## Le Corum – Montpellier, France 2022 From 29 to 31 May

## EUROPEAN CONGRESS AND WORKSHOP ON

Presentations, Workshops on Registries, Classification, Prevention & Research

**Sids Sudi** 

- List of posters
- List of participants
- Lists of partners, sponsors & exhibitors
- Exhibition plan & List of booths

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STUDIES SECTION IS

### BOOK OF ABSTRACTS PROGRAM

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## Sids Sudi 2022

### Welcome to the Meeting to build on a common future !

ANCReMIN (French National Association of SIDS/SUDI Reference Centers) is pleased to invite you to the European congress on Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Death of Infancy (SUDI) in Montpellier (France), millennial city and cradle of medecine.

In 2015, ANCREMIN created a National Observatory (OMIN) in order to obtain precise and exhaustive epidemiological data, to identify new risk factors and to develop scientific research in this field. Armed with this experience, the French SIDS/SUDI reference centers wish to share their work and their results with their European colleagues and hope to start creating European registers. The development of such registers of could mark a real advance in the management and research of SIDS and SUDI.

This European event is part of a desire to lay the foundations for joint work at European level.

The congress will offer lectures from European and international experts, round tables on practices and working groups supervised by qualified scientists. The scientific program will revolve around 4 fundamental axes: the feasibility of European registers on SIDS/SUDI, the harmonization of the classification of these deaths, prevention and research. French and European associations of bereaved parents will be present, families remaining at the heart of our concerns.

We look forward to welcoming you from 29 to 31 May, 2022 at the Corum Conference Center of Montpellier located in the heart of the historical center and near the famous 'Place de la Comédie'.

Organizing and Scientific Committees

### Dear Colleagues, dear Parents,

On behalf of the organizing committee, we wish to invite you to attend the **first European Congress and Workshop on SIDS and SUDI**, to be held in **Montpellier, France, on 29 to 31 May 2022**.

This meeting offers a unique opportunity to listen to the most prestigious specialists studying sudden death, acquire the most recent scientific knowledge on the topic, and launch an extended professional network to gather resources.

As bereaved parents, we invite you to share a moment of remembrance to honour our children who passed away. We also propose to spend some time exchanging about what is done in the different European associations. The goal would be to share resources and tools on how to accompany bereaved families, support research and promote prevention of sudden death.

Facilities will be provided to welcome and integrate the parents who are members of associations. Specific sessions, e-posters and free registration to the meeting are planned.

We hope the attractive program of the meeting and the idea of laying the foundations of a European network between all our associations will encourage you to register. You will find in the joined documents the preliminary program and information on how to register and attend the meeting.

We are looking forward to hearing from you soon.

Yours sincerely,

### Naître et Vivre

# Sids Sudi 2022

### . . . . . . . . . . . . . . . . . .

### COMMITEES

#### . . . . . . . . . . . . . . . . .

#### Local Organizing Committee

President: Inge Harrewijn - Montpellier Vice President:

Gilles Cambonie - Montpellier

Elisabeth Briand-Huchet - Clamart Christèle Gras-Le Guen - Nantes Karine Levieux - Nantes Hugues Patural - Saint-Étienne Odile Pidoux - Montpellier

### Scientific Committee

Peter Blair - *Bristol, UK* Gilles Cambonie - *Montpellier* Christèle Gras-Le Guen - *Nantes* Hugues Patural - *Saint-Étienne* Beatrice Kugener - *Lyon* Odile Pidoux - *Montpellier* Inge Harrewijn - *Montpellier* Elisabeth Briand-Huchet - *Clamart* Karine Levieux - *Nantes* 

### CONTACT

#### . . . . . . . . . . . . . . . .

### Administrative secretariat

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www.alphavisa.com/sids-europe/2022



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### **Abstracts Monday 30 May**

### Plenary Sessions

The continuing decline in SIDS mortality rates and the way forward SIDS/SUDI registries: actual experience	
Parallel Sessions	
Harmonisation of investigations on the causes of death Free presentations on SIDS and SUDI - Harmonisation of investigations on the causes of death	<u>23</u>
Short oral presentations	<u>26</u>
Investments likely to explain the cause of death	<u>34</u>
Free presentations on SIDS and SUDI - Investments likely to explain the cause of death	
Short oral presentations	<u>40</u>

### Abstracts Tuesday 31 May

#### Plenary Sessions

A brief history of SIDS/SUDI classification	
The experience with classification of SIDS/SUDI cases in Europe	
Parallel Sessions	
Furgereen evenenties studenies	<b>F</b> 7

European prevention strategies.	<u>)/</u>
SUDI and joint investigations of legal medecine	<u>51</u>
Free presentations on SIDS and SUDI - European prevention strategies	
Short oral presentations	<u>55</u>
Actualities on SIDS/SUDI research	<u>74</u>
Sudden death in the young (SDY)	<u>78</u>
Care pathway for a SIDS case (in French)	<u>31</u>

### Abstracts of posters

List of posters.	
Posters	
List of participants	
Lists of partners, sponsors & exhibitors	
• Exhibition plan & List of booths	
Hotel location	

		đ	ANNING AT A GLANCE			
EU	IROPEAN CONGRESS AND WORKSHOP ON	00.00	MONDAY 30 MAY	06.90	TUESDAY 31 MAY	
V	From 29 2022	00.00	<b>Congress registration</b>	00.00	<b>Congress registration</b>	
	Le Corum Conference Center - Montpellier, France		Welcome introduction - Film Italy 🔝	00.20	Welcome introduction	
	Joffre Hall (Level 1)		PLENARY SESSION		PLENARY SESSION A brief history of SIDS/SUDI classification	
	Joffre A+B room (Level 1)	10:50	Coffee break Visit of exhibition & Posters	10:50	Coffee break Visit of exhibition & Posters	
	Joffre D room (Level 1)		PLENARY SESSION		PLENARY SESSION The experience with classification of SIDS/SUDI cases in Europe	
	2011re ≠ room (Lever r) 2⊔we Livestorm (digital)	00.21	Lunch Visit of exhibition & Posters	12:50	Lunch Visit of exhibition & Posters	
			Harmonisation of investigations	SNO	European prevention strategies	
13:00	SUNDAY 29 MAY	13313	Free presentations on Sundame	SESSI	SUDI and joint investigations of legal medecine	
			European Parental Associations Session 1	דרבר	Free presentations on SIDS and SUDI	
	ANCHEMIN meeting of referral centers		Workshop on registries for SIDS/SUDI/Sudden - Session 1	, 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8 8	Workshop on classification Session 1	
00.91		15:30	Coffee break Visit of exhibition & Posters	15:30	Coffee break Visit of exhibition & Posters	
00:01	Congress registration		Investments likely to explain and the cause of death	SNO	Actualities on SIDS/SUDI research	
00.11	OPENING CEREMONY	13333	Free presentations on Sun Sun	ISSES	Sudden death in the young (SDY)	
00:/1			European Parental Associations Session 2	רבר√	Care pathway for a SIDS case (in French)	
18:30		18:00	Workshop on registries for SIDS/SUDI/Sudden - Session 2	, AAG	Workshop on classification Session 2	
		-	9:00 Bus departure 19:30 Congress dinner Château Puech-Haut	18:00	Closing ceremony	

### SUNDAY 29 MAY

13:00-16:00	ANCReMIN meeting of referral centers	
16:00-17:00	Congress registration	Joffre Hall (Level 1)
17:00-17:30	Opening ceremony • Classic music cello	Joffre A+B room (Level 1)
17:30-18:30	Remembrance ceremony  • Classic music	

- Testimony parents
- Sudden Infant death has a face
- A flower, a life (classic music)

	MONDAY 30 MAY	•••••
08:00-08:30	Congress registration	Joffre Hall (Level 1
08:30-09:00	Welcome introduction       Image Marrewijn & Odile Pidoux (Montpellier, France)         • Inge Harrewijn & Odile Pidoux (Montpellier, France)	Joffre A+B room (Level 1,
09:00-09:20	Film Italy	
Plenary Se	ession	
09:20-10:20	The continuing decline in SIDS mortality rates and the way forwar	d Joffre A+B room (Level 1,
	Moderation: Martin Chalumeau (Paris, France), Fern R. Hauck & Rac	hel Moon (Virginia, USA)
09:20-09:35	• Sophie de Visme (Nantes, France): National variations in recent tree in Western Europe	nds of sudden unexpected infant death rate
09:35-09:50	• Pete Blair (Bristol, UK): From observation to intervention: identifyin	ng families at high risk of SUDI
09:50-10:05	<ul> <li>Anna Pease (Bristol, UK): Improving uptake of safer sleep advice: SI at increased risk</li> </ul>	DS prevention for families with infants
10:05-10:20	• Martin Chalumeau (Paris - France): Recent historic increase of infa	nt mortality in France
10:20-10:50	Round table discussion	
10:50-11:20	Coffee break - Visit of exhibition & Posters	Joffre Halll (Level 1,
Plenary Se	ession	
11:20-12:05	SIDS/SUDI registries: actual experience	Joffre A+B room (Level 1
	Moderation: Richard D. Goldstein (Boston, USA), Pete Blair (Bristol, UK	) & <b>Christèle Gras-Le Guen</b> (Nantes, France)
11:20-11:35	• <b>Peter Fleming</b> (Bristol, UK): The English National Child Mortality Data and investigating ALL deaths of infants and children	tabase: Insights from identifying

11:35-11:50	<ul> <li>Karine Levieux (Nantes, France): The French prospective mu (OMIN): rationale and study protocol</li> </ul>	ltisite Registry on sudden unexpected infant death
11:50-12:05	• <b>Sharyn Parks Brown</b> & <b>Alexa Erck</b> (Houston, USA): The s a method to improve surveillance	udden unexpected infant death case registry:
12:05-12:50	Round table discussion <ul> <li>Feasibility of European registries</li> </ul>	
12:50-14:00	Lunch - Visit of exhibition & Posters	Joffre Halll (Level 1)
Parallel S	essions	

	Moderation: Christine Tran-Quang (Naître & Vivre, France), The Lullaby Trust, Sa V	ie & Les Rires d'Anna			
14:00-15:30	European Parental Associations - Session 1	Joffre D room (Level 1)			
15:10-15:20	• Carmel Harrington (Sydney - Australia): Butyrylcholinesterase is a potential bioma	arker for SIDS			
15:00-15:10	• Johanna Marie Lundesgaard Eidahl (Oslo, Norway): Aquaporin 4 expression in the hippocampus in sudden unexplained infant death				
14:50-15:00	• <b>Patricia Garcia</b> (Marseille, France): Role of pathogens in Sudden Unexpected Death of Infancy: A 10-year review of the PACA West SUDI reference center, University Hospital, Marseille				
14:40-14:50	• Antoine Coquerel (Caen, France): Study of stress, hypoxia and post-mortem delay markers in unexpected infant death syndrome (SIDS/SUDI)				
14:30-14:40	• Giulia Costagliola (Turin, Italie): A successful collaboration: 24 hours cardiorespiratory recording in infants with surgical congenital anomalies				
14:20-14:30	• <b>Patrick Pladys</b> (Rennes, France): Risk factors for unexpected infant death among very premature infants in France				
14:10-14:20	<ul> <li>Jean-Baptiste Ducloyer (Nantes, France): Assessing retinal hemorrhages with non-invasive post mortem fundus imaging in sudden unexpected infant death (SUDI)</li> </ul>				
14:00-14:10	<ul> <li>Agathe Bascou (Toulouse, France): Feedback on a protocol for the management o death syndrome</li> </ul>	f sudden infant			
	Short oral presentations: Harmonisation of investigations on the causes of death				
<b>Moderation: Hugues Patural</b> (Saint-Étienne, France) & <b>Rosemary S. C. Horne</b> (Melbourne, Australia					
14:00-15:30	Free presentations on SIDS and SUDI	Joffre C room (Level 1)			
14:45-15:30	Round table discussion				
14:30-14:45	• <b>• Arra Cohen</b> (Sheffield, UK): Essentials of the autopsy work				
14:15-14:30	• Torleiv Ole Rognum (Oslo, Norway): Importance of the extent of death Scene investigation for cases of Sudden and Unexpected Death of Infancy (SUDI)				
14:00-14:15	• Christèle Gras-Le Guen (Nantes, France): Analysis of diagnostic work-up in France				
	Moderation: Caroline Rambaud (Paris, France), Arne Stray-Pedersen (Oslo, Norway Patricia Franco (Lyon, France)	<i>ı)</i> &			
14:00-14:45	Harmonisation of investigations on the causes of death	Joffre A+B room (Level 1)			

• Presentations (organisation, actions, prevention strategies, support of bereaved families)

14:00-15:30	Workshop on registries for SIDS/SUDI/	Sudden death in the young - Session 1	Joffre 4 room (Level 1)			
	<b>Moderation: Pete Blair</b> (Bristol, UK), <b>Peter Fleming</b> (Bristol, UK), <b>Karine Levieux</b> (Nantes, France) & Joanna Garstang (Birmingham, UK)					
	The aim of this workshop is to discuss the faisability of implementing registries in Europe					
	Advantages of creating registers in Europe					
	<ul> <li>Agenda and modalities for the impleme</li> </ul>	ntation of national registries				
	<ul> <li>Common minimal data needed for a Europara</li> </ul>	ropean registry				
15:30-16:00	Coffee break - Visit of exhibition & Poste	rs	Joffre Hall (level 1)			
Parallel S	essions					
16:00-17:20	Investments likely to explain the cause	of death	Joffre A+B room (Level 1)			
	Moderation: Christèle Gras-Le Guen (Nar & Rosemary S. C. Horne (Melbourne, Aus	ntes, France), <b>Gilles Cambonie</b> (Montpell tralia)	ier, France)			
16:00-16:15	• Cécile Acquaviva-Bourdain (Lyon, France): Contribution of metabolic invetigations					
16:15-16:30	• • Alban-Elouen Baruteau (Nantes, France): Cardiologic findings in SIDS cases					
16:30-16:45	• Taleb Arrada Ikram (Montpellier, France): Radiologic contributions to the investigation of SIDS					
16:45-17:05	<ul> <li>• Richard D. Goldstein (Boston, USA): The Past, Present and Future of SIDS</li> <li>• Germaine Liebrechts-Akkerman (Apeldoorn, Netherlands): SNPs in SIDS</li> </ul>					
17:05-17:20						
17:20-18:00	Round table discussion					
16:00-18:00	Free presentations on SIDS and SUDI		Joffre C room (Level 1)			
	Moderation: Ursula Kiechl-Kohlendorfer Rachel Moon (Virginia, USA)	(Innsbruck, Autriche), <b>Adèle Engelberts</b> (	(Amsterdam, Netherlands) &			
	Short oral presentations: Investments lik	ely to explain the cause of death				
16:00-16:10	• Caroline Rambaud (Garches - France): (	Dgival palate and Sudden Unexpected De	eath in Infancy (SUDI)			
16:10-16:20	<ul> <li>Mathilde Ducloyer (Nantes, France): Th in Infancy?</li> </ul>	e ogival palate: a new risk marker of Sud	lden Unexpected Death			
16:20-16:30	<ul> <li>Sonia Scaillet (Brussels, Belgium): Saved infant monitored during sleep at home</li> </ul>	I by the bell? A case report concerning a with a cardio-respiratory memory machi	n extreme preterm born ne			
16:30-16:40	<ul> <li>Silje Osberg (Oslo, Norway): Unexplaine Both may be designated SIDS, but are the</li> </ul>	ed infant deaths in bed-sharing situations ney two different entities?	s versus in own bed –			
16:40-16:50	• Patricia Garcia (Marseille, France): Dea	th of an infant in the setting of a COVID <b>2</b>	19 delta variant infection			
16:50-17:00	<ul> <li>Antoine Coquerel (Caen, France): Five c propranolol for hemangiomas</li> </ul>	ases of Sudden Unexpected Death in Infa	ants (SUDI) treated with			
16:00-18:00	European Parental Associations - Sessi	on 2	Joffre D room (Level 1)			
	• Proposition to create European parenta	l working groups				

16:00-18:00	Workshop on registries for SIDS/SUDI/Sudden death in the young - Session 2	Joffre 4 room (Level 1)		
	Moderation: Pete Blair (Bristol, UK), Peter Fleming (Bristol, UK), Karine Levieux (Nantes, France) & Joanna Garstang (Birmingham, UK)			
	<ul> <li>Proposition to create working groups on registries in Europe</li> <li>Registries: how will we move on</li> </ul>			
19:00	Bus departure for the Congress dinner			
19:30	Congress dinner	Château Puech-Haut		

