



# ANNUAL REPORT 2015





**sids**<sup>and</sup>**kids**<sup>®</sup>

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# CHAIRMAN'S REPORT



A key recommendation was the importance of a single structure and a single voice for the organisation.

The past year has seen further progress in the rebuilding of the SIDS and Kids organisation to meet the challenges we face in meeting the goals of the group. One of the principal issues, and it is a challenge faced by all charitable organisations, is to improve the stewardship of the money entrusted to us by the public, whether directly by individual and corporate contribution or indirectly through state and federal government support. One essential element in this stewardship is to simplify our internal structure and organisation reducing waste and duplication of effort. To this end we have continued the process of amalgamating regional and national branches with the goal of having a single management structure in place in the coming financial year. In the year just completed the Western Australian branch joined the single management entity and Queensland has entered the process.

A second step towards ensuring our group has a sustainable future and continuing relevance has been the commencement of a root and branch review of the entire organisation commencing with an audit of all of our activities conducted by an external consultancy. The audit made many recommendations which will enable SIDS and Kids to ensure we are best practice in all our service delivery and administration. A key recommendation was the importance of a single structure and a single voice for the organisation. The Board have adopted the recommendations of the audit in full and we have commenced the change processes needed to deliver the results. This activity will be the main focus of the Board and Management in the coming year.

To achieve anything at all depends on the people in our organisation and we have been well served in this regard. I would like to extend my appreciation of the work done by everyone connected with SIDS and Kids – the volunteers, the paid staff and management and the directors and committee members who have provided their time and expertise.

Thank you all,

**GRAHAM HENDERSON**

*Chairman*

# CHIEF EXECUTIVE OFFICER'S REPORT



The funding from the federal government Department of Health has assisted us to operate the SIDS and Kids bereavement helpline nationally and will also help us to develop an on-line bereavement services.

We have ventured into a timely reflective phase this year at SIDS and Kids Australia. The outcome of the sustainability audit conducted by external consultants provides some clear direction as to the areas of our organisation that we need to work on. It is an exciting game changing project which has resulted in the national board unanimously endorsing the key recommendations on Research, Structure and Governance, Marketing and Branding, Advocacy, Education and Bereavement Services. The audit consisted of in-depth consultations in every state and territory and we are all looking forward to further participation from our members across the country as we work on key aspects of our national strategic and operational efforts.

Other achievements this year include a strong SIDS and Kids presence at the International ISPID/ISA Conference held in Amsterdam, new exciting investments in research, establishment of the Stillbirth Awareness and Prevention Working Group, the launch of our Cot to Bed Health Promotion Program, an increase in our corporate partnerships and pro-bono supporters who are all engaged with our cause, and a solid financial performance.

As the Chair of ISPID (International Society for the Study and Prevention of Perinatal and Infant Death) I am pleased to highlight the success of the "Baby Survival" conference held in Amsterdam in September. One of the major highlights from the conference was the awarding of the ISPID Kaarene Fitzgerald New Investigator Awards and one of our young Australian Researchers, Nicholas Hunt from the University of Sydney, Department of Medicine received an award for his study on 'Decreased orexin immunoreactive expression in the hypothalamus of SIDS infants'. We also had a number of SIDS and Kids staff giving oral and poster presentations at the conference. Our founder's daughter Lacey Fitzgerald was also at the conference filming for a documentary about her mum's achievements and interviewing many of the prominent researchers across the various fields of research. SIDS and Kids has funded other new important studies on addressing new interventions for reducing risk for Aboriginal and Torres Strait Islander babies and an investigation into the effects on intra-uterine growth restriction and the heart and circulation for babies.

Our Cot to Bed Health Promotion program was launched at the Pregnancy, Baby and Children's Expo in Sydney with lots of publicity and incredible radio coverage all around the country. This program has been developed to help families understand what to look at when their baby moves from the cot to a bed and highlights many safety aspects involved in this transition. All the materials can be downloaded from our website in written and electronic form. With over 300,000 babies born every year in Australia this is essential information for all parents of young children.

The funding from the federal government Department of Health has assisted us to operate the SIDS and Kids bereavement helpline nationally and will also help us to develop an on-line bereavement services. The work on this project has commenced with the launch of the services to occur next year. With over 800 new bereaved families being referred to SIDS and Kids nationally, we know there may be some who could be in need of support but are unable to access help. We believe our online services will increase our reach in the community and help us to ensure there isn't anyone who has experienced the sudden death of a baby or child during pregnancy, birth infancy or childhood suffering in isolation.



# CHIEF EXECUTIVE OFFICER'S REPORT

Our assets to liabilities ratio sits at 6:1 and our equity has increased from \$1,195,903 to \$1,217,994 at year end.

Our National Scientific Advisory Group (NSAG) chaired by Professor Jeanine Young has formed the Stillbirth Awareness and Prevention Working Group who have been examining the research evidence on stillbirth prevention and developing key messages to form a public health program. This exciting project is in its early stages and we are awaiting the publication of the Lancet Journal in the near future which has dedicated its October 2015 edition to the topic of stillbirth. Many more babies' lives can be saved through increased knowledge, improved practices and public awareness on how to reduce the risk of stillbirth. We look forward to further outcomes in this area. The NSAG has reviewed and published our information statements on Sleeping with a Baby, Breastfeeding, Using a Dummy or Pacifier, Immunisation, Wrapping, Reflux - Sleeping Position for Babies with Gastroesophageal Reflux and Smoking - all of these can be downloaded from our website.

Our financial result for the company resulted in a year end surplus of \$22,091 which is down on last year's surplus of \$121,593. We managed to maintain our revenue and our subcontracted service delivery expense at the same level as the previous year. Our assets to liabilities ratio sits at 6:1 and our equity has increased from \$1,195,903 to \$1,217,994 at year end.

It has been a busy year at SIDS and Kids Australia and I would like to thank our board members particularly our Chairman plus the staff. We are a small purpose-driven team who have worked very hard to achieve the organisation's mission and support our members with limited resources and much creativity and innovation. It has been a privilege to work with all involved.

**ASSOCIATE PROFESSOR LEANNE RAVEN**

*Chief Executive Officer*

# REFLECTIONS

My baby brother, Glenn, died from SIDS in 1977, he was 8 months old. I was only 2 1/2 years old and this tragic event formed my earliest childhood memory. Sadly I don't remember Glenn being alive but I remember his death and saying goodbye to him in the back of the ambulance.

Back in the 1970s "cot death" or SIDS was not widely known or talked about. My parents Kevin and Kaarene Fitzgerald were understandably stricken by grief; absolutely shocked. They couldn't understand why this happened to their baby; how did it happen and what they could do? There was no organisation to guide or help them through this tragic time, however with the help of friends and family and guidance from Dr Alan Williams (Royal Children's Hospital paediatrician) they initiated the conversations that led to the formation of the SIDS Research Foundation (SIDRF), now SIDS and Kids.

I remember Mum working from home; she was always working and on the phone a lot! As my siblings (Karl, Anita and Mike) and I grew up we became more involved with the foundation; we would form a production line of folding and stuffing the newsletters, and labelling the envelopes. We were actively part of the SIDS Research Foundation and so proud of our parents who had the courage and tenacity to fight for the answers as to why our baby brother died from this mysterious syndrome.

In 2003 our Mum sadly passed away, however she left an incredible legacy. Over those 25 years our Mum transformed her life from a full time mother to an internationally respected leader for SIDS advocacy. She drove a research and public health campaign reducing SIDS in Australia by 80%, she founded Red Nose Day, co-founded the National SIDS Council of Australia, co-founded SIDS International, and founded the Global Strategy Task Force. All her efforts led her to being recognised in 1999 with Australia's highest honour, a Companion of the Order of Australia (AC). We are immensely proud of our Mum and this award meant a great deal to her. When she left school at 14 her teacher told her that her life would never amount to much. How she proved them wrong!

Unfortunately in the decade since our mother's passing, the SIDS 'puzzle' is still not solved. Yes, we know more than we have ever known about SIDS, but there is still no definitive answer as to why these vulnerable babies are still dying. It is this unanswered question that has inspired me to make a documentary on SIDS, our family's story and how the latest research will help bring much needed answers to other families affected by SIDS. Although still in development stage, I have had the privilege to film at events such as the International Society for the Study and Prevention of Perinatal and Infant Death in Amsterdam. Here I reconnected with many of Mum's colleagues and friends such as Dr Henry Krouse from California, Stephanie Cowan from New Zealand and Professor Roger Byard from South Australia. They told some very inspiring stories and I look forward to sharing this project when it is complete.

This year marked the 25th anniversary of the Red Nose Day Remembrance Service. SIDS and Kids kindly invited our family to speak at the service about losing Glenn to SIDS. Although we have all attended the service many times, it was the first time (for most of us) that we actually stood up and spoke. Even though it's been nearly 40 years since Glenn died, it was still an incredibly emotional experience to share our story. Our personal tragedy resonated with so many of those who attended and we, as a family, felt united in our grief. If Red Nose Day is the face of SIDS and Kids then the Remembrance service is its heart.

This year I have been invited to be part of the SIDS and Kids Advocacy Working Group. I am proud and honoured to be involved with SIDS and Kids and hope we can continue to inspire change and policy to assist the researchers to "Help pin down the causes" of SIDS

**LACEY FITZGERALD**

**“ Cot death is like a huge jigsaw puzzle, but someone one day will get all the pieces together. ”**

**- Kaarene Fitzgerald 1983**



# ABOUT SIDS AND KIDS

- **80% reduction in SUDI deaths in Australia since 1989**
- **8,480 babies' lives saved**
- **1,400,000 safe sleeping resources distributed annually**
- **\$16,500,000 spent on research**
- **An average of 16.3 support activities provided per referral\***
- **350 calls monthly to our 1300 308 307 support line which operates 24 hours a day 365 days a year\***
- **Last year 800 new families who have experienced the death of a baby or child were referred to SIDS and Kids for bereavement support\***

\*(2014/2015)

SIDS and Kids is a high profile and well-respected national not-for-profit organisation with a successful history in delivering a safe sleeping health promotion program for babies, bereavement support for families who have experienced the death of a baby or child, advocacy, and supporting research into sudden infant death syndrome (SIDS), perinatal deaths and stillbirth.

