozzi | Lucia Canale | Micaela Darsena | Letizia Giorgini | Simona Maggi |Barbara Donadoni | Laura Mosconi | Alfredo Vannacci | 1-CiaoLapo Foundation for Perinatal Health, Prato, Italy 2-PeaRL - Perinatal Research Laboratory, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy 3-CiaoLapo Charity, Prato, Italy | CiaoLapo Charity, Prato, Italy | CiaoLapo Charity, Prato, Italy | CiaoLapo Charity, Prato, Italy | CiaoLapo Charity, Prato, Italy | CiaoLapo Charity, Prato, Italy | CiaoLapo Charity, Prato, Italy | 1-CiaoLapo Foundation for Perinatal Health, Prato, Italy 2-PeaRL - Perinatal Research Laboratory, Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy | 1- CiaoLapo Foundation for Perinatal Health, Prato, Italy 2-PeaRL - Perinatal Research Laboratory Department of Neurosciences, Psychology, Drug Research and Child Health, University of Florence, Florence, Italy 3-CiaoLapo Charity, Prato, Italy

Objective: According to the international guidelines and the Italian recommendations on stillbirth bereavement care, parents should be discharged with scheduled follow-up visits, both medical and psychological. Before the pandemic, only 15% of parents received follow-up appointments; during the pandemic, this number decreased. From 2019 to 2022, requests for urgent support from bereaved parents to CiaoLapo Charity were almost doubled and CiaoLapo developed the "Primo Sostegno" telehealth project. Trauma-informed care and psychoeducation were chosen as the main approaches to give support to parents and to identify symptoms of complicated grief and post-traumatic stress disorder.

Methods: The “Primo Sostegno” project opened in June 2022. Two counselors specialized in trauma informed care answer parents’ requests by phone (a dedicated toll-free number was activated), e-mail and video call. In the first meeting main topics on grief, loss, bereavement and mourning are usually discussed to assess the type of support parents need. If psychological support is needed, parents are assigned to a psychotherapist (three meetings were offered free of charge) specialized in bereavement support after perinatal loss. At the end of this program, parents can decide to attend a self-help group, to continue with psychological support or to consider psychotherapy.

Results: In 12 months, 514 bereaved parents contacted CiaoLapo Charity. Among them, 119 were referred to psychological support meetings. Four psychotherapists did a total of 272 free of charge meetings. 30 couples joined self-help groups; 21 couples continued psychotherapy sessions at a discounted rate for members of CiaoLapo Charity.

Conclusion: Primo Sostegno was able to give support to bereaved parents discharged from the hospital without follow-up appointments, offering them different support options. The Italian Health System should improve the national bereavement care standard, in order to warrant a high-quality support after baby loss to all the bereaved parents.

P06-4 The impact of SUDC on bereaved siblings

by Nikki Speed | Emily Cooper | SUDC UK | University of Central Lancashire

Objective: This presentation will present case studies from families with siblings bereaved by Sudden Unexplained Death in Childhood (SUDC). These families wanted to share their experience with SUDC UK to raise awareness of the impact on siblings and their children’s emotional and medical journeys following loss. It includes the family’s perception of the care that was provided, what should be available in the future and the expected impact on siblings as they continue to grow and live with their bereavement.

Methods: Parents who had previously asked SUDC UK if they could share information to support learning were asked if they would like to provide written or oral information to help improve understanding on the impact of SUDC on SUDC-siblings. The evidence is shared as a group of case studies including photos and quotes in response to a selection of questions.
Some quotes directly from bereaved children are included.

Results: The evidence from families demonstrates significant variation between medical and emotional bereavement care for siblings in terms of need, accessibility, and impact.
Siblings are often required to attend annual cardiac screening, experience heightened parental anxiety about their well-being and are present as their parents navigate grief.
SUDC siblings are often old enough to remember the traumatic events at the time of the child's death and can have grief complicated by PTSD.

Conclusion: This presentation shares that informed and available support through services and schools can have a huge effect on how a bereaved sibling can cope.
In the UK there are national bereavement pathways for deaths such as miscarriage, stillbirth, and SUDI which contain limited specific information about care for siblings. This evidence suggests that a pathway for sudden unexpected death in childhood should be considered and should be informed by evidence from all members of SUDC families, including siblings.

P06-5 What impact does Sudden Infant Death Syndrome (SIDS) have on siblings?

by Sonia Scopelliti | Lorena Tait | Floriana Diviccaro | Monica Diviccaro | SUID & SIDS Italia | SUID &SIDS Italia | SUID & SIDS Italia | SUID & SIDS Italia

Introduction: Sudden and unexpected death, particularly Sudden Infant

Death Syndrome (SIDS) - an unexpected, inexplicable, and unacceptable event - has significant psychological implications for all members of the family, especially parents but also siblings.

It is important to improve our understanding of this specific situation, as it is impossible to react rationally in the face of such grief and have a clear understanding of the timing and ways to provide the necessary support.

Objective: Existing studies on siblings of children who died from SIDS are insufficient, leading to high uncertainty regarding appropriate psychological support.

It is important to identify the feelings of distress experienced both in anticipation of the event and over time, particularly due to the influence it can have on the parents' perceived experience.

Materials and Methods: The investigation involved parents, siblings present at the time of the loss, and siblings born after a SIDS event.

The investigation was conducted through testimonies and/or interviews.

A total of 30 parents and 15 siblings were interviewed, and 20 testimonies from parents and 10 testimonies from siblings were collected.

Results: The difficulties parents face in providing explanations for the sibling's death are evident. In the testimonies/interviews with the siblings, the difference in the perception of the event's timing is particularly noticeable between those who experienced it during adolescence and those who experienced it during preschool age. Strong distress is also evident in the testimonies of siblings born after a SIDS event.

Conclusions: It is essential to expand studies on the grieving process in siblings, as feelings of distress are likely to be observable even long after the event. There is a clear need for in-depth studies to better understand the psychological distress experienced by siblings born after a SIDS event."

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