	•••••	TUESDAY 31 MAY	•••••
09:00-09:10	Welcome introduction	2 LIVE	loffre A+B room (Level 1)
	• Inge Harrewijn & Odile	Pidoux (Montpellier, France)	
Plenary Se	ession		
09:10-10:10	A brief history of SIDS/S	GUDI classification	Joffre A+B room (Level 1)
	Moderation: Monique L'H	l <b>oir</b> (Wageningen, Netherlands) & <b>Torleiv Ole</b> I	<b>Rognum</b> (Oslo, Norway)
09:10-09:25	• Peter Fleming (Bristol, U	K): How should we categorise and subdivide ur	nexpected deaths of infants and children?
09:25-09:40	• <b>III</b> • <b>Roger W. Byard</b> (Adelaïde, Australia): Pathology – The Elephant in the Room		
09:40-09:55	• Richard D. Goldstein (Bo	oston, USA): The Radcliffe classification and the	e ICD-11
09:55-10:10	• Joanna Garstang (Birmingham, UK): Classifications of sleep-related sudden unexpected death in infancy		
10:10-10:50	Round table discussion		
10:50-11:30	Coffee break - Visit of exh	ibition & Posters	Joffre Hall (Level 1)
Plenary Se	ession		
11:30-12:50	The experience with cla	ssification of SIDS/SUDI cases in Europe	Joffre A+B room (Level 1)
	Moderation: Richard D. G	oldstein (Boston, USA) & Torleiv Ole Rognum	(Oslo, Norway)
11:30-12:10	<ul> <li>Presentations on the exp</li> <li>Silvia Noce (Italy)</li> <li>Monique L'Hoir (Neth</li> <li>Pete Blair (UK)</li> <li>Béatrice Kugener &amp; C</li> <li>Ursula Kiechl-Kohlene</li> </ul>	perience of different countries perlands) <b>Odile Pidoux</b> (France) <b>dorfer</b> (Austria)	
12:10-12:50	Round table discussion		
	• Feasability of harmonis	ation of European SIDS classification	
12:50-14:00	Lunch - Visit of exhibition	& Posters	Joffre Hall (Level 1)
Parallel Se	essions		
14:00-15:00	The continuing decline	in SIDS mortality rates	Joffre A+B room (Level 1)
	Moderation: The Lulaly tru	<b>st</b> (parental association, UK), <b>Anna S. Pease</b> (Bris	stol, UK) & <b>Beatrice Kugener</b> (Lyon, France)
14:00-14:15	• Rachel Moon (Philadelph	ia, USA): Prevention strategies in Europe/Intern	national: do we deliver consistent messages
14:15-14:30	• Fern R. Hauck (Virginia, USA): Impact of SUDI Prevention messages on families: results from the SMART study		
14:30-14:45	• Hugues Patural (Saint-Étienne, France): Prevention of positional skull deformities and sudden infant death syndrome: French Recommendations		
14:45-15:00	• Pete Blair (Bristol, UK): E	European position on cosleeping	
	Downd table discussion		

14:00-15:00	SUDI and joint investigations of legal medecine	Joffre D room (Level 1)			
	Moderation: Siri Hauge Opdal & Torleiv Ole Rognum (Oslo, Norway)				
14:00-14:15	• Joanna Garstang (Birmingham, UK): Keeping families at the centre of SUDI investigation	tigations			
14:15-14:30	• Jonathan Holmes (Lancashire, UK): Experiences of joint agency death investigation - a UK policing perspective				
14:30-14:45	• Arne Stray-Pedersen (Oslo, Norway): Identifying Child Abuse Fatalities during Infancy				
14:45-15:00	• <b>Caroline Rambaud</b> (Paris, France): The French government's plan to combat child abuse and its implications for SIDS/SUDI victims				
15:00-15:30	Round table discussion				
14:00-15:30	Free presentations on SIDS and SUDI	Joffre C room (Level 1)			
	Moderation: Cécile Acquaviva-Bourdain (Lyon, France) & Monique L'Hoir (Wageningen, Netherlands)				
	Short oral presentations: European prevention strategies				
14:00-14:10	• Allegra Bonomi (Florence, Italy): Diversify channels to reach everyone: the Nanna Sicura portal				
14:10-14:20	• Eleonora Dicesare (Turin, Italy): ALTE in Piedmont region during the SARS-CoV-2 pandemic				
14:20-14:30	• Daniela Lo Duca (Padua, Italy): SIDS: Safe sleep and bedsharing or co-sleeping				
14:30-14:40	• Monica Diviccaro (Turin, Italy): SUID & SIDS ITALIA Safe Sleep prevention and criticality on information				
14:40-14:50	• Jenny Ward (London, UK): The importance of engaging with young parents				
14:50-15:00	• Stella Parkin (London, UK): Using a Safer Sleep Tool to Improve Perinatal Health Equity				
15:00-15:10	• Floortje Kanits (Wageningen, Netherlands): Non-compliance of Instagram photos with the infant safe sleeping advice for the prevention of SUDI				
15:10-15:20	• Floortje Kanits (Wageningen, Netherlands): Renewed attention to the current SUDI prevention advice is needed, with additional attention for high-risk groups				
15:20-15:30	• Achille Cernigliaro (Palermo, Italy): Good Parental Practices in the Prevention of Sudden Infant Death Syndrome (SIDS): the Results of a Survey in Sicily (Italy)				
14:00-15:30	Workshop on classification - Session 1	Joffre 4 room (Level 1)			
	Moderation: Richard D. Goldstein (Boston, USA) & Peter Flemming (Bristol, UK)				
	The aim of this workshop is to discuss the faisability for a harmonised SIDS/SUDI classification in Europe				
	<ul> <li>Advantages of harmonisation of classification</li> </ul>				
	<ul> <li>Agenda and procedures for a harmonised classification</li> </ul>				
	<ul> <li>Basis for the creation of a European consensus</li> </ul>				
15:30-16:00	Coffee break - Visit of exhibition & Posters	Joffre Hall (Level 1)			
	<ul> <li>Best poster award &amp; Best oral presentation award</li> <li>Word of the parental organisations &amp; Word of thanks</li> </ul>				
Parallel S	essions				
16:00-17:00	Actualities on SIDS/SUDI research	Joffre A+B room (Level 1)			
	<b>Moderation: Hugues Patural</b> (Saint-Étienne, France), <b>Monique L'Hoir</b> (Wageninge <b>Germaine Liebrechts-Akkerman</b> (Apeldoorn, Netherlands)	n, Netherlands) &			
16:00-16:15	• Patricia Franco (Lyon, France): It's a story of the sleep				
16:15-16:30	• Siri Hauge Opdal (Oslo, Norway): SIDS - is it all in the genes?	/			

16:30-16:45 16:45-17:00	<ul> <li>Christèle Gras-Le Guen (Nantes, France): SIDS: Infection and inflammatory cascade</li> <li>Rosemary S.C. Horne (Melbourne, Australia): The autonomic nervous system and the triple risk model for Sudden Infant Death Syndrome</li> <li>Round table discussion</li> </ul>			
17:00-17:30				
16:00-16:45	Sudden death in the young (SDY)	Joffre C room (Level 1)		
	Moderation: Pete Blair (Bristol, UK) & Gilles Cambonie (Montpellier, France)			
16:00-16:15	• Joanna Garstang (Birmingham, UK): Improving the investigation of ALL child deaths			
16:15-16:30	• <b>Carri Cottengim</b> (Houston, USA): USA's experience with sudden unexpected infant death and sudden death in the young case registries			
16:30-16:45	• <b>Peter Fleming</b> (Bristol, UK): Quality of investigations into unexpected deaths of infants and young children in England after implementation of national child death review procedures			
16:45-17:30	Round table discussion			
	<ul> <li>Creation of working groups on SIDS and Infant death in Europe/International</li> <li>How will we move on</li> </ul>			
16:00-16:45	Care pathway for a SIDS case (in French)	Joffre D room (Level 1)		
	Moderation: Elisabeth Briand-Huchet (Paris, France) & Béatrice Kugener (Lyon, France)	)		
	<ul> <li>Parcours de soins pour un cas de MIN (en français)</li> </ul>			
	<ul> <li>Dr Gilles Duthoit (Toulouse - France): L'intervention du Smur dans le parcours de soin d'une MIN : anecdotique ou pas ?</li> </ul>			
	<ul> <li>Anne Guillaume, Christelle Lapoirie et Stéphanie Lapeyre (Puéricultrices CRMIN Montpellier - France): Intervention de l'équipe du CRMIN</li> </ul>			
	<ul> <li>Karine Bertran de Balenda (Psychologue CRMIN Montpellier - France): Décès inatte répercussions sur le plan psychologique</li> </ul>	ndu, impact et		
16:45-17:30	Round table discussion			
16:00-17:30	Workshop on classification - Session 2	Joffre 4 room (Level 1)		
	Moderation: Richard D. Goldstein (Boston, USA) & Peter Flemming (Bristol, UK)			
	Presentation of difficult cases			
17:30-18:00	Closing ceremony	Joffre A+B room (Level 1)		
	Inge Harrewijn, Odile Pidoux & Gilles Cambonie			

• Presentation International congress ISPID Florence 2023

### EUROPEAN CONGRESS AND WORKSHOP ON SIDS SUDI From 29 2022 to 31 May 2022

••••• Le Corum Conference Center - Montpellier, France •••••

### ABSTRACTS MONDAY 30 MAY

**Plenary Sessions** 

### National variations in recent trends of sudden unexpected infant death rate in Western Europe

<u>Sophie de Visme</u><sup>1, 2</sup> (sophie.devisme@chu-nantes.fr), Martin Chalumeau<sup>2, 3</sup>, Karine Levieux<sup>1, 4</sup>, Hugues Patural<sup>5</sup>, Inge Harrewijn<sup>6</sup>, Elisabeth Briand Huchet<sup>7</sup>, Grégoire Rey<sup>8</sup>, Claire Morgand<sup>8</sup>, Béatrice Blondel<sup>2</sup>, Christèle Gras-Le Guen<sup>1, 2, 4</sup>, Matthieu Hanf<sup>9</sup>

<sup>1</sup> Clinical Investigation Centre 1413, Inserm/CHU de Nantes, Nantes, France

<sup>2</sup> Epidemiology and Biostatistics Sorbonne Paris Cité Centre, Inserm, Paris, France

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**Background:** Sudden unexpected infant death (SUID) rates remain high in some countries with high-income economies. We aimed to study recent epidemiological trends of SUID in Western Europe.

**Methods:** Annual national statistics of death causes for fourteen Western European countries from 2005 to 2015 were analyzed. SUID cases were defined as infants younger than one year with the underlying cause of death classified as "sudden infant death syndrome" (SIDS), "unknown/unattended/unspecified cause" or "accidental threats to breathing". Poisson regression models were used to study temporal trends of SUID rates and source of variation.

**Results:** From 2005 to 2015, SUID accounted for 15,617 deaths, for an SUID rate of 34.9 per 100,000 live births. SUID was the second cause of death after the neonatal period (22.1%) except in Belgium, Finland, France and United Kingdom, where it ranked first. The overall SUID rate significantly decreased from 40.2 to 29.9 per 100,000, with a significant rate reduction experienced for six countries, no significant evolution for seven countries, and a significant increase for Denmark. The SIDS/SUID ratio was 56.7%, with a significant decrease from 64.9% to 49.7% during the study period, and ranged from 6.1% in Portugal to 97.8% in Ireland. We observed between-country variations in SUID and SIDS sex ratios.

**Conclusions:** In studied European countries SUID declined during the study period but remained a major cause of infant deaths, with marked between-country variations in rates, trends and components. Standardization is needed to allow for comparing data and benchmarking to improve the implementation of risk-reduction strategies.

Keywords: Sudden unexpected death in infancy - Sudden infant death syndrome - Infant mortality - Epidemiology.

### From observation to intervention: identifying families at high risk of SUDI

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**Objectives:** Since SIDS was given an ICD code in the 1960s there have been over 90 observational studies conducted in more than 20 countries investigating the epidemiology of these deaths. The characteristic profile of the families, parents and infants is well established and the risk factors surrounding the infant sleep environment have largely been identified. Risk reduction campaigns at the population level have seen these deaths substantially decline in the last 3 decades. In England & Wales the number of SIDS deaths has fallen from nearly 1600 a year in the 1980s to less than 200 a year by 2019. SIDS deaths now occur in the more vulnerable families and the consistent prevalence of modifiable risk factors among current deaths suggest the population-level approach is not working for these families. Given the rarity of SIDS deaths the observational era is coming to an end and a targeted interventionist approach is required. We need to identify these vulnerable high risk families, work with them and get the message across in a way that they think is acceptable. These are the preliminary results of a tool that health professionals can use to target families and families can use to make their own decisions regarding safer infant sleep.

**Methods:** Observational data from both the CESDI (1993-96) and the SWISS study (2003-06) conducted in England were combined. Background characteristics and factors surrounding the birth were modelled to identify families at high risk of SIDS. Factors surrounding the sleeping environment were then added to help flag up the risks that families should avoid.

**Results:** Predictive background characteristics from the CESDI study included maternal and paternal smoking, younger mothers, larger families, unsupported mothers, admission to neonatal intensive care, male gender and low birthweight. The model predicted 49% of SIDS deaths in 9% of the population. The SIDS rate above the cut-off was 1 in 600, and for those below 1 in 6000. The risk factors within the infant sleeping environment to be red flagged included, sleeping position, hazardous bed-sharing, use of a pillow, swaddling, use of duvet, absence of a dummy, infant being unwell and change in routine.

**Conclusion:** The scoring system and planning tool interface will be embedded in a website being developed and used during a personalised planning activity to maintain safety in different sleeping environments, especially when routines are disrupted.

Keywords: SIDS - Epidemiology - High risk groups - Algorithm.

### Improving uptake of safer sleep advice: SIDS prevention for families with infants at increased risk

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**Objectives:** Falls in SIDS rates have not been equal across all groups and safer sleep advice has been less effective for more socially deprived families.<sup>1</sup> Investigating why some families with infants at increased risk of SIDS don't follow safer sleep advice is key to providing appropriate support to those with infants most at risk. Understanding the decision-making processes of these families could support the development of effective interventions to reduce the risks for SIDS and save lives.

**Methods:** A systematic review (commissioned by the Child Safeguarding Practice Review Panel in England) was completed to synthesise the qualitative evidence on parental decision-making for the infant sleep environment amongst families with children considered to be at increased risk.<sup>2</sup>

**Results:** Six overall themes were identified from this synthesis: (1) knowledge as different from action; (2) external advice must be credible; (3) comfort, convenience and disruption to the routine; (4) plausibility of the advice given, and mechanisms of protection; (5) meanings of safety, risk mitigation using alternative strategies; and (6) parents' own expertise, experience and instincts.

**Conclusions:** Interventions that are intended to improve the uptake of safer sleep advice in families with infants at risk of SIDS need to be based on credible advice with mechanisms of protection that are understandable, consistent with other sources, widened to all carers of the infant and fit within the complex practice of caring for infants. A safer sleep planning tool will use these findings to empower families with infants at risk with evidence-based education and realistic strategies for maintaining safety especially during disrupted routines.

Keywords: SIDS - Safer Sleep - Decision-making - Interventions.

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### Recent historic increase of infant mortality in France

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No abstract submitted.

### The English National Mortality Database: insigths from identifying and investigating ALL deaths of Infants and children

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The collection of detailed information and structured investigation of all child deaths (birth to age 18 years) in England has been a legal requirement for local Child Death Review Teams since 2008, but little national aggregation and analysis of these data was undertaken until 2019. Since April 2019 details of all deaths of children must be reported within 48 hours to the National Child Mortality Database (NCMD), based in Bristol University.

Three paediatricians at the NCMD review all death notifications daily, provide a provisional categorisation of the cause of death, and liaise with the local teams to ensure appropriate investigations occur. This allows the identification within 48 hours of all unexpected deaths, and thus the collection of data on the total numbers of unexpected deaths in childhood nationally.

We are also able to monitor in real time any significant changes in the categories of child death, which has allowed us to provide accurate timely information to Government on the impact on child mortality of the COVID19 pandemic and public health interventions in response to the pandemic. The NCMD has immediate access to the outcome of the local investigations and the statutory child death review meetings and has links to other statutory data collection systems relating to maternal and child health. We are thus able to investigate the impact of environmental, family, social, and medical background factors on child deaths in a timely manner.

We have shown the major impact of deprivation on child mortality from almost all conditions, and the lack of any identifiable increase in infant or child mortality during the pandemic. We have also shown that during the periods of major population restrictions ("lockdown") in response to the pandemic, child mortality fell, most markedly in children under 5 years, and those living in the most deprived areas.

The NCMD is a unique facility that allows real-time collection of accurate and complete data on factors contributing to child deaths, both expected and unexpected.

**Keywords:** Child deaths - Mortality - Population - Deprivation - COVID19 pandemic.

### The French prospective multisite Registry on sudden unexpected infant death (OMIN): rationale and study protocol

Karine Levieux

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No abstract submitted.

### The sudden unexpected infant death case registry: a method to improve surveillance

Sharyn Parks Brown and Alexa Erck

Houston - USA)

No abstract submitted.

### EUROPEAN CONGRESS AND WORKSHOP ON SIDS SUDI From 29 2022 to 31 May 2022

••••• Le Corum Conference Center - Montpellier, France •••••

### ABSTRACTS MONDAY 30 MAY

Parallel Sessions

### Analysis of diagnostic work-up in France

Christèle Gras-Le Guen

Nantes - France

No abstract submitted.