The organisation began in 1977 with the founding of the Sudden Infant Death Research Foundation Inc by Kaarene Fitzgerald AC, who had experienced the sudden and unexpected death of a baby from SIDS.

The development of SIDS organisations in other states and territories led to the formation of the National SIDS Council of Australia in 1986, and in March 2002 the change of name to SIDS and Kids was made to reflect the organisation's history and its future.

Services have been broadened beyond SIDS to support families who have experienced the sudden and unexpected death of a baby or child regardless of the cause.

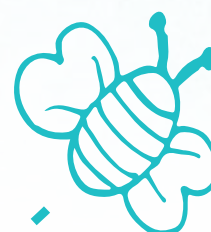
Since its inception our safe sleeping program has been largely responsible for an 80% reduction in sudden unexpected death in infancy (SUDI) in Australia.

SIDS and Kids has offices in every state and territory of Australia as well as a national office in Melbourne.

## OUR MISSION

SIDS and Kids is dedicated to saving the lives of babies and children during pregnancy, birth, infancy and childhood and supporting bereaved families.

We deliver on our mission through funding world class research, delivery of evidence-based education, providing bereavement support, and advocacy.





# 2015 sids<sup>and</sup>kids<sup>®</sup>

## FAST FACTS



BIRTHS IN  
AUSTRALIA 2013<sup>1</sup>

**308,065**

MONEY INVESTED IN  
RESEARCH TO DATE

**\$16.5 million**

RESEARCH CURRENTLY  
BEING FUNDED

- Sudden Unexpected Early Neonatal Death or Collapse in Previously Healthy Term Infants in the First 7 Days of Life
- Underlying Mechanisms of SIDS - investigation in to the effects of intra-uterine growth restriction on the heart and circulation

- SUDC (Sudden Unexpected Death in Childhood) International Research Initiative
- Reducing risk for Aboriginal and Torres Strait Islander babies : trial of a safe sleep enabler to reduce the risk of sudden unexpected deaths in infancy in high risk environments.

PERINATAL DEATHS  
IN 2012<sup>2</sup>

**2,992**

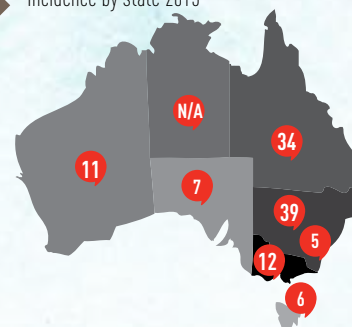
9.6 PER 1,000 BIRTHS

SUDI DEATHS  
IN 2013<sup>3</sup>

**117**

0.4 PER 1,000 BIRTHS

Incidence by state 2013<sup>4</sup>



NEONATAL  
DEATHS 2012

**737**

2.4 PER 1,000 BIRTHS

STILLBIRTHS  
2012

**2,255**

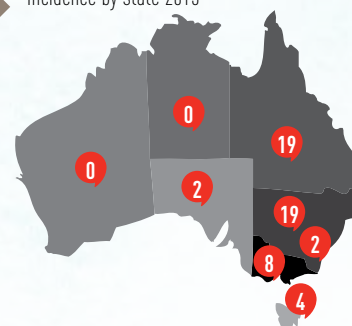
7.2 PER 1,000 BIRTHS

SIDS DEATHS  
IN 2013

**54**

0.2 PER 1,000 BIRTHS

Incidence by state 2013<sup>4</sup>



SUDI DEATHS  
1989-2013<sup>5</sup>

**4,695**

DECREASE IN  
THE RATE OF SUDI  
DEATHS 1989-2013<sup>5</sup>

**80%**

LIVES SAVED SINCE  
RISK REDUCTION  
CAMPAIGNS BEGAN<sup>5-6</sup>

**8,480**

## DEFINITIONS

**SUDI** Sudden Unexpected Deaths in Infancy including SIDS.  
**Perinatal** All fetal and neonatal deaths of at least 400 grams birthweight or at least 20 weeks gestation.  
**Neonatal** Deaths within 28 days of birth.  
**Stillbirth** Fetal deaths (if the birthweight is at least 400 grams or the gestational age is 20 weeks or more).

- 1 Australian Bureau of Statistics (2014). 3301.0 - Births, Australia, 2013. ABS, Canberra.
- 2 Hilder L, Zhichao Z, Parker M, Jahan S, Chambers GM 2014. *Australia's mothers and babies 2012*. Perinatal statistics series no. 30. Cat. no. PER 69. Canberra: AIHW.
- 3 Australian Bureau of Statistics (2015). 3303.0 - Causes of Death, Australia, 2013. ABS, Canberra
- 4 Explanatory note from the ABS: "Data with small values have been randomly assigned to protect the confidentiality of individuals. As a result, some totals will not equal the sum of their components"
- 5 Australian Bureau of Statistics (2003). SIDS in Australia 1981-2000: A statistical overview. ABS, Canberra & Australian Bureau of Statistics (2001-). 3303.0 - Causes of Death, Australia, 2001-. ABS, Canberra
- 6 Includes calculations prepared by SIDS and Kids and confirmed by the ABS

# WHAT WE DO

SIDS and Kids' five key areas of responsibility are:

- 1 Advocating nationally for and funding research into stillbirth prevention and other areas of sudden and unexpected child death.
- 2 Provision of the 'Sleep Safe, My Baby' public health program, ensuring it is evidence-based and providing the most up-to-date information for parents, health professionals and carers of babies.
- 3 Providing funding and resources for bereavement support and counseling to families who have experienced stillbirth or the sudden and unexpected death of a child, regardless of the cause.
- 4 Providing resources for the implementation of the national 'Sleep Safe, My Baby' health promotion program in every state and territory so that it is accessible to the community.
- 5 Facilitating sharing of information with the public and SIDS and Kids organisations.





# HEALTH PROMOTION



'Sleep Safe, My Baby' is a public health campaign that aims to reduce the rates of SIDS and fatal sleeping accidents in Australia.

This evidence-based campaign has been developed in conjunction with researchers from Australasia and internationally. The SIDS and Kids National Scientific Advisory Group ensures recommendations provided by SIDS and Kids are based on the latest scientific evidence.

The campaign aims to provide information to health professionals, childcare workers, new and expectant mothers, parents and anyone who cares for babies. Resources to assist in the delivery of this program include: brochures, FAQs, information statements, mobile apps, a Child Care Kit for Education and Care Services, and an Online Education program.

Since its inception in 1989 the campaign has reduced the incidence of SUDI in Australia by 80%, saving 8,480 babies' lives.

## HOW TO SLEEP YOUR BABY SAFELY:

1. Sleep baby on the back from birth, not on the tummy or side
2. Sleep baby with head and face uncovered
3. Keep baby smoke free before birth and after
4. Provide a safe sleeping environment night and day
5. Sleep baby in their own safe sleeping place in the same room as an adult caregiver for the first six to twelve months
6. Breastfeed baby

# BEREAVEMENT SUPPORT

SIDS and Kids is the largest provider of bereavement support in Australia.

Our bereavement support services are provided to families who have experienced the sudden and unexpected death of a baby or child, during birth, pregnancy or infancy, regardless of the cause.

Services are available in every state and territory of Australia through our member organisations, and include: counselling, parent and family support, peer support, sibling support, grandparent support groups, group activities, annual memorial services, telephone counselling and a national 24 hour 1300 bereavement support line.

Services are available to families and anyone impacted by the death of a baby or child free of charge.





We collaborate with researchers worldwide in gathering data to support research projects and providing advice or commenting on global research strategies and directions.

## RESEARCH FUNDING AND SUPPORT

SIDS and Kids has contributed more than \$16,500,000 towards research into finding the causes of stillbirth and sudden and unexpected death in infancy and childhood.

SIDS and Kids Australia is a member of both the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) and the International Stillbirth Alliance (ISA).

Through these memberships we maintain strong relationships with international researchers and research centres.

We collaborate with researchers worldwide in gathering data to support research projects and providing advice or commenting on global research strategies and directions.

Within Australia, SIDS and Kids has established a National Scientific Advisory Group who review and recommend research development, research initiatives and public health educational campaigns that prevent child deaths.

## ADVOCACY

SIDS and Kids lobbies and collaborates with organisations such as the ACCC, Standards Australia, safety centres, and children's hospitals in every state and territory regarding nursery products.

We hold a strong advocacy role working on a national and state and territory level to ensure that all health professionals who work with new parents and their infants are aware of the evidence-based recommendations and have policy to follow them, hence creating a strong community support system for parents to live within. We also lobby for retail stores and media to give consistent messages and role model safe sleeping.

## COMMUNICATIONS

SIDS and Kids communicates to the public through its website, as well as over 1,000 media articles, plus regular electronic newsletters, including an e-newsletter for Education and Care Services that have purchased our Child Care Kit.

Support for SIDS and Kids member organisations includes monthly electronic newsletters and website support.

Member organisations and the public also have access to ASK Online, an extensive library catalogue of research papers compiled by SIDS and Kids and covering more than 40 major topics including co-sleeping, bereavement, epidemiology, smoking, stillbirth, sleeping positions, sudden infant death and grief.







# KEY ACHIEVEMENTS 2014/15



## SAFE SLEEPING EDUCATION

### LAUNCH OF THE COT TO BED SAFETY RESOURCE

On 23 May 2014 we launched the Cot to Bed Safety resource at the Sydney Pregnancy Babies and Children's Expo. The Android version of the Cot to Bed Safety app was released. Both the iPhone and Android apps include options for Vietnamese, Chinese, Arabic and Hindi languages. A 'whiteboard' style video was completed to complement the app and brochure.

### UPDATED INFORMATION STATEMENTS

After review by our National Scientific Advisory Group the following Information Statements were updated: Sleeping with a Baby, Breastfeeding, Using a Dummy or Pacifier, Immunisation, Wrapping, Reflux – Sleeping Position for Babies with Gastroesophageal Reflux, and Smoking.

### OTHER SAFE SLEEPING RESOURCES UPDATED

Our Safe Sleeping App was launched for Android in five languages.

The Safe Sleeping Easy Read Brochure was translated into Maori.

The Safe Sleeping Long Brochure and Safe Sleeping FAQ were updated to include the advice to use a cot mattress that complies with the voluntary standard for mattress firmness AS/NZS Voluntary Standard (AS/NZS 8811.1:2013 Methods of testing infant products – Sleep Surfaces – Test for firmness), as a soft mattress or sleeping surface can increase the risk of sudden unexpected infant death if baby rolls over onto the tummy.

