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| **ISA ISPID  Abstract Submission  Nº: 223**   |  | | --- | | Topics: SIDS | | Type: **Oral** | | **Developing Hope through the Tragedy of Child Death; the Power of Advocacy beyond Awareness** | | **Raven, LK** 1; **Green, JP**1; **Volpi-Wise, MA**1 *1 - Red Nose Australia (formally National SIDS Council of Australia).* | | **Background** In Australia each year over 3,100 families experience the sudden and unexpected death of a baby or child, either through stillbirth or during the first month of life, infancy or early childhood and many of these deaths are preventable. Red Nose in Australia has provided bereavement support and counselling services since 1977, receiving over 1300 new bereavement referrals each year supporting not only parents but their families and surrounding community. Red Nose has achieved remarkable success in reducing the number of preventable deaths from SUDI through its evidence based “Sleep Safe, My Baby” public health program however with its strengthened vision it has determined that no death is acceptable as it aims to reduce preventable child deaths to ZERO. In meeting this ambitious challenge the role of advocacy and the need to influence, provoke, drive change and make an impact for individuals and on the public at large has become more apparent. The death of a baby or young child has been described by families as the ‘ultimate tragedy’ one of the most overwhelming and stressful events an adult can experience. When these deaths are preventable we cannot remain silent and we must do more that raise awareness within communities.  **Objectives** To present two advocacy case studies which will highlight the importance of learning from child deaths and responding in innovative ways to reduce further deaths in the community through advocating for safer products in the retail sector. Gaps that emerge in product regulation and testing need to be closed to prevent deaths and provide hope for bereaved families who have experienced the death of a child: hope emanates through the wish that no other family should be forced to face a similar experience when it is preventable. The barriers and achievements will be presented drawing upon the experiences of bereaved families and the experiences of public advocacy initiatives with  **Methods** Action research was used to solve identified problems in two areas.  It was led by individuals working and networking with others and using systematic, reflective techniques.  A case study approach was undertaken whereby the journey of each case is articulated, key drivers identified, change improvement initiatives implemented with reflection on these initiatives and outcomes achieved.  **Results**: Key outcomes emerged through participatory action research techniques. These outcomes resulted in the development of new resources and new national standards in Australia for assessment of child products which are available for purchase in retail stores. The power of an educated public whereby parents have the knowledge to influence child product purchases emerged and its strength cannot be underestimated. Parents require clear information to support parental decision making and safe product choices. The application of product standards in the assessment of childcare equipment was identified as a critical change for manufacturers and retailers to address the issue of unsafe products in the market.  **Conclusion** Advocacy for NGO’s such as Red Nose is focused on saving the lives of babies through prevention of deaths and learning from the experiences of bereaved families as well as evidence based research. Our public health programs can be complemented by strong advocacy programs that go further than raising awareness and are based on action research where all the participants can be engaged in problem solving methods to produce the positive outcomes sought. | |  |  |  |  | | --- | --- | | **CONTACT** | | | Name: | **LK** | | Lastname: | **Raven** | | E-mail: | **LeanneRaven@sidsandkids.org** | | Country: | **Australia** | | Institution | **Red Nose Australia (formally National SIDS Council of Australia)** | | Cellphone: | **+64 0419 348 629** | | City: | **Melbourne** | |