### Importance of the extent of death scene investigation for cases of Sudden and Unexpected Death of Infancy (SUDI)

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**Objective:** The investigation of sudden death in infancy and childhood requires consideration of different aspects: the responsibility to take care of the bereaved families, the duty of the police to investigate possible maltreatment or neglect, and the importance of research. A voluntary death scene investigation (DSI) is offered in all cases in which the police concludes with no criminal suspicion. The main purpose of the DSI is to contribute to the determination of cause and manner of death, and thereby increase legal protection. A secondary goal is to gather data about known and possibly unknown risk factors in order to prevent future fatalities.

The aim of the present study was to assess whether the Norwegian model of DSI serves its purpose as a legal safeguard for children, based on an evaluation of the results from the first six years.

**Method:** Since November 2010, death scene investigation (DSI) has been offered in all regions of Norway. The DSIservice exists in parallel with the police investigation. The Department of Forensic Science at Oslo University Hospital has a nationwide responsibility to coordinate the DSI-service. A forensic autopsy is performed in all cases. The DSI is performed by the forensic pathologist and a police expert, and a case conference is held in all cases.

**Results:** In the period 2010-2016, 141 cases were investigated. Voluntary DSI was performed in 75 cases and scene investigation by the police in 41 cases. In 19 cases DSI was declined, and in 6 cases mistakenly not offered.

In cases with DSI a medical disease was disclosed in 21 cases (28%), intoxication in 1 case (1%), suffocation in 1 case (1%). SIDS(1)/SUDC(2) in 41 cases (55%), and 11 (15%) were named undetermined. In cases with police death scene investigation disease was disclosed in 6 cases (15%), violent death in 12 cases (29%), suffocation in 13 cases (32%), SIDS/SUDC in 5 cases (12%), and 5 (12%) were named undetermined. In the 25 cases with no DSI, disease was the cause of death in 24% and 76% was named undetermined.

**Conclusion:** Voluntary DSI increased the ability to rule out accidental suffocation, facilitated evaluations of environmental risk factors, and enabled exclusion of neglect. Of major importance was the ability to radically reduce the label undetermined as a diagnosis. DSI was decisive for the diagnostic process in 14 cases, and should be mandatory (3).

Keywords: SIDS - SUDC - DSI Seath scene investigation.

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### Essentials of the autopsy work

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Objective: To describe the post-mortem investigations in SIDS cases in the UK

**Method:** In the UK, in SUDIC cases a post-mortem is always ordered by the Coroner (England and Wales) or by the Procurator Fiscal (Scotland). Depending on the jurisdictions the Coroner may request the autopsy to be done by a paediatric pathologist alone (if there are no suspicious circumstances) or to be a joint procedure done by a paediatric and a Forensic pathologist, even if there are no suspicious circumstances. Whenever there is any suspicion there is a joint autopsy. Kennedy Guidelines are followed.

**Results**: All relevant clinical information, family history and circumstances of death should be available to the pathologists prior to start the post mortem. This includes external and internal examination, microbiology, metabolic and genetic studies and toxicology. Full X ray (and many times also CT scan and/or MRI) is always performed and reported by a paediatric radiologist BEFORE the post mortem. The body is then photographed on its front, back and side.

The external examination should be detailed, noting nutritional status and hygiene, any abnormal findings or evidence of disease, of malformations and/or medical intervention. Measurements (weight, height and chest, abdominal and head perimeters) taken are compared against the expected for the age and sex.

The internal examination involves the opening of cavities. Incisions are done in such a way that after reconstruction and dressing of the baby they will not be obvious to the parents. Samples for histology are taken from all organs. The brain should not be sampled fresh and formalin fixation is required.

### Investigations:

Genetics: Skin sample.

Bacteriology: CSF, blood, urine, bowel content, swabs from nose, throat and lungs.

Virology: CSF, nasopharyngeal swab, lungs, heart, bowel content.

<u>Frozen tissue for lipid stains</u>: heart, liver, kidney and skeletal muscle.

Frozen tissue for eventual molecular studies: heart, liver, kidney and skeletal muscle (stored frozen at -70°C).

Metabolic studies: skin sample, Guthrie card (Newborn screening card), urine.

<u>Toxicology</u>: blood, urine, vitreous.

**Conclusion**: The report should include a clinical-pathological summary, carefully reviewing the clinical history and autopsy findings including the ancillary investigation results. The paediatric pathologists offer the Coroner a cause of death and an explanation of how this happened will help the Coroner and the parents understand how the baby died.

Keywords: SIDS - Autopsy - Post Mortem.

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### Feedback on a protocol for the management of sudden infant death syndrome

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In 2007, recommendations were issued concerning the management of sudden unexpected death in infancy (SUDI) and sudden infant death syndrome (SIDS) in France. These recommendations include a range of analyses to perform in order to improve the knowledge of the phenomenon, care of families and provide reliable statistics. In spite of these recommendations, the management of the phenomenon remains heterogeneous throughout the country. Since 2016 the University Hospital of Toulouse in France has implemented a protocol for the management of SUDI. The objectives of this work are to provide a feedback on its effectiveness and the difficulties encountered since the beginning of its implementation and to generate data on SUDI and SIDS.

The protocol involves close collaboration between judicial authorities, the pediatrics, emergency and forensic medicine departments of the University Hospital of Toulouse. It consists in the systematic realization of a standard blood test, bacteriological and virologic samples by the pediatricians, in the realization of a full-body CT scan and a forensic autopsy with collection of samples for genetic, toxicological and anatomopathological purposes.

We performed a retrospective analysis of all 63 cases included in the protocol since its inception. The data analyzed included descriptive data of the cases (age, sex ...), the circumstances of death, the existence of risk factors of SUDI, the cause of death and the type of examination performed.

70% of the cases were under 1 years old with a mean age of 4 month. 19 children were included aged 1 to 6 years old in the setting of extended SUDI (sudden unexplained death in childhood). The autopsy was performed on average 1.6 days after death. A precise diagnosis was identified in 37% of cases. Risk factors of SUDI was found in 50% of the cases. 14% of the files were incomplete, thus not permitting a conclusion. The establishment of a protocol appears to improve the management of sudden infant death. It appears to be essential for a better understanding of the phenomenon and to provide answers and appropriate care for bereaved families.

Keywords: SUDI - SIDS - Forensic.

### Assessing retinal hemorrhages with non-invasive post mortem fundus imaging in sudden unexpected infant death (SUDI)

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**Objective:** In case of sudden unexpected death in infancy (SUDI), eye examination should be systematic to detect retinal hemorrhages (RH) that are a crucial hallmark for abuse head trauma (AHT). To date, there is no consensus on the best approach to detect RH. Reports of postmortem fundus examination are very rare and no protocol has been yet validated. Assessing the capacity of postmortem fundus examination to detect RH is very important because it does not require a trained ocular pathologist, it is noninvasive, it avoids the removal of the eyes, it allows screening of a wider range of children without problems of acceptability, and the response is immediate.

The aim of our study is to provide the description of postmortem fundus examination by wide-angle fundus camera (RetCam, Clarity Medical Systems USA) in case of SUDI and to assess its capacity to detect RH.

**Methods:** We conducted a multicentric retrospective analysis of all cases of SUDI under two years of age manage by Nantes or Grenoble SUDI referral centers and who had post-mortem fundus examination by RetCam. The following clinical data were analyzed: age at death, sex, postmortem interval between death and fundus examination, final diagnosis after complete case investigation. Fundus photographs were reviewed randomly, twice, by three ophthalmologists blinded for all clinical data. For each eye, following data were assessed: sufficient image quality to assert presence of RH suggestive of AHT, presence of macular folding, presence of peripheral retinal folding. RH were classified according to a validated grading system for RH in AHT.

**Results:** Thirty cases were included: 23 in Nantes and 7 in Grenoble, 19 girls and 11 boys. Mean age was 6.4 months. Statistical analysis is in progress and will be finished in time to present at the European Congress on SIDS/SUDI the following results: proportion of fundus examinations with quality sufficient to assert the presence of RH suggestive of AHT, intra-observer and inter-observer reproducibility of quality assessment, correlation between image quality and age/post mortem interval/cause of death, description of RH, and correlation between RH and age/cause of death.

**Conclusion:** This pilot study will provide the first description of postmortem fundus examination in case of SUDI by wide-angle fundus camera RetCam and will help to define the best approach to detect RH in case of SUDI.

### Risk factors for unexpected infant death among very premature infants in France

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**Introduction:** Prematurity is one of the risk factors for Sudden Unexpected Infant Death (SUID). Our aim was to look for specific risk factors among very premature infants (VPI) in order to develop a prevention strategy.

**Materials and methods:** The analysis of specific factors associated with SUID among VPI was performed using prospective data collection on the French SUID registry (May 2015-December 2018). The factors associated with SUID among VPI were compared to those observed among full-term infants (FTI). Results are expressed as means (SD) or as medians (IQR).

**Results:** During the study period 719 SUIDs were included in the registry, 36 of which involved VPI [gestational age: 29.2 (2) weeks, 1157 (364) g] and 313 FTI [gestational age: 40 (0.8) weeks, 3298 (452) g]. The infants' postnatal age at the time of death was similar in the two groups 15.5 (12.2; 21.8) vs. 14.5 (7.1; 23.4) weeks. Among the VPI, only 52% were in supine position, and 29% were lying prone at the time of the SUID (compared to 63% and 17% respectively in the FTI group).

**Conclusion:** In this study, VPI and FTI died at similar chronological ages. The proportion of infants who died in prone position was high among VPI. These results suggest that the information given to parents of prematurely born children on sleeping conditions should be reinforced.

Keywords: Prematurity - Sudden unexpected infant death - Sleep position - Registry - Prevention.

### A successful collaboration: 24 hours cardiorespiratory recording in infants with surgical congenital anomalies

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**Objective:** Congenital anomalies are one of the main explained causes of infant death; in most cases they require a major operative intervention in the first days of life. Since 2019 a collaboration with Pediatric Surgery Division has been established to perform 24 hours cardiorespiratory (CR) recording in infants with surgical anomalies, to identify underlying conditions that may increase risk of death.

**Methods:** Retrospective analysis of 24 hours CR recording of babies who were candidates to surgery due to a congenital anomaly in the thoracoabdominal region. CR recording includes pulse oximetry, electrocardiogram and chest wall motion. Extreme events were defined as:1) apnoeas lasting  $\geq$ 20 seconds 2) bradycardias < 80 beats per minute  $\geq$ 5 seconds 3) desaturations < 80% SaO2 lasting  $\geq$  5 seconds. Periodic breathing was considered only if lasting > 30% of total sleep time. Sleep/wakefulness and feeding time were defined as reported by the caregiver. Prematurity and low birth were defined according to WHO definitions.

**Results:** Fifty-three infants underwent a CR recording in the years 2019-2021 (37 males, mean age at the time of the exam  $48 \pm 37$  days). Twenty-two cases (41%) were born preterm; 16 (30%) were low-birth weight. The most common malformations were oesophageal atresia (11/53), congenital aganglionic megacolon (6/53), congenital diaphragmatic hernia (6/53).CR recording was performed mainly after surgery (66% cases) and resulted normal in all patients except for 14 cases (26%). All those patients underwent CR recording after surgery. Two out of 14 presented extreme events only during sleep (desaturations): both were affected by oesophageal atresia and were born at term. Seven patients presented events only during feeding. Other four out of 14 presented periodic breathing; 3/4 were born preterm. The last patient, affected by ano-rectal agenesis, intestinal atresia and Fallot tetralogy in 21 trisomy presented bradycardia during sleep and desaturation during feeding. At the follow-up recording only three out of 14 still presented any abnormalities, which resolved in the subsequent examination.

**Conclusion:** In our cohort cardiorespiratory abnormalities were not infrequent and may increase risk in infants who present a sum of insidious conditions (i.e. congenital anomalies, prematurity and low-birth weight). 24 hours cardiorespiratory recording can help in identifying infants who need a more accurate evaluation prior to hospital discharge.

### Study of stress, hypoxia and post-mortem delay markers in unexpected infant death syndrome (SIDS/SUDI)

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**Objective:** to measure markers of stress and in particular hypoxia while taking into account the post-mortem delay (PMD).

**Methods and Patients:** We studied in children who died of SIDS different markers by immunoanalysis techniques such as RIA/IRMA with groups of 30-50 SIDS/SUDI and controls (n> 30). We chose (i) erythropoietin (EPO) which is regulated by tissue O2 pressure, (ii) stress hormones: Cortisol, ACTH, Beta endorphin, adrenergic markers: catecholamines (by HLPC) and their co-factors i.e. neuropeptide Y (NPY) and Chromogranin A (CGA), (iii) the most reliable markers of the PMD to measure the variations of the biological markers according to the PMD. We studied K+, lactate/glucose ratio and NSE (neuron-specific enolase) in CSF.

**Results:** after establishing the physiological levels of EPO according to the age of the infants, we showed that there was a significant difference in the EPO of SIDS and that of age-matched control infants (Le Cam-Duchez et al, [1]); we excluded pre-mortem anemia in SIDS because the fetal hemoglobin % was normal. At the same time, we have shown that SIDS have an increase in the CSF and the serum of the couple ACTH and beta-endorphin (BE) whose secretion is equimolar and of serum cortisol (M ± SEM: 874 ± 74 nM vs normal < 250 nM) . Unlike ACTH, which is labile (CSF: 28±7 pM; blood: 7±3; normal <15 pM), BE remains stable during post-mortem time (CSF: 123±21 pM; blood: 24±9; normal <15 pM). During agonal stress Cortisol and BE are both greatly increased signifying maximal stress (Coquerel et al. [2]). For adrenergic markers, catecholamines cannot be interpreted because they are very labile; nevertheless, HPLC-MSMS makes it possible to characterize and quantify toxins and drugs. On the other hand, neuropeptide Y and especially Chromogranin A (CGA), which are co-released by the adrenal medulla, are stable in PMD (CGA: m±SEM: 265± 22 vs control infants 105±18 ng/mL). They are greatly increased among the SIDS. As for the DPM markers for PM times > 12 h, the most reliable is the NSE. It also seems necessary to look for toxins and drugs in biological fluids because they can contribute to fatal apnea (Kahn et al, [3]; cf. Propranolol, abstract #6446).

**Conclusion:** most cases of SIDS are characterized by stress markers like Cortisol + endorphin, CGA and long lasting hypoxic episodes (EPO) that can be characterized despite PMDs of up to 48 h.

Keywords: stress hormones - chromagranin A - Erythropoietin (EPO) - Neuron-Specific Enolase - post-mortem delay.

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### Role of pathogens in Sudden Unexpected Death of Infancy A 10-year review of the PACA West SUDI reference center, University Hospital, Marseille

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**Objective:** The main objective of this study was to retrospectively analyze the microbiological data of the cases of Sudden Unexpected Death of Infancy (SUDI)) referred to the reference center of the western part of the Provence-Alpes-Côte d'Azur region, located within Assistance Publique – Hôpitaux de Marseille (AP-HM) over a period of 10 years. These data were collected by the realization of an «infectious» kit.

The secondary objective was to interpret the positive results according to the clinical and histological data.

**Methods:** All dead patients diagnosed with SUDI received at the AP-HM between January 2011 and February 2022 were included. An infectious kit including bacterial, viral and fungal tests by culture, serology and molecular biology (gene amplifications) on various samples: blood, CSF, nasopharyngeal samples and organ biopsies (lung/heart/liver/kidney), and rectal swab was performed.

Each case was subjected to a questionnaire with search for risk factors, biological and toxicological analyses, and an autopsy with pathological analyses. All results were discussed in multidisciplinary meetings.

**Results:** A total of 134 SUDI cases were collected over the study period. The median was 13 cases per year (range [7-17]). The ratio of boys to girls was 1.1 (70 boys and 64 girls) with a median age of 4 months (range [0-820 days]). The study of seasonality shows that 58.5% (79/134) of the cases of MIN occurred during the winter season between the months of November and March.

67.9% of the patients (91/134) had an autopsy.

The «infectious» kit could be performed in 120 infants, 66.4% (89/120) had at least one positive pathogen in at least one sample. A total of 30 different microorganisms were found, 58.5% (100/171) were bacteria, including 40 *Staphylococcus* spp (23%), 28 *Streptococcus* spp (16.4%) and 10 *Escherichia coli* (5.8%).

Viruses represented 40.3% of the microorganisms (69/171) with 22 Rhinoviruses (12.9%), 11 Adenoviruses (6.4%), 4 Influenza viruses (2%) and 2 Sars-CoV-2 (1%).

**Conclusions:** Our rate of detection of microorganisms is consistent with those found in the literature. It is essential to confront microbiological and pathological data with risk factors in order to determine the imputability of these microorganisms in the occurrence of death.

Keywords: SUDI - Microbiological infection - Anatomopathological data - Molecular biology.