In excess of 295 Infant Safe Sleeping Child Care Kits were purchased and distributed during the year.



## BEREAVEMENT SUPPORT

### BEREAVEMENT SERVICES PROVIDED

Nationally, 800 infant and child deaths were referred to SIDS and Kids for bereavement support for the year. Our staff provided an average of 16.3 support activities per referral.

An average of 350 calls per month were made to the 1300 308 307 support line.

### WEBSITE DEVELOPMENT

Work began on the development of the planned bereavement website.

### NEW RESOURCES

A new book bereavement resource *When Relationships Hurt, Too | The impact of grief on parents' relationships after the sudden death of their child* was launched. The book was written by Bereavement Counsellor Petra Nicolette den Hartog in collaboration with bereaved parents.





# KEY ACHIEVEMENTS 2014/15



## RESEARCH SUPPORTED

SIDS and Kids provided funds to support three major research projects during the year.

### **1. Reducing risk for Aboriginal and Torres Strait Islander babies: trial of a safe sleep enabler to reduce the risk of sudden unexpected deaths in infancy in high risk environments.**

SIDS and Kids provided a grant to support the first Australian trial of a sleep enabler to reduce the risk of sudden unexpected deaths in infancy in high risk environments.

The primary aim was to determine the acceptability of the Pepi-pod Program, a portable infant sleep space, amongst Aboriginal and Torres Strait Islander communities in Queensland.

The risk of SUDI is three times higher for Aboriginal and Torres Strait Islander babies compared with non-Indigenous infants. Co-sleeping is a common practice particularly for breastfeeding infants, and the cultural norm in many Indigenous communities. However infant deaths are associated with co-sleeping in hazardous circumstances.

The Pepi-Pod Program operated in Queensland with 10 governmental and NGO Aboriginal controlled medical organisations across over 20 communities from Queensland's southeast corner, to the Cape, and across to Mt Isa.

Results indicated that parents perceived the enabler as safe, convenient and portable.

The program received two national awards in 2014: the Hesta Australian Nursing Award for Team Innovation and the National Lead Clinicians Group Award for the Indigenous Maternal and Child Health Category.





DR EMILY COHEN

## 2. Kaarene Fitzgerald Fellowship

SIDS and Kids has funded the Kaarene Fitzgerald Fellowship, in partnership with SIDS and Kids NSW & VIC, a three-year PhD scholarship allowing Dr Emily Cohen to pursue research into the underlying mechanisms of SIDS at The Ritchie Centre, Monash University in Melbourne.

In collaboration with Utrecht University she is investigating the effects of intra-uterine growth restriction (IUGR) on the heart and circulation.

Intra-uterine growth restriction is when a baby is born too small for its gestational age. It significantly increases the risk of SIDS and has also been linked to cardiovascular disease in adulthood, although the underlying mechanisms have not been elucidated. Intra-uterine growth restriction often results from placental insufficiency, which compromises the delivery of oxygen and nutrients to the fetus. To protect itself under these challenging conditions, the fetus adapts its circulation and although these changes seem beneficial during intrauterine life, it is believed that they persist after birth and “programme” the baby for life-long cardiovascular morbidities.

Emily will be studying growth-restricted and appropriately grown babies longitudinally within the first six months of life when the risk of SIDS is greatest. She will be looking at a variety of parameters that define cardiovascular function, such as their blood pressure and blood pressure control. The results of this study will provide us with more understanding of the “foetal programming concept”, which could lead to early identification of infants at risk and allow targeted interventions to reduce the risk of SIDS and adult cardiovascular morbidity.

## 3. Safe Infant Sleeping (SIS) eLearning Program; Revision and update of current program

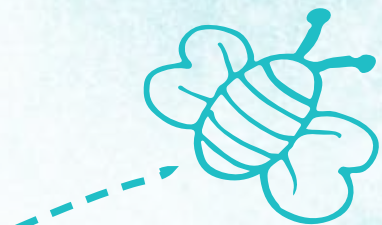
SIDS and Kids funded the revision and update of the Safe Infant Sleeping (SIS) eLearning Program.

This free online course provides health professionals with introduction to current evidence-based information about sudden unexpected deaths in infancy, fatal sleeping accidents, and the infant care practices demonstrated to reduce the risk of infant death.

Health professionals caring for newborn infants have a responsibility to model safe sleeping best practice to parents, and the eLearning package provides up to date, evidence-based information to enable transfer of information to families.

Previously limited to Queensland since its introduction in 2010, the program is now available nationally and has been revised to include national perspectives and policy initiatives, and integrate current evidence contributing to safe infant sleeping messages and align content with SIDS and Kids' 'Sleep Safe, My Baby' safe sleeping campaign. The revision also introduced a refresher package for those who had already completed the package at an earlier time.

This program is the only Safe Infant Sleeping eLearning program endorsed by SIDS and Kids Australia and accredited by peak professional bodies.





# HEALTH PROMOTION AND BEREAVEMENT SUPPORT

Recent national data published in this reporting period indicates the extent of the sudden and unexpected death of children in pregnancy, birth, infancy and childhood. In 2012, 307,474 women gave birth to 312,153 babies in Australia. This was an increase of 10,343 births (3.4%) from that reported in 2011, and a total increase of 21.5% since 2003<sup>1</sup>. Data published within the last year informs us that for every 135 Australian births one baby is stillborn. Released in September 2014, 'Stillbirths in Australia 1991-2009', states that the stillbirth rate in Australia lies between 6.4 and 7.8 per 1000 births<sup>2</sup>. Additionally, a report from ABS investigating the causes of death in Australia indicated that there were 117 Sudden and Unexpected Deaths in Infancy (SUDI) including SIDS and fatal sleeping accidents in 2013 or 0.4 deaths per 1,000 live births, this included 54 deaths whose cause was identified as SIDS.

The burden of stillbirth and SUDI in Australia alone is a significant public health issue.

The major work of our health promotion and bereavement services aligns with our strategic objectives to save the lives of babies and children during pregnancy, birth, infancy and childhood and to support bereaved families. We deliver on our vision through a diverse range of health promotion strategies, methods and support activities. That the incidence of SUDI has reduced dramatically by 80% has been attributed to the 'Reduce the Risk' public health program introduced by SIDS and Kids in 1991 following research and the identification of modifiable risk factors and parents adopting a change in their infant sleeping practices. However, as it still remains

the main cause of unexpected infant mortality in the post-neonatal period between 28 days and 365 days post birth in Australia, SIDS and Kids is committed to empowering parents and carers with evidence-based information to facilitate their confidence and understanding to make informed decisions in relation to caring for their sleeping baby.

Each year over 300,000 new babies are born in Australia and each year our health promotion team work to maintain awareness, work in collaboration with researchers and health authorities, build our social media plan and an agenda for strong and responsive advocacy and strategic partnerships to ensure our children's safety remains a national priority.

The current 'Sleep Safe, My Baby' public health program relies on simple and consistent messages being relayed frequently from different sources. SIDS and Kids ensures that the evidence-based resources to assist the delivery of this program are continually reviewed and new ones developed in response to the needs of health professionals and the general public. These resources are available free on our website [www.SIDSandkids.org](http://www.SIDSandkids.org)

<sup>1</sup>AIHW 2014. Australia's mothers and babies 2012. Perinatal statistics series no. 30. Cat. no. PER 69. Canberra: AIHW

<sup>2</sup>AIHW: Hilder L, Li Z, Zeki R & Sullivan EA 2014. Stillbirths in Australia, 1991-2009. Perinatal statistics series no. 29. Cat. no. PER 63. Canberra: AIHW National Perinatal Epidemiology and Statistics Unit.





## SOME OF THE HIGHLIGHTS THIS LAST YEAR WERE:

- Extensive reprint of our 'Sleep Safe, My Baby' literature. These resources are available free to parents and health professionals to guide safe infant care practices.
- The new Cot to Bed Safety brochure was launched at the Pregnancy, Baby and Children's Expo in Sydney. Following the launch and radio release, SIDS and Kids saw heightened web site visits to download the brochure and apps and requests for media interviews and articles for print media.
- A new Cot to Bed Safety video has been developed and uploaded to our website to be used as an alternative visual tool to educate parents.
- The Information Statement Reflux: sleeping position for babies with Gastro-Oesophageal Reflux was finalised and disseminated through professional health groups such as the Paediatric and Child Division, RACP, FRACGP, RANZCOG, ACM (midwives) due to concerns that paediatricians, GPs and other health professionals have been instructing parents to sleep babies on the side or prone position increasing the risk of SUDI.
- The Safe Sleeping resource 'Frequently Asked Questions' was updated in response to new evidence, standard development and public enquiries.
- Individual Information Statements for Dummy Use, Breastfeeding and Immunisation and Sharing a Sleep Surface have also been reviewed and uploaded to the website.
- Over 290 SIDS and Kids Infant Safe Sleeping Child Care Kits: Information for Educators have been disseminated to support educators in their policy making and practice. The distribution of the new Safe Sleeping e-newsletter for educators has been extremely well received ensuring educators are kept up to date with safe sleeping advice and other safety news relevant to Education and Care Services such as unsafe furniture or toys.



*'Our centre has found the new SIDS and Kids Infant Safe Sleeping Child Care Kit to be an invaluable resource to our service. We use it as a training tool for the educators as well as a source of important information for our families, with its easy to read handouts, pamphlets and educational DVDs. A fantastic resource for all Child Care Centres!'*

*'Information from SIDS and Kids plays a vital role guaranteeing the safety of children at our centre and we refer to it all the time to ensure we are doing everything correctly. Please keep us on the email list!'*

- SIDS and Kids continues to lobby for consistency in safe infant sleeping messages nationally by collaborating and contributing as key stakeholders in the development of position statements, policy and guidelines. This work also includes advocating for the investigation and review of nursery products such as convertible prams, strollers, slings, and beds; feedback on unsafe and available products such as positioners and baby bean bags and promotion of the introduction of standards such as the voluntary standard for cot mattresses (AS/NZS 8811.1:2013 Methods of Testing Sleep Surfaces - Test for Firmness).
- SIDS and Kids is funding the review and update of The Safe Infant Sleeping e-learning education package developed in partnership with Queensland Health and SIDS and Kids, and endorsed by Royal College of Nursing, Australia. This resource is available at no cost to health professionals, carers and childcare workers. Register at [www.sdc.qld.edu.au/courses/126](http://www.sdc.qld.edu.au/courses/126)
- SIDS and Kids has raised awareness of sudden unexpected death in infancy and stillbirth incidence and preventative measures using multiple media opportunities.



# HEALTH PROMOTION AND BEREAVEMENT SUPPORT

## BEREAVEMENT SUPPORT

Further to our health promotion activities, SIDS and Kids has continued to deliver on its core business in providing best-practice bereavement support services to women, their partners and families experiencing grief after the loss of a baby or child during pregnancy, birth, infancy and childhood. SIDS and Kids responded to the call from NGOs for submissions to the National Review of Mental Health Programmes and Services in November 2014 to ensure bereavement support and its role in helping those impacted by the death of a baby or child to create a meaningful life afterwards is seen as a high national priority.

We also continued another busy year of evaluating, consolidating and improving internal operational systems. In particular, these systematic improvements together with increased communication strategies and building resourceful intra relationships with service staff has seen steady improvements and consistency in data collection highlighting statistically the extent of support SIDS and Kids offers at no financial cost to bereaved families after they have experienced the sudden and unexpected death of their baby or child. These include:

- 801 referrals associated with the death of a baby or child during pregnancy, birth, infancy and childhood
- Many associated with the baby/child need support including parents, siblings, grandparents, friends, family and the local community
- 13,063 bereavement support activities undertaken by counsellors and additionally bereavement support activities by peer supporters.
- An average of 16.3 activities of bereavement support per referral have been given by counsellors.
- The 1300 308 307 phone line received an average of 350 calls each month for bereavement support.

The SIDS and Kids 24 hour telephone support line is an integral component of our bereavement services providing individuals with support or information and linking them to further support opportunities. The services and activities provided by SIDS and Kids are evaluated and developed in response to the needs expressed by bereaved families. Families are also offered the opportunity to be involved in all facets of the organisation, these activities not only include peer support, group facilitation and telephone support, but parents may prefer to be involved with a diversity of activities such as fundraising, activities, developing books and resources, memorial days, speaking engagements and representation on committees and boards at local, national and international level.

SIDS and Kids has available a suite of bereavement support literature designed to support families who have experienced the sudden and unexpected death of a baby, toddler or child regardless of the cause. These are available online or in hard copy free from our state and territory services.

- A new booklet 'When Relationships Hurt, Too | The impact of grief on parents' relationships after the sudden death of their child.' has been written by one of our counsellors Petra Nicolette den Hartog, in collaboration with bereaved parents. This booklet was launched and Petra has been an invited presenter at conferences and written articles in regards to relationships after the death of a child.
- Another booklet is near completion. 'The Sudden and Unexpected Death of your Child: Some answers to your questions'. Denise Same, Bereavement Counsellor, has collaborated with bereaved parents to gather information, stories, wisdom and quotes.



## BEREAVEMENT WEBSITE

SIDS and Kids is excited to report that it is in the midst of developing a new national multi-functional online bereavement support service to provide women, their partners and their families with a range of online bereavement support services including counselling, self-help, message boards, virtual memorial wall, information resources and links to other organisations. This service will also provide information to the community and health professionals regarding SIDS and Kids services, resources, referral opportunities and support offerings. These bereavement services will be delivered on a new stand-alone platform that will link to the existing national SIDS and Kids website, [www.SIDSandkids.org](http://www.SIDSandkids.org), taking engagement, user experience and collaboration to the next level. An important part of the development process has been involving bereaved parents and their families and our peer supporters. Their experience, feedback, suggestions and ideas will ensure this bereavement website is unique and can empower others with support, information and hope.

## PARTNERSHIPS AND COLLABORATION

- Progressing vital linkages and collaboration with many national and local organisations such as the national Pregnancy, Birth and Babies Helpline (PBBH) RDNS, Health Direct, ABA, PANDA, SANDS, Raising Children Network, health workers and social workers has consolidated our goal to ensure parent resources relevant to safe sleeping and bereavement are evidence-based, up to date and consistent with information on the SIDS and Kids website.
- On a national and local level, SIDS and Kids has formed and retained collaborative partnerships with many networks including coroners, hospitals, midwives, Maternal Child Health and Community nurses, other health professionals, child protection, emergency responders, child care services, social workers and key safety organisations.

## STILLBIRTH

One of the key discussions within the SIDS and Kids National Scientific Advisory Group was to continue planning strategies to work towards a health promotion program to inform parents how to reduce the risk of stillbirth.

- The Stillbirth Awareness and Prevention Working Group (SAPWG) has been established in this reporting period to advise SIDS and Kids on the development of planning strategies to work towards an awareness and prevention program to inform parents how to reduce the risk of stillbirth and to develop new evidence-based resources for parents and health professionals to promote stillbirth awareness.
- Research is paramount to understand why Australia has such a high SUDI and perinatal death rate. SIDS and Kids in this reporting period have worked collaboratively with organisations such as PSANZ, ISA and ISPID and SANDS. We attended the Stillbirth Research Priority Symposium held in Brisbane to workshop key research priority areas.

The passion, the depth and the enormity of work our counsellors and peer support offer for bereaved parents and their families is inimitable and integral to our service operating successfully. SIDS and Kids has been able to support and acknowledge staff by assisting their attendance and ability to present at conferences and workshops. Two particular conferences during this reporting period were:

- The Australian Centre for Grief and Bereavement, Bridging the Gap between Research and Practice
- The 2014 International Congress on Stillbirth, SIDS and Baby Survival (ISA/ISPID Congress). The aim of the Congress was to identify the 'causes' of the sudden and unexpected baby deaths during pregnancy, labour or in the first year, and the actions to reduce them and best practice supporting bereaved parents and families.

SIDS and Kids is proud of the scale of work we have achieved in this reporting period, the unspoken amount of time our dedicated staff have spent listening to parents, their families and their communities - offering support, counselling and activities to support their grief.



# FUNDRAISING 2014/15

With less than 5% funding from government, the work of SIDS and Kids depends heavily on support from the public, especially through Red Nose Day, and the financial and other support provided by our partners.

## RED NOSE DAY BACKGROUND

The first Red Nose Day was held in 1987 as a fundraiser for Victoria before becoming national in 1988 after SIDS and Kids founder Kaarene Fitzgerald had the foresight and initiative to encourage the other member organisations of the National SIDS Council of Australia to use this unique method of fundraising.

Red Nose Day has been held annually every year since and continues to be the major fundraiser for SIDS and Kids as well as helping to raise awareness of the issues surrounding sudden infant death. Fundraising activities have contributed over \$16.5 million to research and education.

## RED NOSE DAY

Red Nose Day is now in its 27th year and remains a prominent fundraising event for SIDS and Kids and is well supported by the Australian community.

The Red Nose Day 2014 campaign was held throughout the month of June with events and activities culminating on Red Nose Day, Friday 27 June 2014.

The Red Nose Day campaign included product that was sold nationally through our retail partners including Target, Big W, Supercheap Auto and many others. The theme for the campaign was "Say G'Day the Red Nose Way", which was supported by a range of products including plush toys, pens, wristbands and more.

The 2014 campaign featured a limited edition exclusive line of Red Nose Day t-shirts featuring designs created by iconic Australian and New Zealand designers; LIFEwithBIRD, Manning Cartell, Nicola Finetti and Trelise Cooper.

The introduction of Dare to Care was another highlight of Red Nose Day 2014. Dare to Care is an online fundraising initiative where participants were asked to take on a dare and ask family and friends to support their fundraising efforts.

SIDS and Kids would like to thank all their retail, corporate and community supporters for their involvement in helping Red Nose Day raise the vital funds needed to continue our life-saving work.







MANNING CARTELL TRELISE COOPER NICOLA FINETTI  
LIFewithBIRD

**RED NOSE DAY LIMITED EDITION T-SHIRTS AVAILABLE  
NOW THROUGH [WWW.REDNOSEDAY.COM.AU](http://WWW.REDNOSEDAY.COM.AU)**

**sids and kids**  
red nose day

## RED NOSE DAY VOLUNTEER INTERN

SIDS and Kids and CareerDC joined forces to provide a volunteer opportunity for Rachel Stanislowski a Marketing and Communications graduate from North Dakota, USA. Rachel spent six months with SIDS and Kids working on Red Nose Day communications and planning. Rachel was seeking experience with an Australian charity and whilst here had the opportunity to do some travelling. Rachel was a tremendous asset to our organisation and made many friends during her time with us. We wish Rachel all the best with her career now she is back home in America.



Rachel Stanislowski, Carly Bourke & Tracey Marasco

## DARE TO CARE FUNDRAISING

The Dare to Care initiative was a new addition to the 2014 Red Nose Day campaign and intended to engage members of the Australian public in a fun manner.

Our community supporters nationally once again got behind Red Nose Day by setting up their own fundraising accounts with Everyday Hero and setting themselves challenges to complete. Our supporters raised a total of \$94,083 which was an amazing effort and could not have been achieved without the support of their families, friends, work colleagues and local communities.

Once again we thank and congratulate Clare Field on being our number one fundraiser through Everyday Hero, raising over \$8,000 in 2014. This is the third year Clare has been crowned our number one fundraiser and we thank Clare and her support base, including The Wiggles, for their ongoing support.

Congratulations and thank you to everyone who supported Red Nose Day through Dare to Care.







# RED NOSE DAY RETAIL PARTNERS

## TARGET

Target has been a major supporter of SIDS and Kids since 2008 and proudly sells Red Nose Day promotional merchandise in all stores during the campaign month of June. Since their support began they have raised more than \$1.2 million for Red Nose Day.



## BIG W

Big W has proudly supported Red Nose Day since 2008. Big W stores nationally sell Red Nose Day merchandise during the month of June. Good planning and communication between Big W and SIDS and Kids has ensured the Red Nose Day campaigns have been successful. Big W has raised more than \$1 million for Red Nose Day.



## SUPER RETAIL GROUP

Super Retail Group has been a proud and strong supporter of Red Nose Day since 2008. Super Retail Group stores continue to stock Red Nose Day product nationally during the month of June. They further support the event by engaging with their senior management and staff, which generates much enthusiasm and competitiveness between stores. They also include Red Nose Day merchandise in their "product of the week" promotions and product catalogues. Their support since 2008 has generated in excess of \$720,000 to support education and support services.