### Aquaporin 4 expression in the hippocampus in sudden unexplained infant death

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**Objective:** There is evidence that disturbance in the development and regulation of brain function is involved in sudden infant death syndrome (SIDS), perhaps involving abnormalities in a network of neural pathways controlling critical homeostatic mechanisms. In the hippocampus from SIDS/SUDC (sudden unexplained death in childhood) it is reported both neuronal apoptosis and abnormalities similar to lesions associated with temporal lobe epilepsy. It is further known that the water distribution in neural tissue is often dysregulated after a hypoxic neural injury, making aquaporin 4 (AQP4), the main water channel in the brain, of interest. The aim of this study was to determine the distribution of AQP4 positive astrocytes in the hippocampus of SIDS/SUDC and controls, and also to examine relationships between hippocampal AQP4 expression and AQP4 genotype.

**Methods:** The study included 26 SIDS cases, 4 SUDC cases, and 26 controls (9 infants ≤ 52 weeks of age and 17 children >52 weeks of age). Tissue sections from the anterior hippocampus were stained using immunohistochemistry and anti-AQP4. AQP4 positive astrocytes were quantified using a 40x objective and a 10x ocular equipped with a grid. Three specific layers of the hippocampus were quantified separately, and the average AQP4 positive astrocyte count for each subject was calculated as the mean count across all three layers. The AQP4 polymorphism rs2075575 were genotyped using TaqMan SNP genotyping assay.

**Results:** The AQP4-positive astrocyte count differs significantly with age, being higher for infants  $\leq$ 12 weeks of corrected age than for ages 12.1-52 weeks (p=0.022) and >52 weeks (p=0.014). There were however no differences in the mean AQP4-positive astrocyte count between SIDS/SUDC cases and controls. The AQP4-positive astrocyte count is lower in infants with the rs2075575 CT/TT genotype than the CC genotype and higher in the youngest infants (p=0.025).

**Conclusion:** The study indicates that AQP4 expression in infants may be influenced by both age and genotype. Based on the high brain water content in the youngest infants and our previous finding of an association between the CT/ TT genotype and the brain/body weight ratio in SIDS <12 weeks of age, the present study strengthen the hypothesis that the rs2075575 CT/TT genotypes represent a genetic risk factor for a subset of SIDS.

**Keywords:** Aquaporin 4 - Hippocampus - Immunohistochemistry - rs2075575 - Sudden infant death syndrome.

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### Butyrylcholinesterase is a potential biomarker for SIDS

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**Objective:** Autonomic dysfunction has been implicated in the pathophysiology of the Sudden Infant Death Syndrome (SIDS). Butyrylcholinesterase is an enzyme of the cholinergic system, a major branch of the autonomic system, and may provide a measure of autonomic (dys)function. This study was undertaken to evaluate Butyrylcholinesterase activity in infants and young children who had died from Sudden Infant Death or Sudden Unexpected Death.

**Methods:** In this case-control study we measured Butyrylcholinesterase activity and total protein in the eluate of  $5\mu$ L spots punched from the dried blood spots taken at birth as part of the newborn screening program. Results for each of 67 SUDI deaths classified by the coroner (aged 1 week – 104 weeks) = Cases, were compared to 10 date of birth - and gender-matched surviving controls (Controls), with five cases reclassified to meet criteria for SIDS, including the criterion of age 3 weeks to 1 year.

**Results:** Conditional logistic regression showed that in groups where cases were reported as "SIDS death" there was strong evidence that lower BChEsa was associated with death (OR=0.73 per U/mg, 95% CI 0.60 – 0.89, P=0.0014), whereas in groups with a "Non-SIDS death" as the case there was no evidence of a linear association between BChEsa and death (OR=1.001 per U/mg, 95% CI 0.89 – 1.13, P=0.99).

**Conclusion:** BChEsa, measured in dried blood spots taken 2-3 days after birth, was lower in babies who subsequently died of SIDS compared to surviving controls and other Non-SIDS deaths. We conclude that a previously unidentified cholinergic deficit, identifiable by abnormal Butyrylcholinesterase Specific Activity, is present at birth in SIDS babies and represents a measurable, specific vulnerability prior to their death.

This is the first study to identify a measurable biochemical marker in infants who succumb to SIDS, during their newborn period while they are still alive, and one that could plausibly produce functional alterations to an infant's autonomic and arousal responses to an exogenous stressor leaving them vulnerable to sudden death. Further work investigating this area needs to be undertaken with urgency, to determine if specific activity of BChE could potentially be used as a biomarker to identify and prevent future SIDS deaths.

**Keywords:** Sudden Infant Death Syndrome - Butyrylcholinesterase - Cholinergic deficit - Autonomic Function - Arousal.

### **References:**

1. Harrington CT, Al Hafid N, Waters K. Butyrylcholinsterase is a potential biomarker for SIDS. May 2022 eBioMedicine; accepted, in press.

### **Contribution of metabolic invetigations**

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Inborn errors of metabolism (IEM) represents almost 700 different genetic disorders occurring especially during infancy and particularly severe in the neonatal period. Among them, IEM causing energy deficiency and/or intoxication are possibly associated with sudden infant death, the most likely being inherited defects of mitochondrial fatty acid oxidation. It is important to notice that some of IEM leading to sudden infant death are included in newborn screening (NBS) programmes as many of them are treatable. However worldwide, newborn screening programmes differ respect the disorders screened even if expansion to include IEM is still ongoing in some countries like in France. It is also important to keep in mind that fatal neonatal metabolic decompensation may occur before the result of NBS test or even before blood collection for NBS emphazing the need to screen for metabolic disorders even when death occurs whithin the first days of life.

Based on retrospective studies, IEM are estimated to account for 0.9% to 6% of sudden infant death highlighting the importance of collecting and storing appropriate samples for metabolic workup including systematically acylcarnitine profile allowing diagnosing fatty acid oxidation defects. As post-mortem sampling often lead to non-specific rise in some acylcarnitines, interpretation should consider these secondary abnormalities and could be challenging in some cases. A more reliable acylcarnitine profile could be obtained using the neonatal Guthrie card when available and stored in good condition.

Anyway, further tests are always needed mainly genetic investigation to confirm diagnosis and to provide genetic counselling for the family.

**Keywords:** Inborn Errors of Metabolism - Fatty acid oxidation defect - Newborn screening - Sudden infant death.

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### Importance and extent of infectious investigations

Aymeric Cantais

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No abstract submitted.

### **Cardiologic findings in SIDS cases**

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No abstract submitted.
### Radiologic contributions to the investigation of SIDS

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The *Haute Autorité de Santé* defines "Unexpected infant death" as a death that occurs suddenly in an infant with no known medical history of the infant to predict it (2007). In France, there are 240 deaths per year due to Sudden Infant Death Syndrome (SIDS).

Recommendations for investigations include radiological examinations of the entire skeleton and crosssectional brain imaging (CT or MRI), carried out and interpreted by trained professionals.

The main objectives of radiological examinations are: to exclude non-accidental trauma; to identify cause of death; to guide the (blood) sampling and to substitute for autopsy in case of autopsy refusal.

Skeletal radiography has good spatial resolution, particularly for the extremities to detect metaphyseal fractures. CT is relevant for bones, it can differentiate skull fractures from sutures, it detects rib fractures, even those close to the chondro-costal cartilage. CT also detects intracranial haemorrhage.

MRI has excellent resolution for soft tissue and solid organs but its limitations are a lower availability than CT scan, a long examination time of 30-45 min and poor performance in cardiac pathology.

Although not recommended, ultrasound can be useful for guiding biopsies in minimally invasive autopsy.

However, post mortem considerations must be known for proper interpretation of the examinations such as intestinal tract gas distension, intravascular gases, intracardiac clots and pulmonary changes.

The literature review shows that the different imaging modalities are complementary.

Radiological examinations can be useful and complementary to autopsy and in some cases replace it on Sudden Infant Death Syndrome.

Keywords: Radiological examination - Skeletal radiography - Brain imaging - Autopsy - Sudden infant death syndrome.

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### The Past, Present and Future of SIDS

Richard D. Goldstein

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No abstract submitted.

### **SNPs in SIDS**

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March 16th I will defend my thesis named SNPs in SIDS. For this PhD project I gathered 200 Dutch SIDS cases were autopsy was performed upon dating from 1985-2005 (the year before I sarted this project). We revised all histology slides and reports of these cases. Evaluated all known environmental factors of these cases. And last but not least we did genetica analysis on the case group regarding both regulatory genes for breathing control and LQTS-associated genes. In 19 we found a probable cause of death in histology review, 7 had a possible contributing effect in the Phox2B-gene and 26 had a possible genetic cardiac arrythmia. Furthermore we were the first to statistically prove that sigarrette smoking of the father poses a risk factor for SIDS independetly from the mothers smoking behaviour. I would love to give further details in an oral presentation.

### Keywords: autopsy - Lqts - smoking.

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### Ogival palate and Sudden Unexpected Death in Infancy (SUDI)

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Ogival palate or high arched palate is an easy feature to identify. It only requires to open the mouth of the infant and to look into it. An ogival palate is a facial feature indicating a narrow, small nasomaxillary complex. We previously showed that this morphologic feature present in autopsied children is associated with obstructive sleep breathing disorders in living children matching with the dead ones for age, gender and high and narrow vaulted palate (1). **Objective:** To observe the distribution of ogival palate in SUDI versus controls.

**Methods:** Retrospective study including all consecutive autopsies of infants ≤1 year of age including SUDIs and other causes of death, performed between 1st January 2020 and 30 th April 2022.

The characteristic "ogival palate" was identified during the morphological examination at autopsy and quoted by either yes or no.

The two groups were compared using the Pearson's Chi-squared test.

**Results:** There were 94 consecutive autopsies of infants aged 0-1 year. All the autopsies were performed by the same pathologist who evaluated the palate characteristics of each infant. There were 47 SUDI (22 males ; mean age = 3 m 3 w) and 47 controls (30 males ; mean age = 4 m 2 w) (icluding16 sub-dural hematomas, 7 dehydration during acute gastroenteritis, 5 cardiac pathologies, 5 digestive tract pathologies, 4 severe infections, 2 drownings, 2 severe bleedings, 2 neurologic pathologies and 4 others).

The SUDI group was made of 28 (59.6%) ogival palates and 19 (40.4%) normal palates ; the control group was made of 18 (38.3%) ogival palates and 29 (61.7%) normal palates. The p-value between the two groups is 0.039.

**Conclusion:** Ogival palate is a morphologic characteristic that seems highly associated with SUDI. As a marker of a narrow upper airway, it constitutes an indicator of sleep breathing disorders and thus is a risk factor for SUDI, a risk that is even higher if combined with an even mild upper airway infection and/or prone position. This study needs to be repeated on a larger number of cases.

Keywords: SUDI - Ogival palate - Autopsy - Risk factor.

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### The ogival palate: a new risk marker of Sudden Unexpected Death in Infancy?

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**Background:** Ogival palate is defined as narrow and high-arched palate. It is usually found in obstructive breath disorder but has been described in infants unexpectedly deceased. We studied the association between ogival palate and sudden unexpected death in infancy (SUDI) on the basis of a computed tomography (CT) evaluation.

**Methods:** We conducted a monocentric case-control study of children under 2 years of age died of SUDI, for which a head CT scan and an autopsy were performed between 2011 and 2018 at the University Hospital of Nantes. Each case was matched by sex and age (±30 days) to two controls selected among living children in the same center who benefited from a cranio-encephalic CT scan. Four parameters of the hard palate were measured by CT: height, width, length, and sagittal angle; the height/width ratio was calculated. The ogival form of the palate was also subjectively evaluated by the radiologists, independently from the measurements, by a global appreciation of the sagittal curvature and the coronal narrowness of the hard palate. Standardized odds ratios (OR) were calculated using conditional logistic regression models, all expressed for +1 standard deviation (SD).

**Results:** Thirty-two deceased children were matched to 64 living control children. Mean ages were 5.0 and 5.3 months, respectively. The mean heights of the hard palate were significantly higher in the deceased children (4.1 ( $\pm$ 0.7) millimeters (mm)) than in the living children (3.2 ( $\pm$ 0.6) mm), with OR ( $\pm$ 1SD) = 4.30 (95% confidence interval [CI], 2.04-9.06). The mean widths of the hard palate were 21.0 ( $\pm$ 1.9) mm and 23.2 ( $\pm$ 2.1) mm, respectively, with OR = 0.15 (95% CI, 0.06-0.40). The mean sagittal angles were significantly more acute in deceased children (134.5° ( $\pm$ 9.3)) than in living children (142.9° ( $\pm$ 8.1)), with OR = 0.28 (95% CI, 0.14-0.56). The mean height/width ratios were 19.8 ( $\pm$ 3.7) and 14.1 ( $\pm$ 3.3), respectively, with OR=6.10 (95% CI, 2.50-14.9). The hard palate was subjectively considered as ogival in 59.4% (19/32) of the cases versus 12.5% (8/64) of the controls.

**Conclusion:** Radiological features of the ogival palate were strongly associated with SUDI. Complementary studies are needed to confirm this observation and the corresponding clinical features must be identified.

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# Saved by the bell? A case report concerning an extreme preterm born infant monitored during sleep at home with a cardio-respiratory memory machine

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**Abstract:** Very preterm infants are at risk of sudden unexpected infant death. At discharge these children are equipped with a memory monitor to detect cardiorespiratory events. Follow-up includes reading out of the monitor memory and polysomnography. Both provide important and sometimes dissimilar information as is illustrated by this case report.

**Introduction:** Sudden unexpected infant death (SUID) is associated with prematurity, with rates increasing as gestational age decreases.

**Case report:** This report describes the polysomnographies and the reading out of the cardio-respiratory memory for a child born after 25 weeks and 1 day of gestation with a birth weight of 640 gr.

**Results:** The first PSG was abnormal in that it showed a large number of apnea (index: 36/hour of sleep), associated with fluctuating hypoxia.

The second PSG, performed two months after discharge, was markedly improved and could be considered normal for his age.

However, the reading of the monitor's memory was not normal.

The memory covered a period of two months use at home during sleep, between the two polysomnographies performed at the sleep laboratory of HUDERF.

558 events were recorded, and there were 30 alarms for bradycardia. Of those, 5 events were noteworthy in that they involved asystole, the longest 8.5 seconds.

**Discussion:** The second polysomnography, performed at 48 weeks corrected age (5 ½ months alive) did not show any asystole or any noteworthy bradycardia. However, reading out of the monitor showed a long asystole, accompanied with an alarm that took place at 45 weeks corrected age, just 3 weeks before the second PSG. That alarm woke up the child, as there is evidence of movement following the alarm. The parents probably woke up and went to investigate, but by then the child was awake and did not show any signs of breathing difficulties or other worrisome signs. They never contacted the sleep unit to report the event.

**Conclusion:** The alarms that accompany bradycardia, and in this case a long asystole provided an auditory stimulation which woke the child. The waking up (movements recorded after the alarm) terminated the obnoxious event, as the heart rate resumed in a normal fashion after the incident. It is absolutely impossible to know if the child would have woken up without the alarm, but in this case it would seem that the alarm was salutary.

Keywords: Infant - Premature - Suddent Infant death - Cardiorespiratory monitor - Polysomnography.

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### Unexplained infant deaths in bed-sharing situations versus in own bed – Both may be designated SIDS, but are they two different entities?

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Bed-sharing is according to the San Diego definition regarded as a risk factor for SIDS. In the Nordic countries, who have observed steadily declining SIDS-rates, the paradox is that bed-sharing seem more and more common among new parents. A recent questionnaire study showed that nearly two-thirds of Norwegian parents report routinely practice of bed-sharing with their babies. A large proportion also describe a history with hazardous sleeping arrangements such as having co-slept on a sofa or after consuming alcohol.

Bed-sharing proposedly increases the risk for hyperthermia, re-breathing of expired air, but also the possibility of accidental asphyxia and wedging. To rule out asphyxia and wedging, which should not be designated SIDS, a thorough post-mortem examination and death scene investigation is requisite.

We have set forth to perform a systematic study of autopsied cases of infant death from the last three decades in Norway. Only cases that have underwent investigation of the death scene will be included. We will determine the clinicopathological features in cases designated SIDS in bed-sharing situation and SIDS deaths found dead prone in own bed. The control group consists of victims of undoubted asphyxia, by smothering, wedging or other forms of suffocation. Our hypothesis is that bed-sharing SIDS cases are younger by age and more often premature or dysmature than SIDS victims found prone in own bed. Furthermore, we hypothesize that distinct features regularly observed at autopsy of SIDS victims, macroscopically and histologically, differs between bed-sharing SIDS victims, prone position SIDS cases and victims of mechanical airways obstruction. Such features of hitherto uncertain significance include presence of petechial hemorrhages on organic membranes, partial lung atelectasis, thymic stress signs and extravascular hemorrhages in airway tissue. Furthermore, we will study biochemical markers of inflammation and hypoxia in cases and controls, which may provide valuable insights to improved understanding of the death mechanism in SIDS and in asphyxic deaths. The outline of the ongoing study and preliminary results will be presented.