## CLARK RUBBER

Clark Rubber has been a Red Nose Day partner since 2012 with its stores stocking Red Nose Day merchandise during June and year round stocking our My Bub Nursery Range. Clark Rubber Head Office held a Red Nose Day and My Bub store display competition with state winners receiving a \$500 gift voucher for use by their stores.



On behalf of the National Board, CEO and staff of SIDS and Kids Red Nose Day, we would like to acknowledge and thank the support of all our retail partners who have been long term proud supporters of the event. The valuable funds and awareness they raise contributes significantly to our education and support services, research and advocacy programs nationally.



# RED NOSE DAY NATIONAL SUPPORTERS

SIDS and Kids would also like to acknowledge the invaluable support it receives from a range of supporters who provided media, public relations, and transport and distribution services for Red Nose Day.



## MITCHELL

Mitchell are Australia's largest media buyer and provide Red Nose Day with invaluable advertising and media support. This includes the placement of television, print, radio, outdoor and shopping centre advertising nationally. Their e-mitch division also supports Red Nose Day with digital advertising across a range of sites.

This partnership allows SIDS and Kids to reduce advertising and marketing costs significantly for the campaign and at the same time extend our reach within the community at large.

In 2014, Red Nose Day received \$976,095 of in-kind support from this partnership.



## TOLL IPEC

Toll IPEC have been a proud national supporter of Red Nose Day and SIDS and Kids since 2009. Toll IPEC provide Red Nose Day branded satchels that support the distribution of Red Nose Day product and marketing materials across Australia. Our partnership is central to keeping our transport costs low and distributing our product to store partners, small business and our community supporters in a timely and efficient manner. We would like to thank Toll IPEC for their ongoing support of Red Nose Day and SIDS and Kids and look forward to our continued partnership.



## SPARK COMMUNICATIONS

Spark Communications was engaged by SIDS and Kids to implement a public relations campaign for Red Nose Day 2014. Spark helped Red Nose Day achieve more than \$3.6 million in editorial value across TV, radio, print and online.



## BORDER EXPRESS

Border Express have been a proud supporter of Red Nose Day since 1997. They manage our transport nationally and donate their services, time and staff to deliver pallets of Red Nose Day product around the country.







### WOMPRO

Wompro have supported Red Nose Day since meeting the founder of SIDS and Kids, Kaarene Fitzgerald, in 1996. Wompro supply all Red Nose Day creative services pro-bono and provide product design and development for our Red Nose Day campaigns. The success of the Red Nose Day campaign has been recognised both nationally and internationally, winning multiple platinum, gold and silver industry awards.



### COBALT

Cobalt Marketing plays an important role in helping us to distribute our Red Nose Day products to our national partners. The team at Cobalt Marketing are always there to help us to ensure that orders are processed accurately and quickly.



### BENCH

Bench Creative is a graphic design studio with over 15 years' experience in the print and design industries. They have been a proud supporter of SIDS and Kids and Red Nose Day for the past nine years and have worked on a wide range of projects from our recent Safe Sleeping review through to Red Nose Day. They understand our brand and the range of education, support and fundraising materials we need to create, and have consistently come up with designs that are to brief and meet our requirements.



# SIDS AND KIDS AMBASSADORS 2014

## THE WIGGLES

The Wiggles have supported SIDS and Kids Red Nose Day for over 20 years and have provided invaluable support with our Red Nose Day Campaign and raising awareness of safe sleeping nationally.

The Wiggles have a strong personal link to SIDS and Kids and supporting our services, Bernadette Field, the daughter of Paul Field, Managing Director of The Wiggles and brother to Anthony, died from SIDS in 1988 at just 8 months of age.

The support provided to Red Nose Day includes the development of television, radio, retail store announcements and advertising materials, along with providing prizes for our colouring in competition, media interviews and appearances to support our PR and marketing.

The Wiggles have supported SIDS and Kids for over two decades now and have played a major role in helping us to reduce the number of deaths from SIDS in Australia during that time.

We thank them for their generosity and support of our organisation.





### DEBORAH THOMAS

Deborah Thomas, CEO of Ardent Leisure, has assisted in building the profile of SIDS and Kids to corporate businesses, supporters and the Australian community. She has supported SIDS and Kids through editorial, media interviews and participation in the national corporate DVD. She has given her support to Red Nose Day campaigns by attending events in New South Wales and the A.C.T. on our behalf, and by providing media commentary



### EAMON SULLIVAN

Eamon Sullivan chose SIDS and Kids as his charity of choice when he competed on television show Dancing with the Stars in September and October 2014.

Each week viewers voted who would stay on the show, and Eamon and his partner Ash-Leigh Hunter were the fourth couple eliminated.

We thank Eamon for supporting SIDS and Kids and helping to raise the profile of our organisation and awareness of the issues we work with.



### NADIA BARTEL

Nadia Bartel supported Red Nose Day through promoting the Red Nose Day T-shirts line up through print media and via her social media accounts. We thank Nadia for her support and assistance in helping with this project.



### LAUREN PHILLIPS

Television host and presenter Lauren Phillips supported Red Nose Day through segments on Kids WB and across her social media accounts. Always happy to help she was a delight to work with.





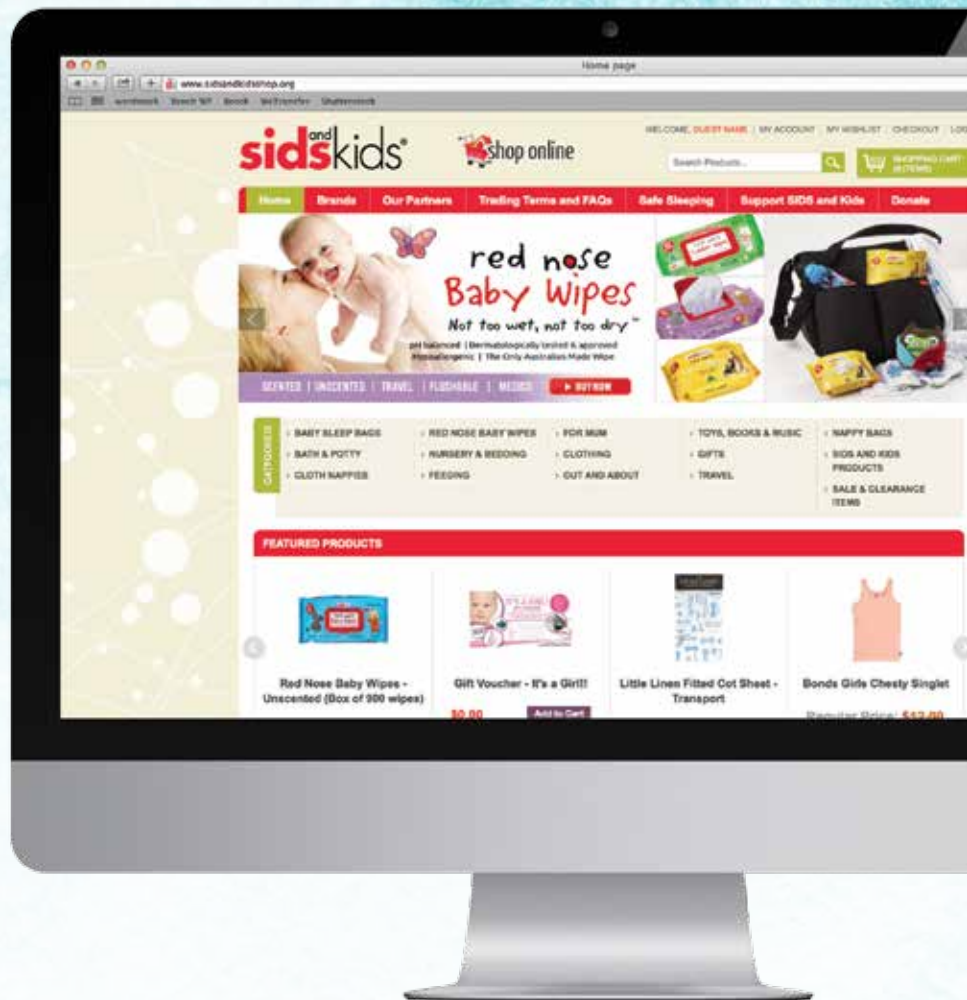
# SIDS AND KIDS SHOP ONLINE

The SIDS and Kids Shop Online has been in operation for over ten years and offers an extensive range of babies', toddlers' and children's products including gifts for everyone in the family. It continues to be an important source of funding for SIDS and Kids with a minimum of 30% of sales being donated back to support our services.

Our redeveloped website has been welcomed by our partners and customers and has seen increased traffic and sales to the site over the past financial year. The revenue received from the Shop Online represents 11% of our overall income.

During the period we have also welcomed new partners to the online shop including Bonds, Bubba Blue, Mattel, NRL, AFL, Philips Avent and VTech. We continue to work with our existing partners to expand ranges and choice for our customers.

Thank you to all our partners for their support and interest in the SIDS and Kids Shop Online.





# CORPORATE PARTNERSHIPS AND SUPPORTERS

## CUA

The partnership formed in February 2014 with CUA, Australia's largest customer-owned financial institution, is an important partnership for SIDS and Kids. The partnership provides significant funding and volunteer support for our organisation nationally.



CUA have been instrumental in the funding of the expansion of our Online Safe Sleeping Education package which is aimed at health care professionals and is an accredited training package. Professor Jeanine Young, FACN, PhD, BSc (Hons) Nursing, Adv. Dip Nursing Care RGN, Reg Midwife, ENB 405 & 998 and Chair of the SIDS and Kids National Scientific Advisory Group is taking a lead on the project.

The online package was available only in Queensland and with the support of CUA we have been able to nationalise the platform making it relevant to each State and Territory of Australia. The site will be relaunched in late 2015.

They have also supported SIDS and Kids Safe Sleeping messages via social media platforms and to their dedicated staff nationally.

## VOLUNTEERING

Throughout the year CUA have provided more than 50 volunteers for over 300 hours of volunteer work covering a range of activities including:

- Red Nose Day product sales within their branches
- Volunteer support for Red Nose Day activities
- Packing of Red Nose Day product boxes
- Volunteers to assist with our Special Events including our breakfast events, Sunshine Beach Run in WA and the Harry Parker Golf Day in Queensland
- Administration Support at our Offices in Queensland and Victoria
- Judging of our National Red Nose Day Colouring in Competition

*A regular volunteering program has also been established at CUA in Melbourne.*

SIDS and Kids thanks CUA for their support and consider it a privilege to work alongside CUA and look forward to working with CUA into the future.



CUA Executive Team in support of SIDS and Kids



Demi and Hazel, CUA Volunteers with Leanne Raven, CEO, SIDS and Kids (centre)

# CAUSE-RELATED PARTNERSHIPS

SIDS and Kids works with a range of companies in the area of cause-related partnerships. Our partnerships support SIDS and Kids in various ways, including annual donations, percentage of sales in the marketplace, support for specific programs, creating publicity, in-kind product donations and providing us with volunteers for various activities and events.

## PLUM

PLUM have been a proud partner of SIDS and Kids since 2011 and are a flagship partner for our National Safe Sleeping education campaign.

Our partnership with PLUM funds our Safe Sleeping education program nationally including the distribution of brochures to health care professionals, hospitals, community centres and child care centres.

PLUM has also generously donated infant sleeping bags to be included in Baby Baskets distributed to eligible Cape York families as part of Apunipima Cape York Health Council's Baby One Program. The Baby One Program is a structured Aboriginal and Torres Strait Islander Health Worker led family visiting program delivered from pregnancy up to the first 1,000 days of a child's life. The Baby Baskets delivered within this program include health promotion resources, supplying Aboriginal and Torres Strait Islander mums and families with essential personal hygiene and age appropriate baby items. The PLUM sleep bags have been incorporated into the Baby Baskets provided when a child is five months old.

PLUM baby sleep bags are also featured on our SIDS and Kids Shop Online and are available for purchase year round.

PLUM



## RED NOSE BABY WIPES

Aussie Wipes has been a partner of SIDS and Kids since 2013 when Red Nose Baby Wipes were officially launched in Australia. Since that time Red Nose Baby Wipes have enjoyed significant growth and support from the Australian community and the retail sector with wipes now being available in Big W, Target, selected IGA and Supa IGA stores, Supabarn, Foodland and SPAR Stores. This year also saw the introduction of an exclusive 600 Value Pack for Big W offering even better value for Australian families.

The Red Nose Baby Wipes range includes scented, unscented, travel, flushable and medico medical grade wipes for the home. Our scented, unscented and travel wipes are environmentally sustainable and remain the only baby wipe available in Australia with FSC® certification (FSC® licence code: FSC-C 113129). To find out more about Forest Stewardship Council Certification visit <http://fc.fsc.org>.

Red Nose Baby Wipes have been developed to the highest standard by Aussie Wipes and are dermatologically tested and approved, pH balanced and hypoallergenic, so ensuring they are soft and gentle on babies' skin.

Aussie Wipes are an Australian owned company with their manufacturing base in Melbourne and Corporate Office in Sydney.

For more information on Red Nose Baby Wipes visit [www.SIDSandkidsshop.org](http://www.SIDSandkidsshop.org).





## MY BUB NURSERY RANGE

The Comfort Group and SIDS and Kids launched the My Bub nursery range in 2011 which features a range of products for new and expectant mothers including breast feeding cushions, cot and bassinet mattresses and back support cushions and more.

My Bub continues to be available through Clark Rubber and Amart stores nationally as well as through the SIDS and Kids Shop Online [www.SIDSandkidsshop.org](http://www.SIDSandkidsshop.org).



## PROTECT-A-BED

Protect-a-Bed and SIDS and Kids have been in partnership since 2013 and together have developed resources on how to safely transition a toddler from a cot to a bed. The Cot to Bed Safety brochure and smart phone apps were launched in 2013 and 2014 and have proven to be an invaluable resource for families.

SIDS and Kids Cot to Bed Safety information and links to resources can be found on Protect-a-Bed's range of cot mattress protectors which are currently being sold nationally through major retailers. The Protect-a-Bed range is also available through the SIDS and Kids Shop Online at: [www.SIDSandkidsshop.org](http://www.SIDSandkidsshop.org).





# CAUSE-RELATED PARTNERSHIPS



## SHERIDAN

Sheridan and SIDS and Kids partnership under the SIDS and Kids Friendly brand commenced in 2014 becoming the first Australian bed linen partner of SIDS and Kids. The partnership was formed around the Sheridan Baby Collection and features the SIDS and Kids Friendly logo and safe sleeping information and links.

The Sheridan Baby Collection is available in selected Sheridan Boutiques and David Jones stores. You can also purchase online at [www.sheridan.com.au](http://www.sheridan.com.au).



## RED NOSE KIDS CUTS

Red Nose Kids Cuts is a children's hairdressers that supports SIDS and Kids education and support services.

Owners Tony and Kelly Stoker opened the Dee Why Salon in New South Wales in October 2013 and since that time have developed a strong following within the Northern Beaches community, fast becoming the salon of choice for families.

Both Kelly and Tony remain committed to supporting SIDS and Kids as it is a charity that sits deep within their hearts and are proud to support.









# GOVERNMENT FUNDING, TRUSTS AND FOUNDATIONS AND CORPORATE GIVING

## TRUSTS AND FOUNDATIONS

During the year SIDS and Kids gained support from a number of Trusts and Foundations who supported vital projects.

Google continued to support SIDS and Kids by providing \$US10,000 per month in Adwords advertising through its Google Ad Grants programme.

A \$1,500 grant came from The Peter Isaacson Foundation.

## BOW TIE CLUB

SIDS and Kids has partnered with the Bow Tie Club, a group that get together socially a few times every year to renew old friendships and perhaps make new ones. They have chosen SIDS and Kids to be their charity of choice and have raised funds in excess of \$5,000 by hosting a number of luncheons and cocktail parties.

SIDS and Kids would like to thank Graeme Hart, the founder and the Bow Tie Club committee and members for their support of our education and support services.

## CORPORATE GIVING

SIDS and Kids is supported by a number of corporate organisations who support our education and bereavement support services through payroll giving and volunteering.

We would like to acknowledge and thank CUA, Microsoft, BHP Billiton and NAB.

CAF Community Fund, an organisation who connects not-for-profit organisations with Australian businesses, has also supported SIDS and Kids by connecting us with donors and supporters throughout the year.

## TELSTRA PROMOTES SIDS AND KIDS FOR #GIVINGTUESDAY

SIDS and Kids joined Telstra for their #givingtuesday promotion held on December 2nd, 2014 at their Melbourne Head Office. It was a great opportunity to talk with Telstra staff about the work of SIDS and Kids and to raise awareness about safe sleeping practices, our research projects and support services. Telstra staff were encouraged to not only donate to SIDS and Kids but to also become a skilled volunteer.

SIDS and Kids thanks Telstra for such an invaluable opportunity to promote our organisation.







## COMMONWEALTH GOVERNMENT FUNDING

The Department of Health has continued to support SIDS and Kids to provide nationwide bereavement services through the Maternity Peer Support Program in collaboration with the Pregnancy, Birth and Baby Helpline. The aim of the program is to better support the mental health and wellbeing of women, their partners and their families during pregnancy and following birth.

Bereavement support and its role in helping those impacted by the sudden and unexpected death of a baby or child to create a meaningful life afterwards is a high national priority for SIDS and Kids. In the past year over 13,000 bereavement support activities were undertaken by counsellors and additionally bereavement support activities by peer supporters.

The funding provided by the Department of Health assists SIDS and Kids to continue to provide services including:

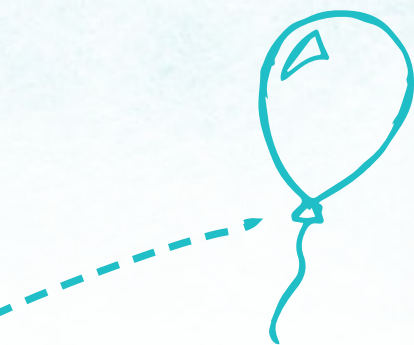
- 24 hour National Bereavement Support Helpline
- Peer support and bereavement counselling
- A diverse range of service activities for bereaved families

This funding has also supported SIDS and Kids to work towards the development of a national, multifunctional bereavement support website. This project will allow SIDS and Kids to expand their bereavement support model to offer information and services and to further develop a regional approach that increases reach in all communities of Australia.

SIDS and Kids acknowledges that the sudden and unexpected death of a baby or child is incomparable and a devastating tragedy. The impact of the death is far reaching and can have a life-long effect on the well-being of the parents, family and their surrounding community.

SIDS and Kids relies on ongoing financial support to provide free national bereavement services to families and their communities. Our services are not time-limited but are available for as many years as parents need.

Thank you to the Department of Health for their support.





# ONLINE FUNDRAISING

SIDS and Kids uses a number of online fundraising platforms to enable supporters to support us through a range of events and activities.

## KARMA CURRENCY

Karma Currency provides SIDS and Kids with access to an online fundraising platform that provides the community, businesses and corporate with the opportunity to make a donation to their charity of choice. This gives SIDS and Kids an opportunity to seek donations to fund particular education and support programs including the provision of support materials to bereaved families and education to new and expectant mothers.

To find out more visit [www.karmacurrency.com.au/charity/SIDS-and-Kids](http://www.karmacurrency.com.au/charity/SIDS-and-Kids).



## JUST GIVING

Just Giving is an online fundraising site available to not-for-profit organisations. The Just Giving site supports our fundraising through a range of initiatives and events for SIDS and Kids supporters in Australia and overseas.

Just Giving provides the opportunity to supporters to donate through an event or to set up their own fundraising or In Memory page.

To find out more visit <https://www.justgiving.com/SIDSandKids>

The logo for Just Giving, with the text "JustGiving" in a purple, sans-serif font.

## EVERYDAY HERO

Everyday Hero is an online fundraising site providing not-for-profit organisations opportunities to fundraise through a range of events and activities. SIDS and Kids has been a member of Everyday Hero since its inception with campaigns including Red Nose Day Dare to Care, In Memory and SIDS and Kids fundraising pages.

To find out more visit <https://nfp.everydayhero.com.au/SIDS-and-kids>



## INCLUDE A CHARITY

Include a Charity is a campaign made up of over 100 Australian charities who work together to encourage the Australian community to leave a gift in their will. SIDS and Kids has been a member of Include a Charity since 2011 participating in a range of campaigns through the year with the main one being laC Week which is held in September each year.