Keywords: SIDS - Bed-sharing - Asphyxia.

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### Death of an infant in the setting of a COVID 19 delta variant infection

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**Objective:** The main objective was to report a case of COVID 19 infection of an infant with an unfavorable outcome and to point out the possible severity of COVID infection in small infants.

**Method:** This is the presentation of a case of COVID 19 infection in an infant of 2 months of age. She was considered as a "near miss" in a context of COVID infection. This female child was born prematurely at 32 weeks of gestation and from a monochorial monoamniotic twin pregnancy. The evolution in the neonatal period was simple with normal neurological check-up and a discharge at home at 1 month of life.

At 2 months of age, she presented a rhinorrhea without fever in the context of a family COVID ; 1 week later, her condition deteriorated with asthenia, pallor and severe respiratory distress. At hospital her respiratory condition worsened further (ph 7.06 and pCO2 92 mmHg) and she convulsed. She was intubated, ventilated and given diazepam, transferred to the intensive care unit.

**Results:** In context of polyvisceral failure, a complete workup was performed.

The PCR was 11 mg/l and the PCT  $0.47\mu$ g/l; the lumbar puncture was sterile (negative viral and bacterial PCR); the microbiological samples revealed a COVID 19 mutation L452R and P681 R in the nasopharyngeal area and the bronchial aspiration.

The brain scan showed diffuse sustentorial hypodensity with possible diffuse ischemic injury; the brain MRI showed diffuse lesions related to prolonged anoxic ischemia or COVID encephalitis (lesions comparable to those described in adults). In addition, there is evidence of status epilepticus.

The child continued to worsen and died 2 days after hospitalization (lack of therapeutic escalation due to the severity of the neurological lesions).

**Conclusion:** Few articles in the literature are devoted to infant deaths in the context of COVID 19 infection. Only 1% of children (newborns to 17 years old included) die and 1% present convulsions with meningoencephalitis (positive nasopharyngeal and blood samples but negative CSF). Some people explain the differences in the clinical picture according to the polymorphism of the host, including its immune skills, but also by the mutations of the virus. Papers on pregnant women infected with COVID 19 variant delta seem to show more in utero deaths and fetal vascular events compared to previous variants. This suggests that this variant was more aggressive and that care should be taken in cases of COVID 19 infection in small infants with risk factors.

Keywords: COVID 19 infection - SUDI - Infant - Premature infant - Neurological effects of COVID 19.

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- 2. ABOLFAZL Adli, 2022, J Med Virol, 1-20.

# Five cases of Sudden Unexpected Death in Infants (SUDI) treated with propranolol for hemangiomas

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**Objective:** Hemangioma, a benign vascular tumor, affects 4-10% of newborns. For 13 years, propranolol has become the first-line treatment (Leaute-Labreze, 2008). To date, only one case of SUID has been published by Canadian health authorities. We report 5 other worldwide cases of infants who died of MIN while receiving propranolol for several weeks. The causes of SUID/SIDS (Sudden Infant Death Syndrome) are complex and use a so-called 'triple risk' model (Kinney, 2009) combining congenital causes, environment and triggering factors.

**Method:** Experts in French (F) and Australian (A) hemangiomas brought together the various cases collected from the pharmacovigilance banks from France, EMA, Canada (C) and Australia. All the analyzes recommended for cases of SUDI/SIDS have been carried out, including the risk factors, neonatal history and circumstances of death; the autopsy findings and the measurement of propranolol concentrations (3/5) in post-mortem blood were noted.

**Results:** Four of the children were born at term, the other at 35 weeks. In the 5 cases, the indication of propranolol was formal because of the growth of the hemangioma. All microbiological analyzes were negative except for one pneumococcus, probably artefactual. The toxicological screenings were negative and propranolol was assayed at non-toxic concentrations. Four of these deaths are unexplained and are classified as SUDI/SIDS; the 5th death occurred after severe hypoxia following bronchiolitis in a context of hypopituitarism and multiple minor malformations. The other post-mortem examinations reveal signs of SUDI: pulmonary and cerebral edema, and petechial hemorrhagic suffusions on the lungs and the thymus.

**Discussion:** during the MA studies, 2 doses of 1 and 3 mg/kg were studied with similar efficacy and adverse effects. Previous brainstem studies showed a lack of Epinephrine (responsible of arousal and cardio-respiratory stimulation) due to the absence the terminal enzyme PNMT (phenyl-N-methyl transferase) in the restricted area of medulla of the totally unexplained SIDS cases (Kopp, 1993).

**Conclusion:** These 5+1 cases of SUID treated with propranolol are few compared to the number of infants on propranolol for hemangiomas suggesting a coincidence. However, the lipophily of the beta-blocker and an eventual PNMT maturation delay could be implicated in these rare fatal respiratory failures.

Keywords: SIDS - PNMT - Epinephrine - beta-blokers - Hemangioma.

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- 2. Kinney H and Thach. 2009, N Engl J Med ;361(8):795-805.
- 3. Kopp N et al., 1993, Neuropediatrics ; 24(1): 25-29.

# EUROPEAN CONGRESS AND WORKSHOP ON SIDS SUDI From 29 2022 to 31 May 2022

••••• Le Corum Conference Center - Montpellier, France •••••

### ABSTRACTS TUESDAY 31 MAY

**Plenary Sessions** 

### How should we categorise and subdivide unexpected deaths of infants and children?

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Sudden unexpected deaths of infants and children have been recognised since antiquity, and various facile (and wrong) explanations devised (e.g. "*Status Thymus Lymphaticus*"). Such deaths are far more common in the first year of life, and since 1969 the term "Sudden Infant Death Syndrome" (SIDS) has been inconsistently used to identify those infant deaths for which those responsible for investigation could find no complete explanation. The question of whether certain observations of the infant's sleep environment (e.g. prone sleep position or bedsharing) could be considered a contributory factor, part, or even the whole of the causal process remains largely unanswered. Careful examination of the circumstances and scene of the death by appropriate experts may identify the possibility of entrapment or "overlaying" as part of the process, but there are no pathological findings that categorically identify asphyxia as the "cause" of death, and it is never possible to know whether overlaying preceded deaths or occurred because the infant who had already died did not respond to the presence of the adult.

Although several population-based studies of unexpected infant deaths have shown that between 25 and 50% of such deaths are "fully explained", no consistent criteria have been established to reach this conclusion. To date, there have been no large-scale population-based studies to identify the total incidence of unexpected deaths of older children, as those deaths that are subsequently identified as being due to specific conditions are registered under those conditions rather than unexpected or unexplained deaths.

Many professionals are unhappy with the designation "Syndrome" for unexplained deaths as it implies a consistency or commonality in the causal process.

The Avon clinicopathological classification system makes no assumptions about specific causal processes, but categorises the factors identified in the detailed investigation and assigns each factor a score based on its likely contribution to the death. The classification thus produces a grid for each death in which the factors are assigned possible, probable, and (less commonly) definite strength of causality to the death. It thus allows all unexpected deaths to be considered. This classification system although not yet universally used has been adopted as part of the statutory process of investigating unexpected child deaths at all ages in England.

Keywords: SIDS - SUDI - Unexpected deaths - SUDC - Avon classification.

### Pathology – The Elephant in the Room

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There have been very clear definitions of sudden infant death syndrome (SIDS) published in the literature for over half a century which specify the following requirements before SIDS can be accepted as a possible reason for the tragic death of an infant: medical history review, death scene examination and an autopsy. Despite this, researchers persist in ignoring these requirements often calling all cases of unexpected infant death "SIDS". Proof of this was found in a recent study of SIDS papers published in the English language peer-reviewed literature from 2019 to 2021 where nearly 2/3 of the papers did not use or cite standard definitions. On occasion authors admitted that their cases of "SIDS" had not even had autopsy examinations. An analogy would be for cardiologists to study patients with heart attacks based solely on a complaint of chest pain without any further investigations. This clearly would not occur and would not be published as standards are being upheld. How then in the SIDS field do non-pathological investigations exclude occult myocarditis, aortic stenosis, congenital heart disease, meningitis, trauma etc etc.? Surely it will not be possible to compare, evaluate and validate research if we do not apply the same diagnostic and definitional parameters? Finally, how do we explain this highly unsatisfactory situation to parents?

Keywords: SIDS - Definitions - Poor research - Failure.

- 1. Sterling SO, Byard RW. Is academic rigor in sudden infant death syndrome (SIDS) research in decline? Acta Paediatrica 2022; 111: 1015-1018.
- 2. Tan L, Byard RW. An analysis of the use of standard SIDS definitions in the English language literature over a threeyear period (2019-2021). Acta Paediatrica 2022; 111: 1019-1022.

### The Radcliffe classification and the ICD-11

Richard D. Goldstein

Boston - USA

No abstract submitted.

### Classifications of sleep-related sudden unexpected death in infancy

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**Objectives:** To compare Child Death Overview Panel (CDOP) classification of sleep related SUDI cases.

To explore recent classification of SUDI in Birmingham, UK.

**Methods:** Survey of CDOPs and paediatric pathologists using typical case examples of SIDS, SIDS with co-sleeping and accidental asphyxia. The survey took place during 2017. (1)

Analysis of CDOP data on sleep related SUDI for Birmingham 2018-2022.

**Results:** 38/92 CDOPs and 13/90 pathologists returned questionnaires. 31 (97%) CDOPs and 7 (53%) pathologists agreed with the cause of death in the accidental asphyxia case; 24 (75%) CDOPs and 9 (69%) pathologists in the typical SIDS case; and 11 (34%) CDOPs and 1 (8%) pathologist in the co-sleeping SIDS case.

Birmingham CDOP data recorded 17 sleep related SUDI, 8/17 were classified as SIDS, 8/17 as unascertained, 1/17 as Sudden Unexpected Early Neonatal Death (SUEND). No deaths were officially classified as accidental asphyxia. One infant was found with a blood stained nappy sack on their mouth and nose, this death classified as SIDS. One infant co-slept with a parent on a sofa, and at autopsy was found to have multiple rib fractures that occurred 1-2 hours pre-death suggesting a crush injury, this death was classified as unascertained.

Modifiable risk factors for SIDS/SUEND were: 1 tobacco only, 2 tobacco and cannabis, 2 soft-bedding, 1 potential asphyxia (nappy sack), 3 cases had no modifiable risk factors.

Modifiable risk factors for unascertained deaths were: 2 co-sleeping and tobacco, 2 co-sleeping with parental alcohol, cannabis and tobacco use, 1 soft-bedding only, 3 cases had no modifiable risk factors. Two of the co-sleeping deaths were on sofas, and two on beds.

**Conclusions:** Infant deaths from accidental asphyxia remain under-recognised. There are few differences between deaths labelled as SIDS or unascertained. There should be more discussion between pathologists, paediatricians and coroners to ensure an accurate cause of death is recorded.

Keywords: SUDI - SIDS - Accidental asphyxia.

### **References:**

1. Garstang J, Cohen M, Mitchell EA, Sidebotham P. Classification of sleep-related sudden unexpected death in infancy: A national survey. Acta Paediatr. 2020.

### SUID surveillance in Piedmont Region: methodology and preliminary results

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<sup>2</sup> Department of Public Health, ASL Città di Torino, Turin, Italy

<sup>3</sup> University of Turin, School of Pediatrics, Turin, Italy

<sup>4</sup> Department of Pediatrics, Ospedale Ferrero, Verduno, Italy

**Introduction:** Sudden Unexpected Infant Death (SUID) is the main cause of infant mortality in Western Countries. In Piedmont Region, a Centre for SIDS (Sudden Infant Death Syndrome) surveillance and prevention was founded in 1994. In the present work we describe the methodology used for data collection and we show the preliminary results of Sudden Unexpected Infant Deaths surveillance in the years 2004-2015. The analysis of quinquennium 2016-2020 data is still in progress.

**Methods:** Retrospective review of all charts filled in case of death of a child aged 0-24 months in the years 2004-2015; active data collection in case of SUID notified by Emergency Services and/or Emergency Department. Data were collected according to standardized forms and a regional database was filled in. Mortality rate was calculated according to the number of children born alive in Piedmont every year as reported by Regional Statistic Database. **Results:** In the years 2004-2015 1249 infants aged 0-24 months died in Piedmont (infant mortality rate 2.8 per mil live birth). Among them, 89 sudden unexpected infant deaths occurred (SUID mortality rate 0.2 per mil live birth). Thirty-seven out of 89 were explained Sudden Unexpected Infant Deaths, 37 were sudden unexplained infant deaths (SIDS) according to Krous classification and the remaining 15 were not classifiable; SIDS mortality rate in the years studied was 0.08 per mil live births.

**Conclusion:** Piedmont SUID surveillance, based on both retrospective analysis and real time investigation, allowed us to have the most complete number of SUID in the region with sustainable costs. Future efforts should be aimed at activating a national registry, to have stronger data to compare with international results.

Keywords: SUID - SIDS - Infant death - Epidemiology - Surveillance.

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- 2. Shapiro-Mendoza, CK. et al. (2014) Classification system for the Sudden Unexpected Infant Death Case Registry and its application. Pediatrics.134(1):e210-e219. doi:10.1542/peds.2014-0180.
- 3. Levieux, K., et al. (2018) The French prospective multisite registry on sudden unexpected infant death (OMIN): rationale and study protocol. BMJ Open. 17;8(4):e020883. doi: 10.1136/bmjopen-2017-020883.

### **Child Death Reviews in the Netherlands**

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In many countries the death of a child is examined in a systematic way by a multidisciplinary team (USA, Canada, Australia, New Zealand and UK). This is called a Child Death Review (CDR). Sometimes this concerns children of all ages, sometimes it concerns a specific group of children.

In the Netherlands, all children that die and are unexplained up to the age of 18 are reported to one of the 7 academic hospitals and reviewed every three to four months per hospital. This is called the NODOK-procedure (NODOK= Further Examination of the Causes of death in Children). The cause of death is determined by means of an audit procedure in which relevant experts participate. Of 176 children reviewed in 2016-2020, 51% of deaths occurred before the age of one. When eventually a cause of death was found, this contributes to the grieving process of relatives, and for example, when genetic, it also added to the prevention of further deaths in family members. In 23% of these child deaths, the cause of death remained unknown.

Next to this NODOK-procedure, a more in-depth method is used for SUDI-cases in the Netherlands. Families with a SUDI-child are visited at home, and an extensive questionnaire is filled in. This has proven to be a sound way to collect epidemiological data, which are needed to develop specific prevention programs for SUDI.

CDR objectives developed by the AAP are to (1) improve the quality of the procedure with regard to the determination of the cause of death as well as the death statistics, (2) identify avoidable factors that give directions for prevention, (3) translate the results into possible interventions and (4) support the family.

Unfortunately, there is a wide variety of methods and what seems to be the most promising, consistent way of child death reviewing? Is CDR indicated for the particular groups of child deaths, namely those who die unexpected, unexplained child deaths? Should it be standard supplemented with an epidemiological approach, which exists of home visits? This means talking with the parents, instead of talking about them.

We will present to what extent the existing procedures of the Dutch organizations cover the four CDR objectives in responding to a child's death. Furthermore, by exchanging facts, findings and thoughts with the audience present, we hope to collect clues how we can improve the coordination and standardising of these reviews.

Keywords: Child Death Reviews - Epidemiology - SIDS SUDI.

- 1. Gijzen S, Petter S, L'Hoir MP, boere-Boonekamp MM, Need A. (2017). Procedures in child deaths in The Netherlands: a comparison with child death review. J Public Health DOI 10.1007/s10389-017-0800-9.
- 2. Garstang J, Griffiths F, Sidebotham P (2014). What do bereaved parents want from professionals after the sudden death of their child: a systematic review of the literature. BMC Pediatrics, 14:269.

### Classification of SIDS/SUDI in the UK (and elsewhere)

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<sup>1</sup> Centre for Academic Child Health, Bristol Medical School, University of Bristol, UK <sup>2</sup> Department of Midwifery, Royal United Hospitals Bath NHS Foundation Trust, UK

**Background:** Sudden Unexpected Deaths in Infancy (SUDI) is an umbrella term for explained and unexplained deaths. SUDI does not have an International Classification of Diseases-10 (ICD-10) code but, as Taylor et al indicated several ICD codes can be used to represent SUDI cases.<sup>1</sup> The main problem is that this collection of codes mixes up unexplained causes (e.g. SIDS-R95) with explained causes (e.g. accidental strangulation and suffocation in bed ASSB-W75). The aim is to present the trends in classification in the UK and compare with other countries.

**Methods:** Four of the codes suggested by Taylor (R96, R98, W78 and W79) are rarely used so this presentation focuses on the codes R95 (SIDS), R99 (Unspecified) and W75 (ASSB) as well as a composite of all 7 codes to represent SUDI deaths and the PNM rate from 2001 to 2017.