To find out more visit <http://includeacharity.com.au/SIDS-and-kids>

The logo for Include a Charity, with the text "include a charity" in a mix of black and red fonts, and the tagline "Help the work live on." in a smaller font below it.









# MEDIA

## RED NOSE DAY 2014

The Red Nose Day 2014 media campaign began in March with media releases promoting the new 'Say G'day the Red Nose Way' theme, new fundraiser 'Dare to Care', new Australian animal toys, and the new line of Red Nose Day designer t-shirts designed by LIFEwithBIRD, Manning Cartell, Nicola Finetti and Trelise Cooper. A radio release was also distributed and SIDS and Kids Chief Executive Leanne Raven contributed audio grabs and interviews.

Media ambassadors this year were The Wiggles, Lauren Phillips, and Nadia Bartel, while social media support came from Julia Morris, Megan Gale, Bridg and Lehmo, Daily Edition, the *Winners and Losers* cast, Katherine Hicks, Studio 10, David Campbell, Lauren Brain, Alex Davis, and 2014 *The Block* winners Chantel and Steve.

The Wiggles once again created and performed in television and radio ads promoting Red Nose Day and appeared at the Crocosaurus Cove in Darwin.

Highlights of media coverage include Red Nose Day focused weather crosses throughout the Channel 9 *Sunday Today Show* prior to Red Nose Day. Ambassador Lauren Phillips appeared in the *Herald Sun*. The new T-shirts received wide coverage including *The Australian* newspaper, the *Herald Sun*, and *Cleo*, while Nadia Bartel made the front page of free newspaper *MX* wearing a Manning Cartell T-shirt.

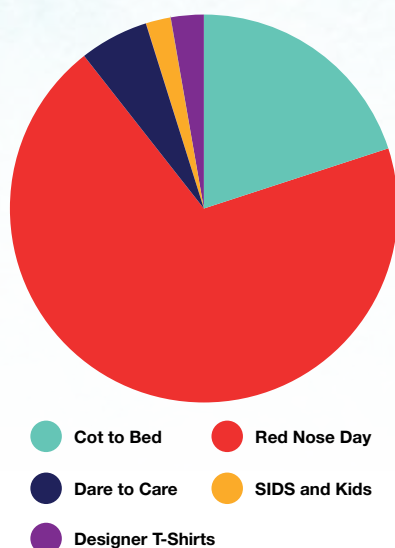
Personal stories included that of Duncan and Ashley Griffiths whose son Harry died aged six weeks. Their story was covered in the *Sunday Tasmanian* and *Sunday Telegraph*.

The Red Nose Day media campaign delivered \$3,594,162.85 in editorial value, with 840 media hits, 15,493,902 circulation, 690 radio hits, 20 TV hits, 105 print hits, and 33 online hits.

The advertising campaign, provided by Mitchell and Partners, for Red Nose Day was to the value of \$976,094.88 (exceeding last year's value of \$743,053).

Medium	Market Value	No. of ads placed
Press	\$52,535.68	71
Radio	\$435,995	7192
TV	\$441,714.20	5006
Digital and Outdoor Print	\$45,850	NA

**MEDIA HITS BREAKDOWN  
QUANTITY**



## SIDS AND KIDS

In April 2014 Adelaide researchers reported a link between SIDS and a severe lack of oxygen. Media coverage included ABC Radio's PM program featuring Professor Roger Byard (SIDS and Kids NSAG member) of Adelaide University, plus from SIDS and Kids, Chief Executive Leanne Raven and Manager Bereavement and Education Services Jill Green.

Jill Green was interviewed by Little Rockers Radio in early April 2014 about Safe Sleeping, Cot to Bed Safety and Red Nose Day.

In May 2014 the official launch in Sydney of the Cot to Bed Safety resource was supported by a media release highlighting injuries sustained by babies and toddlers falling out of cots and beds.

The September 2014 edition of *Australian Midwifery News* published a story submitted by SIDS and Kids about 'Supporting parents through grief after a stillbirth or perinatal death'.

The December 2014 edition of *Interaction*, the official publication of Childbirth and Parenting Educators of Australia Incorporated, published a story submitted by SIDS and Kids on 'Sleeping Baby Safely – helping parents understand the importance of safe sleeping practices'.



## Wiggles on red alert in battle against SIDS

THE Wiggles will be sporting more than a big red car today. They'll be donning big red noses, too, in support of the fight against Sudden Infant Death Syndrome. It's a cause close to blue Wiggle Anthony Field's

heart after he lost his niece Bernadette to SIDS when she was eight months old. The children's group has been helping SIDS and Kids for more than 22 years. Field said Bernadette's death had a profound effect

on him, and now that he was a father he could relate to what his brother Paul and sister-in-law went through. Red Nose Day today raises money for vital services and programs. With a focus on bereavement

support, education, research, awareness and advocacy, the charity is dedicated to saving the lives of babies and children. For more information visit [rednoseday.com.au](http://rednoseday.com.au) **Jamie First**



**Seeing red:** Wiggles Anthony (blue), Emma (yellow), Lachy (purple) and Simon (red) and Captain Featherstone (back) don red noses for SIDS and Kids. Picture: JAY TOWN





# SOCIAL MEDIA

## RED NOSE DAY 2014

For Red Nose Day 2014 social media support came from Julia Morris, Megan Gale, Bridg and Lehmo, Daily Edition, the *Winners and Losers* cast, Katherine Hicks, Studio 10, David Campbell, Lauren Brain, Alex Davis, and 2014 *The Block* winners Chantel and Steve.

Red Nose Day supporters were encouraged to use the hashtags **#rednosedayoz** and **#dare2care** on any of their social media platforms. **#rednosedayoz** was used **158 times** from 1 April to 30 June 2014.

For the first time, Red Nose Day was on Instagram and has attracted over 900 followers.

The Facebook page attracted over 2,000 new likes in June 2014, while lifetime likes increased from 24,478 to 27,158 for the year ending March 2015.

Twitter followers increased to 1,463, up from 1,292.

The Red Nose Day YouTube page had just over 58,000 views for the year. The Wiggles' Community Service Announcement (CSA) for Red Nose Day was watched on YouTube over 7,127 times. The CSA featuring Anthony Field was watched 854 times.

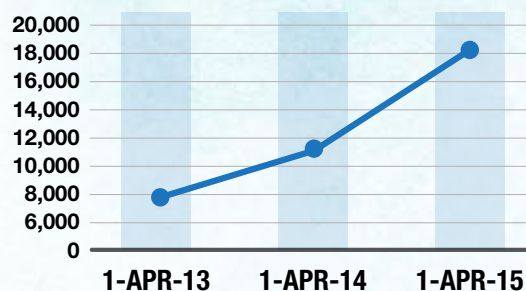
## SIDS AND KIDS

The SIDS and Kids Facebook and Twitter accounts provide information on how to access information on safe sleeping, SIDS and Kids Shop Online products, and ACCC alerts on unsafe kids' products.

Facebook lifetime total likes increased from 11,160 to 18,062 for the year ending March 2015. Twitter followers increased from 830 to 1003.

The YouTube account had 23,509 views. The most-watched video was The Wiggles' 'Sleep Safe, My Baby' with just over 20,000 views.

### SIDS AND KIDS FACEBOOK: LIFETIME "LIKES"



**#REDNOSEDAYOZ**

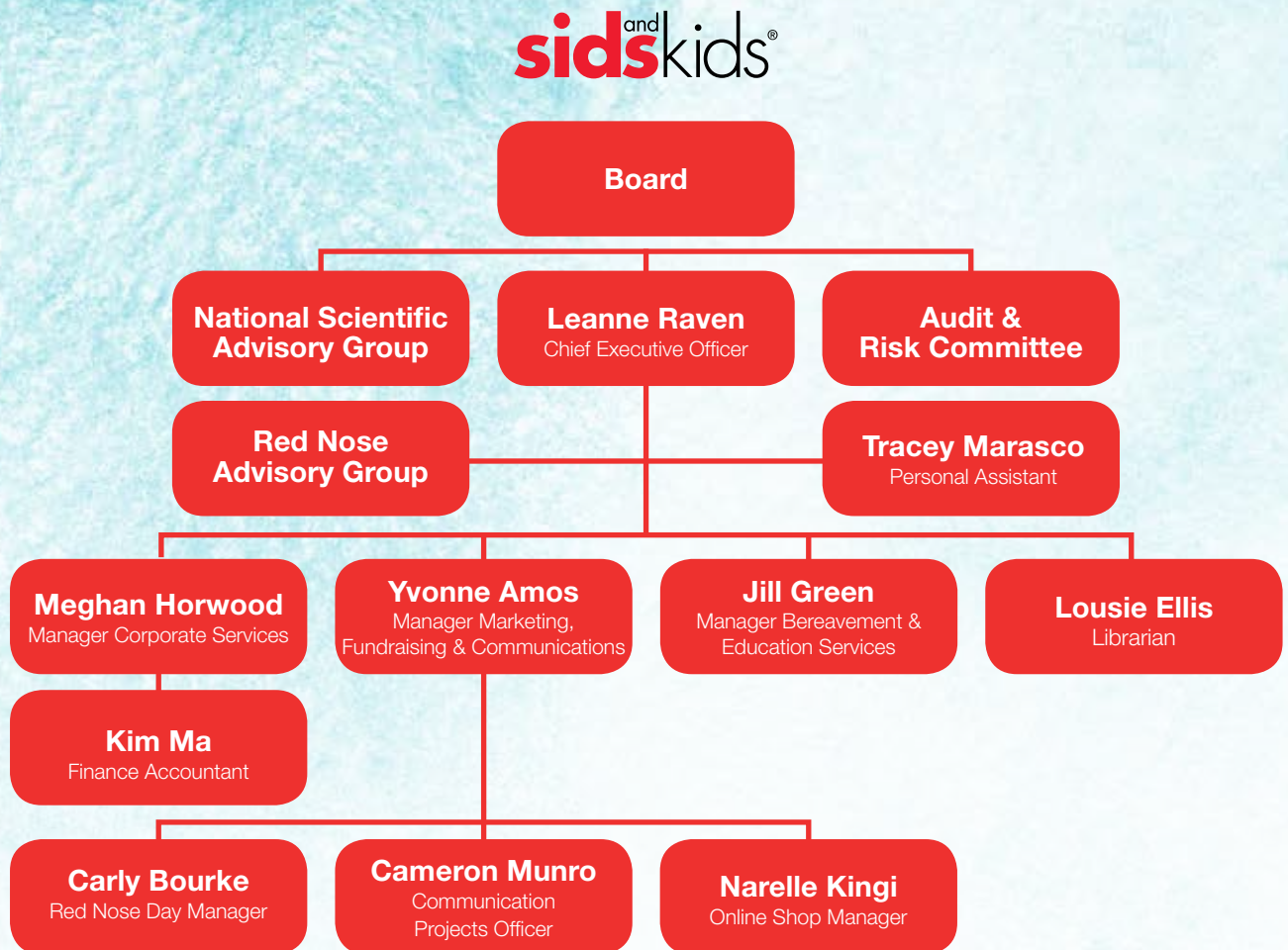
**#REDNOSEDAYOZ**







# GOVERNANCE



## THE SIDS AND KIDS NATIONAL BOARD

The SIDS and Kids National Board is a dedicated group of professionals who work tirelessly in support of our cause. The Board includes representatives from each state and territory.