**Results:** In England & Wales, R95 and R99 are commonly used, W75 rarely, and the SUDI rate fell from 0.61 to 0.32 per 1000 livebirths over the 17 year period (48% decrease). In Scotland R95 is predominantly used with a slight recent increasing use of W75 and the SUDI rate fell from 0.68 to 0.45 per 1000 livebirths over the 17 year period (34% decrease).Similar data will also be presented from Germany, Israel, Australia, NZ, Colombia, Canada and the US) **Conclusion:** Examining SUDI deaths using different ICD codes helps understand the varying trends between countries and in most countries the SUDI rate has declined over the 17 years. However the codes are being applied differently in different countries and more worryingly there appears to be a diagnostic shift to using W75 in some countries with no clear evidence of why these deaths are fully explained.

### **References:**

1. Taylor BJ et al. Arch Dis Child 2015;100(11):1018-23.

### **Béatrice Kugener** and **Odile Pidoux**

France

No abstract submitted.

### The experience with classification of SIDS/SUDI cases in Europe

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Head Department of Pediatrics II (Neonatology), Medical University Innsbruck, Innsbruck, Austria

The diagnosis of SIDS/SUDI requires a complete post mortem examination with a negative autopsy and a negative clinical history.

A medico-legal examination is carried out by the police and a medical officer of health (a certified physician) if the death is sudden and unexpected. This examination includes a death scene investigation with particular focus on surroundings regarding the death including data from interviews with relatives and data from hospital records.

Autopsies are being conducted by paediatric pathologists or forensic pathologists with special paediatric experience usually one or two at each department.

Autopsies include a full macroscopic post-mortem examination in addition to a histological examination (brain, heart, lung, liver, kidney, and thymus). Bacteriological and virological investigations, metabolic studies, as well as other analyses, such as genetic, biochemical or toxicological investigations are done in selected cases. Body fluids and dried blood spots are stored (in case additional examinations will be necessary).

In conclusion, the final cause of death will be classified following the review of the post-mortem findings and of the clinical history available to the pathologist at the time of the autopsy (including any details of the death scene investigation).

In Austria, all deaths are listed at http://www.statistik.at. SIDS/SUDI is coded as "Plötzlicher Kindstod" (R 95).

# EUROPEAN CONGRESS AND WORKSHOP ON SIDS SUDI From 29 2022 to 31 May 2022

••••• Le Corum Conference Center - Montpellier, France •••••

### ABSTRACTS TUESDAY 31 MAY

Parallel Sessions

### Prevention strategies in Europe/International: do we deliver consistent messages

Rachel Moon

Philadelphia - USA

No abstract submitted.

### Impact of SUDI Prevention messages on families: results from the SMART study

Fern Hauck (frh8e@virginia.edu)

### University of Virginia, Charlottesville, Virginia, United States

**Objective:** Inadequate adherence to recommendations known to reduce the risk of SUDI has contributed to a slowing in the decline of these deaths. Our objective was to assess the effectiveness of 2 interventions to promote infant safe sleep practices compared with control interventions.

**Methods:** Mothers of healthy term newborns were recruited at 16 US hospitals and randomly allocated to one of 4 study arms. All participants were beneficiaries of a nursing quality improvement campaign in infant safe sleep practices (intervention) or breastfeeding (control), and then received a 60-day mobile health program, in which mothers received frequent emails or text messages containing short videos with educational content about infant safe sleep practices (intervention) or breastfeeding (control) and queries about infant care practices. The primary outcome was maternal self-reported adherence to 4 infant safe sleep practices of sleep position (supine), sleep location (room sharing without bed sharing), soft bedding use (none), and pacifier use (any); data were collected by maternal survey when the infant was 60 to 240 days.

**Result:** Of the 1600 mothers who were randomized to 1 of 4 groups (400 per group), 1263 completed the survey (78.9%). The mean (SD) maternal age was 28.1 years (5.8 years) and 32.8% of respondents were non-Hispanic white, 32.3% Hispanic, 27.2% non-Hispanic black, and 7.7% other race/ethnicity. The mean (SD) infant age was 11.2 weeks (4.4 weeks) and 51.2% were female. In the adjusted analyses, mothers receiving the safe sleep mobile health intervention had higher prevalence of placing their infants supine compared with mothers receiving the control mobile health intervention (89.1% vs 80.2%, respectively); room sharing without bed sharing (82.8% vs 70.4%); no soft bedding use (79.4% vs 67.6%); and any pacifier use (68.5% vs 59.8%). Interactions between the 2 interventions were only significant for the supine sleep position.

**Conclusion:** Among mothers of healthy term newborns, a mobile health intervention, but not a nursing quality improvement intervention, improved adherence to infant safe sleep practices compared with control interventions. Whether widespread implementation is feasible or if it reduces SUDI rates remains to be studied.

Keywords: Sudden unexpected death in infancy - Mobile health - Safe sleep - Breastfeeding.

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- 2. Kellams A, et al. 2022 February 4, Acad Pediatr: https://doi.org/10.1016/j.acap.2022.01.016

### Prevention of positional skull deformities and sudden infant death syndrome: French Recommendations

### Hugues Patural (hugues.patural@chu-st-etienne.fr)

### Inserm, U1059, SAINBIOSE, Neonatal Intensive care Unit, Centre Hospitalier Saint-Etienne, Saint-Etienne, France

The increase of positional skull deformities in babies (plagiocephaly) and the aesthetic fear that this induces may lead parents and some health professionals to doubt the necessity of putting babies on their backs. It can encourage them to put them back on their side or, worse, their stomachs.

The French High Authority of Health (HAS) publishes a memo sheet with the National Professional Pediatric Council that recalls the means of prevention of unexpected infant death and plagiocephaly.

### **Reassure and support parents**

Plagiocephaly in babies is a source of concern for parents. However, they must be reassured. These cranial deformities are benign and have no consequences without causal link with neurodevelopmental delay or specific ophthalmological, oculomotor, vestibular troubles. In most cases, cranial deformities disappear by the age of 2 years. In all cases, professionals working with infants and their parents must address the subject, explain the measures to prevent plagiocephaly, and give the right advice before and after birth, especially in the first six months of life when the skull is most malleable.

### Prevent plagiocephaly by letting the baby move

If sleeping on the back remains the only position to adopt, he should not be constantly immobilized the rest of the time and prevented from consistently positioning his head on the same side. Daily, parents, therefore, are the main actors in preventing this deformation. They should leave their child to move freely, including on his stomach when awake and always if supervised. HAS also recommends varying the infant's postures and encouraging spontaneous head rotations through sensory prompts (tactile, visual, auditory). During his awakening phases, it is recommended to install him on a firm mat on the ground with toys positioned around him, avoiding arches and mobiles that will fix his attention in a single place. HAS also pointed out the harmful effects of headrests, seat shells, and anti-flat head cushions, which are multiplied in babies' environment and prevent them from moving freely.

### In case of confirmed plagiocephaly, it is necessary to combine daily gestures and adapted interventions

Physiotherapy care should be prescribed as soon as possible if the child has difficulty moving his neck (torticollis). In the absence of improvement in the skull deformity after appropriate care, the child must be referred possibly from the end of the first semester, to a reference center for craniofacial malformations.

Keywords: Skull deformity - Plagiocephaly - Sudden infant death.

### European position on co-sleeping

Peter Blair<sup>1</sup> (p.s.blair@bris.ac.uk), Anna Pease<sup>1</sup>, Jenny Ingram<sup>1</sup>, Karen Patrick<sup>2</sup>, Becky Ali<sup>1</sup>, Peter Fleming<sup>1</sup>

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<sup>2</sup> Department of Midwifery, Royal United Hospitals Bath NHS Foundation Trust, Bath, United Kingdom

**Objectives:** Initial observations of an increased risk of sudden infant death syndrome (SIDS) associated with bedsharing have come under scrutiny and revealed the risk is mainly limited to the particular circumstances in which bedsharing occurs (if parents smoke, drink alcohol, take drugs, use sofas or where the infant is particularly vulnerable). The public health question is whether we advise against bed-sharing completely or advise parents about the specific circumstances that can make bed-sharing more risky. In the last two decades most European countries have followed a didactic approach to varying degrees advising against bed-sharing, although notably England & Wales have not; acknowledging that bed-sharing will happen, discussing with parents the particular risks involved and giving them an informed choice. The rates of SUDI in Europe and prevalence of bed-sharing are explored to assess impact and the way forward.

**Methods:** Rates of SUDI (using the approach suggested by Barry Taylor) are presented from 2000 to 2017 in 5 European countries, including diagnostic shift. The prevalence of bed-sharing is presented from peer-reviewed literature.

**Results:** The SUDI rates have continued to fall in Europe, after the sharp decline in the 1990's the rates in 5 countries (France, England & Wales, Scotland, Netherlands & Germany) have steadily fallen in the last two decades by around 50%. A slight diagnostic shift from R95 (SIDS) to W75 (accidental strangulation and suffocation in bed) has only occurred in one country (Scotland). The prevalence of bed-sharing is relatively high in most countries and there is some evidence it has increased in this time period. The reasons for this and the way forward will be explored.

**Conclusion:** The infant care practice of bed-sharing is difficult to influence and the vulnerable families in which SIDS deaths now occur are often those where population-level advice seems to have the least impact. A targeted educational approach working with high risk families may reduce SUDI rates further.

Keywords: SIDS - Bed-sharing.

### Keeping families at the centre of SUDI investigations

Joanna Garstang (joanna.garstang@nhs.net)

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**Objective:** Information from families is vital for effective SUDI investigation, but professionals may worry that detailed investigation particularly with police and medical staff working together causes additional parental distress. This presentation will explore parents' and professionals' experiences of joint agency SUDI investigation and current difficulties with their involvement.

**Methods:** Qualitative interviews with bereaved SUDI parents, whose infants died during 2010-2012 and professionals working with them (1), and comparison with recent Child Death Overview Panel (CDOP) data from Birmingham UK. **Results:** There were 21 parental and 26 professional interviews. There was a conflict between the need to support parents and thoroughly investigate deaths. Most parents appreciated the Joint Home Visit by police and medical staff, although some found it too upsetting and did not engage. Police and medical staff found joint working practices very helpful.

There were 17 sleep – related SUDI reviewed by Birmingham CDOP during 2018-2022. Not all had Joint Home Visits, these often did not occur if police were concerned that criminal activity may have taken place. Criminal concerns included child neglect and overlay of infants while parents were intoxicated with alcohol or drugs. If a Joint Home Visit did not occur, the sleep circumstances were rarely understood. There were no prosecutions of parents due to lack of evidence.

All parents were offered follow-up visits by the paediatrician to discuss the cause of death, but some did not want this.

**Conclusion:** Joint home visits, with detailed history from the parents and examination of the scene of death are a vital part of SUDI investigation and appreciated by most families. When joint home visits do not occur, important information on what happened is lost. Police and paediatricians need to ensure effective joint working in SUDI cases where there are criminal concerns.

Keywords: SUDI - SIDS - Multi-agency working.

### **References:**

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### Experiences of joint agency death investigation - a UK policing perspective

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Jonathan Holmes was formerly a Detective Superintendent in Lancashire Police in the North-West of the United Kingdom, retiring in January 2022 as Head of Major Crime. He was a formally accredited Senior Investigating Officer who led several successful homicide investigations including the murder of children. He is a long-serving member of the UK Police National Child Death Working Group where he led the recent national review of training in this critical area. He co-authored recently revised national guidance for UK policing, introducing a new 'Three Principle Framework' to guide the policing approach throughout the investigation. He recently drafted operational policing guidance for the obtaining of blood samples from bereaved parents, focused on achieving the balance between compassion and the needs of the investigation. He has a research specialism in the complexities of investigative decision-making within incidents of child death. His thesis 'Understanding the role of uncertainty and anxiety in police decision-making during the investigation of sudden unexpected deaths in children' was published recently in the Journal of Investigative Psychology and Offender Profiling.

In his presentation to conference, 'Experiences of Joint Agency Death Investigation - a UK Policing Perspective', Jonathan will draw on thirty years of operational policing experience to provide an overview of joint-agency investigative processes operating within the UK, looking at the benefits and the challenges that these approaches bring. He will reference his research into investigative decision-making and invite the audience to reflect on the unique challenges facing Lead Investigators. He will also refer back the early stages of the pandemic and how agencies came together to adapt existing frameworks to unprecedented operating environments.

Keywords: Joint - Police - Decision - Investigation - Balance.

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### Identifying Child Abuse Fatalities during Infancy

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More than 150 years ago, Ambroise Tardieu described typical manifestations of child abuse and the characteristics of infanticides. By systematic physical examination and careful autopsy, he observed multiple bruising of different colors, bruising located elsewhere than bony prominences, patches of hair loss and skeletal fractures. The fatalities of child abuse typically had presence of skull fractures and blood covering the brain (subdural hematoma). In contrast to fractures secondary to birth or to an accidental fall, he noted that inflicted skull fractures were more likely complex (multiple and/or depressed). Tardieu's descriptions of violence against children were largely ignored by the medical society and the public. A century later, the improved possibilities to detect fractures by X-ray paved the way for Kempe and colleagues to redescribe what characterizes the "battered child".

Advances in radiological scanning technology, laboratory analyses, computer assessments and visualization techniques have improved our ability to detect injuries, better comprehend pathophysiology and mechanisms of injury and reduce diagnostic uncertainty. From several decades of research, we now also have a lot more knowledge about the epidemiology, risk factors and red flags of child abuse. Nevertheless, few subjects in the field of forensic medicine are as heavily debated in current times as child abuse and infanticides. Critics are arguing the medical evidence is yet insufficient to prove an inflicted cause. They claim complications of birth trauma, disorders of brain development and cerebrospinal fluid homeostasis are overlooked, bone fragility is little investigated and hemorrhages may occur spontaneously. In their opinion, the problem is that parents are wrongfully accused and convicted of child abuse. How can we as physicians precisely identify child abuse fatalities? We know that there are no pathognomonic findings of inflicted trauma; neither bruises, fractures, subdural hematoma, retinal hemorrhages, nor brain lesions. However, there are certain patterns, features and combinations that may substantially increase the probability of abuse. Detecting evidence of inflicted trauma requires interdisciplinary collaboration and involves taking advantage of current knowledge and technology. The forensic pathologist's most robust tool however, remains simple and low-tech, using a meticulous autopsy protocol and systematic approach ad modum Tardieu.

Keywords: Child abuse - Infant death - Shaken baby syndrome - Autopsy - Child maltreatment.

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# The French government's plan to combat child abuse and its implications for SIDS/SUDI victims

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No abstract submitted.

### Diversify channels to reach everyone: the Nanna Sicura portal

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The digital world is immense and has a potentially infinite user base. Over the past 20 years, the advent of social media has offered the possibility of increasing communication channels and we have learned that redundancy is a plus and not a defect.

Semi per la SIDS is currently present online with its own institutional website, a Facebook page that informs about new initiatives and an Instagram profile that works more on the emotions using suggestive images and very concise content.

We have known for years that it is not easy to talk about cot death and that our sad topic is an obstacle not only in involving childcare companies, but also in being joined by those new parents or expectant parents who psychologically reject the thought of a possible tragic event connected with the birth of their child.

In addition, the scope of the recommendations has been greatly expanded. It is no coincidence that in the USA since 2012 we have been talking about Safe to sleep and no longer just about Back to sleep

Furthermore, the various acronyms SIDS, SUID, SUDC... present in our logos and Internet domains do not favour the natural discovery of our URLS on the net to the public.

We are therefore working on a new information channel. The site www.nannasicura.it.

Its web pages are powered and managed by Semi per la SIDS and the contents clearly refer to the Association's institutional website. Nanna Sicura, however, deals exclusively with SIDS Prevention, (so there is no mention of bereavement) in the wider context of sleep hygiene. The editorial approach is very different: it acts as a portal dedicated to safe and peaceful sleep of children.

With this new site we expect to achieve some important goals:

Reach out to new parents looking online for advice on children's sleep in general and inform them about the rules of safe sleep in a reassuring context.

Involve pharmaceutical and childcare companies as sponsors in our initiatives on SIDS prevention, relying on the different style of communication and different context.

This channel supports and does not replace the institutional site of the Association which will have substantially the same contents in the pages that talk about reducing the SIDS risk.

Keywords: Safe Sleep - Communication - Prevention.

### ALTE in Piedmont region during the SARS-CoV-2 pandemic

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**Introduction:** the acronym ALTE (apparent life-threatening event) is a sudden and unexpected event in children aged <1 year that alarms witnesses and is therefore historically related to SIDS.

It is not a disease, but a set of signs and symptoms often linked to paraphysiological behaviours of the infant and more rarely related to various pathological conditions.

With the advent of the new SARS-CoV-2 pathogen and the onset of the pandemic it was questioned whether infection might play a role in the ALTE phenomenon.

**Objectives:** to carry out an epidemiological surveillance of ALTE in Piedmont before and during pandemic; to investigate the application of regional recommendations on the management of infants with ALTE and to identify any peculiarities of patients with ALTE tested positive for COVID-19.

**Methods:** The study was conducted through a retrospective analysis of a large series of patients who presented with an ALTE or a postnatal collapse episode, referred to the Center for Pediatric Sleep Medicine and SIDS and/or to 13 other Pediatric and / or Neonatal Divisions in Piedmont with subsequent hospitalization. An Excel database was used for data collection. The observation concerns the period from 01/01/2019 to 31/08/2021.

**Results:** the sample consisted of 563 patients (age 0-24 months), with an average age at the first episode of 58 days 84, premature births in 26% of cases. In 98% of cases, the episode resolved quickly following a tactile stimulationfrom the parents. The ALTE was managed according to the regional recommendations in a homogeneous way with the execution of the main tests required by the protocol (capillary Blood Gas Analysis -CBG-, electrocardiogram and 24h cardiorespiratory monitoring) in about 80% of cases. Six children (0.9%) tested positive for SARS CoV-2; in none of them the episode of ALTE had characteristics of particular gravity, nor were any pathological events recorded during the 24-hour cardiorespiratory monitoring. The capillary CBG was impaired in only one out of six cases. Only a patient had signs of pulmonary involvement. The incidence of ALTE in Piedmont was 8 ‰ in 2019 and increased to 9.6 ‰ in 2020.

**Conclusions**: the slightly increasing trend in ALTE incidence could be explained by the state of anxiety that has affected families in the context of a pandemic. COVID-19 positive children did not present characteristics dissimilar to those of ALTE patients infected by other respiratory tracts pathogens.

Keywords: ALTE - COVID-19 - Infants - Epidemiology - Surveillance.

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### SIDS: Safe sleep and bedsharing or co-sleeping

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SIDS is a sudden and unexpected death of an infant, apparently in sleep, between the first and twelfth month of life. This event remains unexplained even after complete post-mortem investigations. The AAP promotes actions that reduce risk in the first year of life, including SAFE SLEEP. The terms «bed-sharing» and «cosleeping» are often and erroneously used interchangeably. Until 2004 it was argued that sharing the parents' bed («bedsharing») was a safe practice and that it was not recommended for parents who smoke, in conditions of parental fatigue or taking drugs that may alter the ability to face the urges of the child. Among the prevention practices there is co-sleeping, which is the set of all the care practices of parents and children who sleep in the same room, all night or part of it without sharing a bed.

**Objectives:** This study aims to understand and verify the risk conditions in bed sharing, favoring co-sleeping. It also aims to provide transparency and improve understanding for healthcare professionals so they can help parents adopt safer sleep strategies for their baby.

**Methodology:** Literature review of articles to answer the question. These articles have been identified by the keywords SIDS, BEDSHARING, CO-SLEEPING, PREVENTION from the PUBMED database, linked articles, sector sites. **Results:** 10 articles were selected to answer the review question. Both the AAP and the Australian agency recommend not putting the baby in the same bed as the parents as this could increase the risk of SIDS, but stress the importance of having the baby fall asleep in the same room as the parents (in separate beds) thus reducing the risk of SIDS by 50%. Some of the benefits of co-sleeping are: greater success of breastfeeding; reduction of stress and crying in the first days of life; calming effect of contact by releasing endogenous opioids; better cardiovascular stability and oxygenation; better thermoregulation. These benefits include co-sleeping among the nurturing practices best correlated with secure attachment. The articles analyzed agree with the thesis that bed sharing increases the risk of infant death, even more so in dangerous contexts (parental smoking, preterm infants, low birth weight...).

**Conclusions:** Room sharing the room is recommended by all the articles analyzed; the risk of bedsharing still needs a definitive answer. Personalized advice can be offered to families, evaluating with them the presence of any risk factors that may increase risk.

Keywords: Coosleeping - SIDS.

### SUID & SIDS ITALIA Safe Sleep prevention and criticality on information

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### SUID & SIDS ITALIA, Torino, Italy

**Introduction:** SUID & SIDS Italia is an Italian organization, founded in 2016, has set itself as its main objective a greater development, in its territory, of the complete knowledge of the recommendations for the prevention of Sudden Infant Death Syndrome and other events related to sleep.

**Objective:** The development of the recommendations on Safe Sleep has provided for a verification analysis on the knowledge of parents and operators to determine any critical issues on a correct and complete information in an era in which the greater dissemination of information is developed through the web and social networks.

**Materials and Methods:** The survey conducted examined the assistance provided directly or through the ISTAGRAM and Facebook channels on a sample of 800 individuals (new parents, operators and other figures) Microsoft Excel Professional software used to analyze the collected data.

**Results:** The results obtained demonstrate among the main critical issues the lack of knowledge for the maintenance of a safe sleep environment and a lack of information on the management of the child's sleep since it manifests a motor capacity such as to vary the position.

Conclusions: It is important to correct the major critical issues detected through an action that aims to provide the necessary information on the aspects that can determine a danger to the child's life and also provide information for the management of prevention.

Keywords: Safe Sleep.

### The importance of engaging with young parents

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The Lullaby Trust, London, United Kingdom

**Objectives:** Babies born to mothers below the age of 20 are 4 times more likely to die from sudden infant death syndrome (ONS, 2018).

To reduce the risk of babies born to mums under 20, dying of SIDS.

To reduce isolation and loneliness amongst young parents

To ensure young parents are receiving safer sleep messaging

**Methods:** We have a dedicated, regular Young Parent Panel who we meet with every other month. We outreach to young parents (YPs) and YPs get in touch to share their parenting experiences. YPs take over our Instagram channel every other week, giving them the opportunity to help give other young mums and dads an insight into their life. We conducted a survey focusing on YPs loneliness and isolation levels, as well as measuring the impact of Little Lullaby (LL).

Results: 59% of young parents said that LL had reduced their feelings of isolation

80% felt part of the LL online community

90% felt lonely during pregnancy or parenthood, with the majority (57%) saying they felt lonely 'a lot' 94% said they felt more lonely during the Covid-19 pandemic

Acacia (a charity that offers mental health support to young parents between 16 and 25) said parents with health anxiety do not engage with SIDS information at all

We have applied for funding to expand the project, which will allow us to reach more young parents **Conclusions:** A clear need for the project and awareness of SIDS among YPs.

Building partnerships is integral and will help to reach more young parents

LL has recently restarted (March 2021) after a closure of two years. Original members have re-joined since.

Covid-19 pandemic has shown the importance and need for a strong digital platform for YPs to access.

### Using a Safer Sleep tool to improve perinatal health equity

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**Objectives: The Lullaby Trust** and **South West Academic Health Science Network** developed a safer sleep tool as part of SWAHSN perinatal health equity programme. Two key outcomes the programme is working toward are: Reduction in the modifiable risk factors associated with poorer health – focus on deprived communities in South West England

Improved access to resources for Healthcare Practitioners – facilitating meaningful conversations about health inequalities families maybe facing

Practitioners to use it to spot modifiable SIDS risks associated with living in disadvantaged home environments, and explore suitable solutions with families to reduce individual infant risk.

**Method:** Development of an A5 card with images reflecting deprived living environments e.g. temporary accommodation and cramped conditions. High-risk sleep spaces are shown e.g. baby asleep in a cluttered cot, a sofa, a pod, car seat and top of an adult bed. These are numbered. Corresponding safer sleep advice is on reverse of card enabling discussion with the family.

**Results:** Initial pilot with midwife teams in settings with vulnerable families focused on acceptability of the tool and sought feedback about images and text. Feedback included:

Language at level parents could understand. No changes to any language;

Loved the picture content, especially the modern imagery including the vape on bed;

Promoted conversation and discussion between staff and parents;

Helped with difficult conversations and brought an element of fun into the conversation with the parent;

Helped staff have impactful conversations with mums with learning difficulties. Likened to Easy Read format; Helped staff target level of discussion. Adaptable to fit context, culture, non-English speaking, educational level of parents;

Suggestions - add pet and blind cord; use with example of ideal safer sleep environment;

Evaluation of roll out to focus on implementation and usability. Also impact on staff about confidence to raise and have meaningful conversations, and on families about changes they've made to reduce modifiable SIDS risks.

**Conclusion:** Initial feedback indicates the tool is an effective way to improve engagement of women/parents from more deprived communities and supports practitioners to improve accessibility of safer sleep resources. We see potential for national adoption and by other practitioners/teams.

**Keywords:** Safer sleep tool - Perinatal health inequity - Modifiable risk factors - Disadvantaged home environments - Meaningful conversations.

### Non-compliance of Instagram photos with the infant safe sleeping advice for the prevention of SUDI

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**Objective:** Instagram is an increasingly used social media platform, especially among young people who are the current and/or future parents. Social media has an influence on peoples' behavior, and can therefore also influence parental behavior regarding SUDI prevention. This study aims to determine the compliance of Instagram photos of sleeping infants to the Dutch safe sleeping advice.

**Methods:** In a systematic social media analysis, Instagram photos depicting sleeping infants where searched via hashtags, influencers and infant related companies. Photos were analyzed on compliance to the Dutch SUDI prevention advice. Data collection is currently still ongoing.

**Results:** So far, a total of 232 Instagram photos were analyzed of which 120 searched via popular hashtags, 42 from influencers, and 70 from companies. 126 photos (54%) showed an infant sleeping in the supine position, 52 (22%) in an own bed, 25 (11%) in a sleep sack, and 25 (11%) in an empty bed without soft materials. Only 9 photos (4%) in total complied with all four of these advices. None of the photos from influencers or companies complied with all advices.

**Conclusion:** With the potential influence of social media on behavior and the popularity of Instagram, the SUDI prevention advice being rarely depicted on photos on this social media platform is worrisome. Current and future parents should be informed about the discrepancy between photos on social media and the infant safe sleep advice, and correct photos should be shared more often.

# Renewed attention to the current SUDI prevention advice is needed, with additional attention for high-risk groups

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**Objective:** With a low SUDI incidence in the Netherlands, prevention advice may receive less attention, potentially leading to increasing incidence rates. Our aim is to determine if it is necessary to adapt the SUDI prevention advice towards current needs. Therefore, this study describes the prevalence of parental behavior recommended in these advices, andexamines the current risks and preventive factors for SUDI in Dutch infants.

**Methods:** A case-control study was conducted to compare SUDI cases aged 0-12 months from 2014-2020 in the Netherlands (n=47), to a Dutch national survey control group from 2017 including infants <12 months (n=1192). Prevalence of recommended behavior was described in this control group, and compared to the previous survey in 2010/11 (n=1955) with a z-test.

**Results:** Elevated risks were observed for: duvet use (aOR = 8.6), mother smoked during pregnancy (aOR = 9.7), or after pregnancy (aOR = 5.4) and the prone sleeping position (aOR = 4.6). Reduced risks were observed for: room-sharing (aOR = 0.3), sleep sack use (aOR = 0.3), breastfeeding (aOR = 0.3), and pacifier use (aOR = 0.4). In 2017, less infants were placed in the supine position compared to 2010/11, with more infants sleeping prone or on the side. More infants were placed to sleep in a sleep sack, and shared a room with parents. However, the prevalence of bed-sharing also increased between 2010/11 and 2017.

**Conclusion:** Although the risk for SUDI is generally low in the Netherlands, some factors may increase this risk. Renewed attention to the current prevention advice is needed, with additional attention for high-risk groups, to increase the prevalence of recommended infant care behaviors.

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- Kanits F, L'Hoir MP, Boere-Boonekamp MM, Engelberts AC and Feskens EJM (2021) Renewed Attention Needed for Prevention of Sudden Unexpected Death in Infancy in the Netherlands. Front. Pediatr. 9:757530. doi: 10.3389/ fped.2021.757530.
# Good parental practices in the prevention of Sudden Infant Death Syndrome (SIDS): the results of a survey in Sicily (Italy)

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**Objective:** Measure the occurrence of determinants of SIDS. Estimate their association with the babies' supine position during sleep, as the main risk factor for SIDS, taking into account characteristics of parents, child and pre-, intra- and post-childbirth period.

**Methods:** A prospective cohort study was carried out. A sample of Sicilian women, who gave birth between April and July 2017 was selected. The data were collected at the 1st month after delivery through a telephone questionnaire. The prevalence (%) of risk factors for SIDS were calculated. A multivariate logistic analysis was conducted to estimate (ODD RATIO - OR; Confidence Intervals at 95% - 95% IC) the associations between the supine position of babies during sleep and the exclusive breastfeeding at the 1st month, with the age, marital status, nationality, job, education, economic level and smoking of mothers, and pre-partum course, rooming-in, prescription of the formula at discharge, use of the pacifier.

**Results:** 1055 women were studied. The 62% of mothers putted their babies in the supine position and the 84% of practiced room-sharing. The 11% of mothers currently smoked. The 38% of babies were exclusively breastfed at the 1st month and the 34% used a pacifier. The multivariate logistic analysis highlighted that the supine position is positively associate with exclusive breastfeeding at the 1st month (OR=1.82 95%CI 1.34-2.48), age>35 (vs≤25 OR=2.43 95% CI 1.52-3.88), medium-high maternal education (OR=1.80 95%CI 1.30-2.49), medium-high economic level (OR=1.50 95%CI 1.13-1.99) and negatively associated with postpartum smoking (OR=0.61 95%CI 0.39-0.95).

**Conclusion:** The study confirms that exclusive breastfeeding can be considered a good practices for the babies' health and for SIDS prevention, such as the adoption of supine position during sleep in particular. Instead, unhealthy behaviors, like smoking, are predictive of greater recourse to the prone or side position. Health policies must be promoting safe sleep and other infant care practices. Prevention interventions must be aimed at all families of newborns and strengthened in those population groups where inequality and socio-economic disadvantage are most concentrated. Indeed, inequality as priori predictors of many risk factors for health of population, including SIDS, and must be taken into account when promove healthy lifestyles in all care areas and in the maternal-infant in particular where the health gain can be higher.

**Keywords:** SIDS prevention - SIDS determinants - Supin sleep position - Inequality health - Socio-economic disadvantage.

# It's a story of the sleep

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No abstract submitted.

Actualities on SIDS/SUDI research

# SIDS – is it all in the genes?

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**Objective:** A widely accepted theory for the causation of SIDS (sudden infant death syndrome) is the so-called triple-risk hypothesis or fatal triangle, which both propose that for SIDS to occur three factors have to be present: 1) a vulnerable developmental stage of the central nervous system and immune system, 2) external trigger events such as prone sleeping, maternal smoking or a slight infection, and 3) predisposing factors, including a genetic predisposition or vulnerability. According to this theory, an immune activation and overstimulation of the rapidly developing immune system will induce a cytokine storm which may induce respiratory disturbances, apnea and ineffective arousal. This starts a downregulation of respiration and accumulation of hypoxic markers which may contribute to a self-amplifying vicious circle leading to death.

**Methods:** The abstract and presentation is based on the most recent literature regarding a genetic contribution to sudden unexplained death in infants (SIDS) and small children (SUDC).

**Results:** Recent advances in molecular and genetic studies indicate that as much as one-third of SIDS and SUDC cases may have a genetic predisposition. It is however important to distinguish between polymorphisms that might predispose to death in critical situations, and deleterious mutations that may cause a lethal genetic disorder resulting in an explained cause of death rather than SIDS/SUDC.

So far, genes involved in the regulation of the immune response, cardiac function, the serotonergic network, and in brain development and function have emerged as the most important with regard to SIDS/SUDC. This includes among others genes encoding interleukins, polymorphisms/mutations in cardiac ion channels, genes encoding the serotonin transporter (5-HTT), monoamine oxidase A (MAOA), and several genes involved in brain water homeostasis, including the aquaporins (AQP1, 4, and 9). Other important genes and groups of genes include genes involved in respiratory control, detoxification processes, genes encoding sodium and potassium channels, and mtDNA.

**Conclusion:** SIDS may result from several pathophysiological pathways. In several of these, a genetic predisposition or vulnerability is likely involved. This most likely represents a polygenic inheritance pattern in which a combination of different gene variants and polymorphisms together represents a vulnerability if the other factors in the fatal triangle also are present.

Keywords: SIDS - SUDC - Genetics - Predisposition - Vicious circle.

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# SIDS: Infection and inflammatory cascade

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No abstract submitted.

# The autonomic nervous system and the triple risk model for Sudden Infant Death Syndrome

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It is currently believed that babies die suddenly and unexpectedly during sleep when they fail to respond appropriately to a life-threatening challenge. The triple risk model of sudden infant death syndrome (SIDS) has been proposed to explain the multifactorial nature of SIDS and how it may occur when a vulnerable infant is faced with an exogenous stress during a critical developmental period.

The major risk factors for SIDS, prone sleeping, head covering, exposure to cigarette smoke and being born prematurely, all impair cardiorespiratory control and arousal during sleep. Conversely, those factors that reduce the risk od SIDS, including breast feeding, immunisation and sucking on a dummy/pacifier, increase cardiovascular control. Understanding the physiological mechanisms that likely underpin risk and protective factors is important so that parents and health professionals are aware that safe sleeping messages are supported by sound physiological evidence.

Keywords: Sleep - Arousal - Triple risk model.

# Improving investigation of all child deaths

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**Objective:** In England, all child deaths from any cause are subject to detailed multi-agency Child Death Review (CDR) with the aim of identifying the full causes and risk factors for death, and identifying learning to prevent future deaths. Data from Birmingham Child Death Overview Panel (CDOP) for the year 2021-22 are presented, to illustrate patterns of mortality and learning from child deaths

**Methods:** We analysed data from Birmingham CDOP for children aged 0 to 18 years with death reviews completed during 01 April 2021- 31 March 2022, data were obtained using the local electronic CDOP system.

**Results:** There were 152 deaths of which 58 (38%) were due to perinatal/neonatal causes, 54 (36%) genetic/ congenital conditions, 23 (15%) other medical causes, 3 (2%) inflicted injury, 9 (6%) trauma, 2 (1%) suicide, 3 (2%) unexplained.

75/152 (47%) were aged under 1 month, 26 (17%) 1-11 (15%) months, 23 (15%) 1-9 years, 28 (18%) 10-17 years. 53/152 (35%) had modifiable factors or learning identified even if the death was not preventable.

27 deaths had modifiable factors relating to maternal health, parenting and social environment: 16 mothers with obesity, 17 mothers smoking tobacco, 6 with missed appointments or refusal of medical treatment, 1 concealed pregnancy.

6 deaths had modifiable factors relating to physical environment: poor home conditions, unsafe sleep environments, lack of window locks.

13 deaths had modifiable factors relating to service provision. In 6 cases, there was poor communication with families, or between professionals leading to errors in healthcare. In 12 cases there were healthcare failings such as delay in delivery of infants, not giving antibiotics, or not transferring children to hospital.

Learning included improvements to SUDI investigation processes, lack of access to palliative care, home safety campaigns, services to prevent criminal exploitation of teenagers.

**Conclusion:** Robust child death review enables learning from deaths and should contribute to improvement in the quality of care for children and families.

**Keywords:** Child Death Review - Child mortality - Prevention.

# USA's experience with sudden unexpected infant death and sudden death in the young case registries

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No abstract submitted.

# Quality of investigations into unexpected deaths of infants and young children after implementation of national child death review procedures

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In 2008 new statutory procedures were introduced in England for the investigation of all child deaths (under 18 years). For those deaths that were unexpected a standardised mandatory Joint Agency Response (JAR) procedure forms part of this. The nature, organisation, content, and procedures for the mandatory investigation of all unexpected child deaths were updated in 2016(1), with detailed guidance on the necessary investigations and involvement of statutory and other agencies in the JAR, further clarified in the revised 2018 Statutory Guidance(2).

We have previously investigated the way in which these procedures were being implemented prior to the updated guidance(3).

As part of the National Child Mortality Database (NCMD) work aimed at improving the quality of all Child Death Reviews, we have now conducted a detailed review of the JAR procedures for children aged under 10 years who died unexpectedly in England between August and October 2019. This period was chosen to ensure the procedures (which may take many months) have been completed, but to avoid the effect of the COVID19 pandemic.

This study has shown significant improvements in the overall quality of investigations since our previous investigation, particularly in the quality and completeness of pathology investigations. There remain many difficulties in inter-agency communication, and the quality of the process was at times adversely affected by lack of effective communication between the main agencies involved – the Police, Social Care, and Health Care professionals.

The communication difficulties resulted from apparent differences between professionals from the different agencies in overall philosophy of how such investigations should function.

As a result of this study, we are implementing a programme of online multi-agency training with the aim of clarifying the roles and emphasising the importance of communications between the various agencies involved.

**Keywords:** Unexpected child deaths - Investigation of deaths - Joint Agency Response - Child Death reviews - National Child mortality database.

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# L'intervention du Smur dans le parcours de soin d'une MIN : anecdotique ou pas ?

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Résumé non soumis.

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# Décès inattendu, impact et répercussions sur le plan psychologique

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# EUROPEAN CONGRESS AND WORKSHOP ON SIDS SUDI From 29 2022 to 31 May 2022

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# INTERS INTERS

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WARD	Jenny	The Impact of Social Media on Safer Sleep Choices	P07

# Precarious socio-economic conditions and SIDS risk in Sicily

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**Clinical case:** C. C. was born on Sept 30th, 2019, in Cefalù (Sicily-Italy), from spontaneous birth at 41st week. The APGAR index at 1st: 9 at 5th: 10. The socio-economic conditions of the family were precarious. The mother being a minor (17 years old), with mild mental retardation and living with an older smoker man (58 years). The baby has been formula fed since birth. During sleep, the baby usually shared the same bed with her parents, sometimes even slept on the sofa. During the 3rd month of her life, more than an hour after feeding, the baby was found dead on the sofa. At the end of the judicial investigations and clinical-diagnostic practices, a diagnosis of SIDS was made.

**Discussion:** In Sicily, two fact-finding surveys on the nursing standards for the reduction the SIDS risk were conducted (2015 and 2017). All Sicilian vaccination centers (273) participated at the first survey. 2,692 babies who received the first vaccination dose during May 2015 were involving and a questionnaire were administered to theirs' mothers. In May-July 2017 the second survey involved 1,055 mothers representative of Sicilian women who gave birth in the 30 days before. The surveys highlighted that is important consider individual social and economic disadvantage and context inequality of residence in addition to the other SIDS determinants already know.

The data and the respective estimates highlighted that SIDS risk factors are favored by incorrect adherence to healthy lifestyles and hindered in change by misleading messages circulating improperly in the area (e.g., formula prescription, advertising, failure to adhere to institutional birth accompaniment paths and so on) with grater disadvantage in particular. These aspects must attract attention of decision-makers and health professionals. The Information campaigns must necessarily be strengthened in those contexts that express greater aspects of socio-cultural deprivation and/or disadvantage, and where are higher the risk of inappropriate practices.

The information campaign on safe sleep, as a reduction of the SIDS risk in the population, must fit into a broader context which is the promotion of the health of the newborn and infant during the first 1,000 days. Information and training campaigns must be spread homogeneously throughout the territory, but must also be, where necessary, capillary and individualized to ensure the best quality of short-term health for the child and subsequently for that of the adult.

Keywords: SIDS clinical case - Survey - Context inequality - Individual socioeconomic disadvantage.

POSTERS

#### Do we prevent to save babies life?

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**Objective:** The present survey, carried out in Italy, was aimed to verifying the level of knowledge of the SUDI/SIDS prevention strategies by the parents and to detecting any critical issues that may increase the risk.

**Methods:** From February 2022 we administered an online questionnaire to parents with babies aged 0/24 months. The data were reported in EXCEL. The questionnaire was promoted by the association's channels; both health professionals and other figures collaborated in data collection. The questionnaire in the first two sections provided for the data about child (sex, age, birth weight, gestational age) and parents (age, weight, body size, lifestyle, habits). The third section of the questionnaire provided for the data about information received during pregnancy, at birth, after birth, and on the daily practices adopted at home.

**Results:** 749 questionnaires were collected from the ongoing survey. 48% of babies were aged 0-6 months, 35% 7-12 months.

40 babies presented low birth weight and were born preterm. In more than 1/3 of the caregiver interviewed there were significant risks factors such as smoking, alcool and drugs assumption.

21% of parents did not receive any information about safe Sleep in any circumstances.

At post-birth hospital discharge 30% of parents received incomplete information, while 37% received no information. 70% of the interviewees had never dealt with issues relating to risks deriving from overheating, sleeping context, Bed Sharing, danger of sitting devices with their family pediatrician.

92% of respondents shared the same sleeping surface (65% bed, 23% sofa, 12% armchair or other surfaces) with the baby. Only 11% of parents were aware of the SIDS risk, 74% were aware of accidental risks (suffocation, entrapment, strangulation, crushing, falls or involuntary blows), 5% were unaware of the risks.

**Conclusions:** Basing on the data collected, it is necessary to continue with further investigation, as the current results could be the consequence of a lack of assistance generated by the COVID 19 Health Emergency.

Healthcare professionals must always disclose complete and clear information on Safe Sleep, dedicating the right assistance to detect any critical issues that could compromise the child's life.

The high percentage of parents who share the same sleeping surfaces unaware of the risks should make us reflect on the right communication also on this important but controversial aspect.

Keywords: Safe Sleep - SIDS - Prevent.

POSTERS

#### Actions for assistance to SUDI or SIDS victims

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**Objective:** The suffering deriving from the deaths of Sudden and Unexpected Death in various forms, has its own specificity. Death in general always causes great suffering, but the death that is not expected (especially that of one's own child) is even more difficult and acute in the its intensity and its unsustainability. In particular, unexplained events are at the origin of great psychological and social problems. Analyzing the Italian situation for the aspect of the regulations in force, the data collected and the assistance provided to parents is essential for understanding the critical issues of your country.

**Methods:** Analysis of the documentation found (regulations, protocols, email responses, etc.) and analysis of the testimonies of the victim families.

**Results:** The results obtained highlight the criticalities deriving from the lack of homogeneity of the services received which vary according to the different region of belonging. It is clear from the situations that the problems are evident not only for the assistance to the victims but also for the absence of a single operational protocol that allows the management of the case with consequent uniformity also in the data collection.

**Conclusions:** Despite the existing regulations on the subject and the existence of diagnostic protocols, it is also necessary to standardize through an intervention protocol all those actions necessary for standardized data collection, assistance to victims, especially due to the specific nature of this type of death.

Keywords: Actions - SIDS - Grief.

POSTERS

# The psychological consequences of SIDS (Sudden Infant Death Syndrome) for the family. A systematic review of the literature

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**Objective:** This paper presents the results of a systematic review on SIDS. The aim of the review was to examine the psychological consequences of SIDS at the individual, family, and couple levels. The process of grieving and adjusting to loss appears to be complicated by the sudden and unexplained circumstances of death. This systematic review aims to better understand the difficulties of the bereaved in providing appropriate psychological support in relation to needs.

**Methods:** The systematic review was conducted using the PRISMA statement in three databases containing psychological publications: PsycInfo, PsycArticles, and Proquest Psychology. It ended in December 2021.

**Results:** 1430 records were identified, 44 full-text articles were evaluated, and 24 met inclusion criteria for review. Quantitative methods were used in 16 studies, qualitative methods were used in 5 studies, and mixed methods were used in 3 studies. The data show that more attention is paid to the experiences of mothers than to the experiences of other family members. Maternal symptoms are more severe and acute in the immediate period after loss; however, some symptoms may persist beyond the next 6 months, and Persistent Complicated Grief Disorder may occur. In couples, SIDS leads to a sudden change in the roles and responsibilities of the partners, which differ in terms of gender-specific grieving processes. The few studies that are available on siblings show an increase in internalizing and externalizing problems after the SIDS event and difficulties for parents to provide explanations for the death of the little brother or sister. Grandparents' experiences are complex because they are involved in the relationship with both the son or daughter and the dead baby.

**Conclusion:** The systematic review indicates the need for an intervention that focuses on the needs of each family member and is tailored to the specifics of SIDS loss rather than general grief. The role of the psychologist is central in the moments after loss to maximize the use of resources and reduce risk factors as much as possible.

Keywords: SIDS - Systematic review - Psychological impact - Family grief - Couple grief.

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#### Improving experiences and relationships between health professionals and young parents

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Research has shown that young parents (YPs) are less likely to follow safer sleep advice because of a lack of trust in health professionals (HPs) and experiences of discrimination and loneliness which engenders a sense of needing to 'go it alone'. YPs have expressed negative experiences with some HPs where they have felt stigmatised and discriminated against due to their age, resulting in disengaging with HPs during maternity and postpartum care.

**Objectives:** To bridge the gap between young parents and health professionals

To raise awareness of Little Lullaby amongst health professionals and other professionals so they can encourage young parents to engage with our services.

To improve the perspectives and relationships between young parents and health professionals so safer sleep messaging is disseminated to young parents.

**Methods:** Outreach to health professionals and HP influencers. Digital/print pack of resources for HPs including top 10 tips on how to engage with YPs, and our services Events inviting HPs and YPs to open dialogue. Inviting HPs to panels to gain YPs' trust. HP online Q&As.

We conducted a survey focusing on YPs maternity experiences with HPs.

**Results:** Approximately half of young parents told us they faced challenges with health professionals before (44%), during (43%) and after (51%) the birth of their baby.

46% felt 'very' discriminated against because of their age during maternity care. That's nearly 1 in 4 young parents surveyed.

"No one believed me about my pain in childbirth, and I often had comments about my baby being an "accident" and that most girls my age would've just had an abortion." (young mum).

**Conclusions:** Breakdown in communication can lead to missed health appointments, which could be dangerous for parent and baby

Tops tips for professionals could increase understanding and clinical approach.

Organisations including HPs in their outreach and face-to-face work will regain/gain trust of YP and therefore improve barrier.

POSTERS

# Safer Sleep Guidance in Practice for Homeless Families in Temporary Accommodation

Natalie McKie<sup>1</sup> (nataliem@lullabytrust.org.uk), Sam Pratt<sup>2</sup>, Jenny Ward<sup>1</sup>

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**Objective:** The Child Mortality and Social Deprivation report published from the findings of the National Child Mortality Database (NCMD) in Spring 2021 highlighted the link between social deprivation and child mortality, with the latter increasing by 10% with each decile of deprivation. Additionally, the data from the NCMD showed that one of the most frequent modifiable risk factors associated with child deaths was unsafe sleeping arrangements. A group that is particularly affected by these issues are families in temporary accommodation as a result of homelessness. This project aimed to conduct research into the current state of affairs in terms of local council policy towards providing safer sleep spaces to families, with infants under 12 months, facing homelessness.

**Methods:** The aim was to identify the specific challenges facing homeless families, with infants under 12 months, and to understand the barriers preventing these families from following safer sleep guidelines. This was conducted through discussion with practitioners working with these families and via a survey of local councils in England. The discussion and survey aimed to assess the current knowledge of safer sleep guidelines amongst those providing temporary accommodation, to establish what internal guidelines are in place for councils, if any, and to find out where responsibility for providing a safe sleep space for babies lies.

**Results:** There were multiple safeguarding issues identified that were associated with safer sleeping spaces for families in temporary accommodation with infants under 12 months; including but not limited to lack of space for a cot, unsuitable cots, lack of adequate regulation around mattress use and re-use as well as bedsharing in unsafe circumstances. However, there were examples of good practice that could be circulated more widely with other local councils.

**Conclusions:** Safer sleep advice and training needs to be given to all organisations involved with providing accommodation to homeless families so that they are aware of minimum requirements for a safer sleep environment. In addition, there needs to be clear guidance and policy for local councils around the provision of safe sleep space for families in temporary accommodation with an infant under 12 months so that adequate policies can be put in place to prevent babies being put at risk of SIDS.

Keywords: SIDS - Homelessness.

# The Impact of Social Media on Safer Sleep Choices

Natalie McKie (nataliem@lullabytrust.org.uk), Calum Ross, Nimtaz-Tanya Noordin, Laura Barker, Charlotte McIntosh, Jessica Coolbear, <u>Jenny Ward</u>

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**Objective:** Anecdotal evidence, gained through engagement with The Lullaby Trust by parents, carers and professionals, has suggested that parents and carer's use of social media sites, such as Instagram and Facebook, is having an impact on their parenting choices. It is concerning that some popular baby sleeping products promoted on social media by influencers, celebrities and content creators do not always conform to safer sleep advice and could potentially put babies at risk. With this in mind, The Lullaby Trust wanted to conduct a survey to discover more about the impact that these images were having on parents' and carers' choices and to make this the focus of their Safer Sleep Week 2022 to raise awareness of the issue.

**Methods:** The survey was conducted prior to Safer Sleep Week (14th – 20th March 2022), in conjunction with Bounty – an organisation supporting new parents, and was promoted on The Lullaby Trust's social media channels with a £100 Love 2 Shop Voucher incentive. The survey received over 4,600 responses.

**Results:** The Lullaby Trust found that, as predicted, social media was having a significant impact on parenting decisions. Of those surveyed, 67% followed celebrities and influencers who have babies. From those who followed these influencers, 51% stated they do so 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.

**Conclusions:** As the survey showed that content shared online can greatly influence new parents, The Lullaby Trust's Safer Sleep Week campaign aimed to raise awareness of this. The Lullaby Trust's social media channels were used to highlight the issue and encourage users to post pictures of their sleeping babies in safer sleep environments using the hashtag #letskeepitclear. As Safer Sleep Week is due to conclude on 20th March 2022, at the time of creating the poster we will also have the impact report from the campaign to display as part of the poster.

Keywords: Social media - Safer sleep practices.

# EUROPEAN CONGRESS AND WORKSHOP ON SIDS SUDI From 29 2022 to 31 May 2022

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# **1** Ibis Styles Montpellier Centre Comédie \*\*\*

Located 10 minutes-walk from 'Le Corum'. Parking:  $\in$  14 / 24h



# **2** Campanile Montpellier Centre \*\*\*

Located 15 minutes-walk from 'Le Corum'. By tram (line 2/1): 13 minutes (2 stops). Parking:  $\notin$  20 / 24h (subject to availability). Public car park:  $\notin$  26.40 / 24h.



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