## AUDIT AND RISK COMMITTEE

The Audit and Risk Committee provide assistance to the Board in fulfilling its corporate governance and monitoring responsibility in relation to risks associated with the integrity of financial reporting, internal controls systems and external audit functions.

## NATIONAL SCIENTIFIC ADVISORY GROUP (NSAG)

The National Scientific Advisory Group (NSAG) provides advice on research initiatives and gaps in policy in relation to SIDS and Kids. NSAG reviews and recommends research development, research initiatives and public and health professional educational campaigns. Members of the group are also responsible for providing advice to SIDS and Kids on the projects that best fall within SIDS and Kids' research funding protocol.



# REPORT OF THE AUDIT AND RISK COMMITTEE

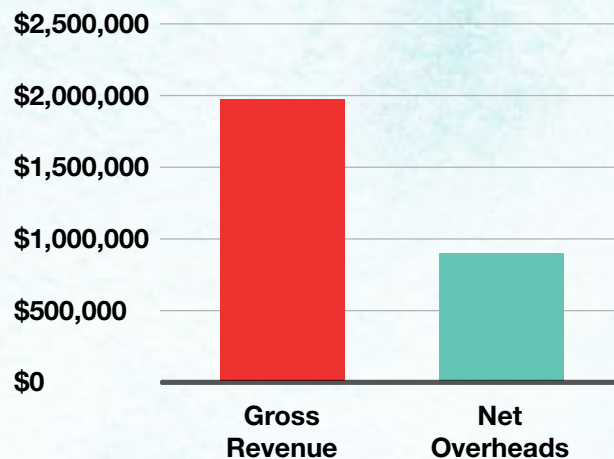
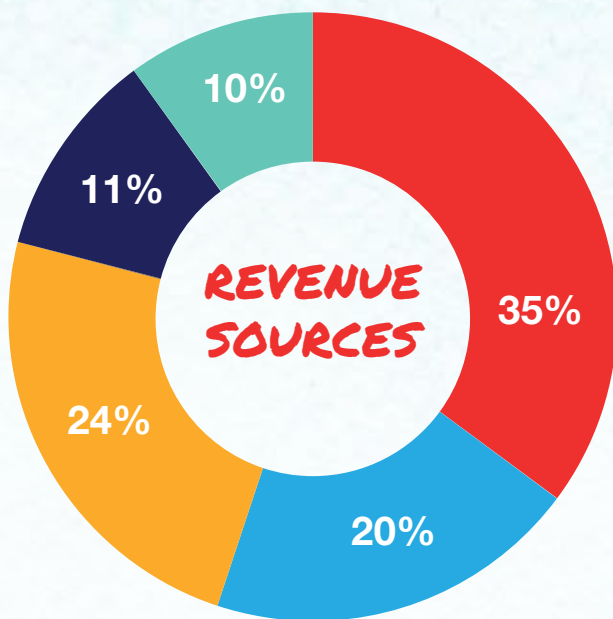
The Audit and Risk Committee met three times in the past year to provide assistance to the Board in fulfilling its corporate governance and monitoring responsibility in relation to risks associated with the integrity of financial reporting, internal controls systems and external audit functions.

The members were Graham Henderson, Andrew Kennedy, Paul Roderique and Craig Heatley.

SIDS and Kids Australia finished the year with a net operating surplus of \$22,091.

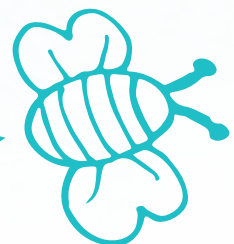
Revenue sources are outlined in the graph below. Donations and corporate partnerships are increasing and the bulk of the government funding is provided to our members delivering bereavement services nationally.

Net overheads include operating expenses, administration costs and staffing costs for delivering services.



For detailed financial information please refer to our audited financial report for Year Ended 31 March 2015.

- Red Nose Day
- Government
- Shop Online
- Other income
- Donations & Corporate Partnerships





# SIDS AND KIDS BOARD MEMBERS



**Mr Graham Henderson**  
**B.Econ BA MA. (Vic)**  
- *Chairman*

Graham has many years' experience in business in the IT and financial services industry. Since 2004 he has operated a management consultancy business. Graham joined the board of SIDS and Kids Victoria in 2004

and the board of the National SIDS Council of Australia Limited in 2006. For the three years prior to becoming Chairman he served as Treasurer. He lives outside Melbourne with his wife Dianne.



**Mr Craig Heatley B.Bus, CA, RCA (WA)**  
- *Deputy Chairman and Secretary*

Craig is an Assurance Partner with PricewaterhouseCoopers (PwC) and has been with the firm for over 15 years both in USA and Australia. Craig is experienced in external and internal audit services, accounting

and broader business advice across a broad spectrum of industries covering resources, services and construction and engineering. Craig leads client focused teams in the provision of services to clients and has had considerable experience reporting to Boards and Audit Committees. Married with three children, Craig strives to maintain a healthy work life balance and serves on several other not for profit boards.



**Mr Andrew Kennedy (independent director)**  
- *Treasurer*

Andrew is a civil engineer currently working as a Project Manager for construction company Thiess. Since completing his bachelor degree with honours in 1997, Andrew has worked as an engineering consultant,

construction contractor and in government in various roles in Australia and overseas. Andrew's most recent achievement was the construction of the \$107M Brighton Bypass highway project in southern Tasmania. Andrew has also gained valuable experience being a Board Member for both SIDS and Kids Victoria and the Civil Contractors Federation in Tasmania. Andrew's first involvement with SIDS and Kids was through the bereavement support he and his family received following

the death of his first daughter, Saoirse during delivery in 2004. Andrew is passionate about the potential for reducing the incidence of perinatal death just as the SIDS campaign brought about a dramatic reduction of SIDS deaths in the 1980s and 90s. Andrew and his wife Karyn have since had two more children, Asha 7 and Daniel 5. They live in Melbourne having recently returned from Hobart where they lived for 3 years.



**Professor Paul Colditz (Qld)**  
- *Member*

Professor Paul Colditz is the foundation Professor of Perinatal Medicine at the University of Queensland and Director of the Perinatal Research Centre. He is a practicing clinician in neonatology as well as holding a Masters in

Biomedical Engineering from the University of NSW and a Doctor of Philosophy from the University of Oxford, UK. He brings together a multidisciplinary research team from diverse backgrounds including medicine, science, nursing, psychology, physiotherapy, other allied health, signal processing and biomedical engineering to focus on improving health outcomes for mothers and babies through clinical and translational research.



**Mr Mark Sheehy (SA)**  
- *Member*

Mark Sheehy is a 47-year-old father of four children and currently lives in Adelaide. Mark has been a member of the South Australia Police Force for 18 years and is currently a Detective within the Serious and Organised Crime Branch. Mark has had various his career including Armed Robbery Squad, Drug Squad, Homicide Squad and also involved in numerous protracted investigations relating to child abuse and child death criminal matters.

Mark became involved with SIDS and Kids through his investigations with child deaths in South Australia. Mark has held various roles with SIDS South Australia including vice chair and chairman positions over his tenure.





**Ms Sheri Norton (ACT)**  
- Member

Sheri has more than 30 years' experience in corporate and operational management, including 15 years at the level of Director or General Manager. She has worked for some of Australia's largest public companies including Westfield,

Macquarie Bank and Coles Myer, as well as not-for-profit organisations Youth Off the Streets and the Benevolent Society.

She has worked as the General Manager Finance and Business Services for Waste Service NSW, overseeing the restructure of that organisation from a Government Trading Enterprise to a State Owned Corporation and also established and managed the VSA Shared Corporate Services arrangement between Tourism NSW, Centennial Parklands and the Royal Botanic Gardens before moving on to the University of NSW as Director of Commercial Services.

Sheri has a Bachelor of Economics Degree in Accounting and Financial Management, a Master's Degree in Commercial Law and has completed the Company Directors Course at the Australian Institute of Company Directors.



**Jenny Goddard, BSc**  
- Member

Jenny joined the Board of SIDS and Kids NSW in 2001 at the time of the merger with SANDS (Stillbirth and Neonatal Death Support) in NSW. Jenny was President of SANDS NSW and a member of the working party that guided the merger process.

She was also a member of the planning groups for the SOS (SIDS and Kids focusing on Stillbirth) Conference, November 2001, and the subsequent SOS Pathology Working Party Conference, November 2002.

Jenny represented SIDS and Kids NSW on the NSW Health Stillbirth Reference Group, the SIDS and Kids and PSANZ Perinatal Mortality Group Conference in Perth in April, 2006, and also at IMPACT (Interdisciplinary Maternal Perinatal Australasian Clinical Trials Network) meetings. She has previously been a NSW delegate on the National Council of SIDS and Kids and returned to this position for SIDS and Kids NSW & VIC in November 2013.

Jenny's professional background is in television, having been a Producer and Director of a range of programs for the Australian Broadcasting Corporation and ATN Channel 7. She holds a Bachelor of Science degree from Macquarie University and now writes on and consults in sustainability in the built environment.

Jenny is married and has a sixteen-year-old son. She and her husband John experienced the loss of a son to late, unexplained stillbirth in September 1996.



**Mr Paul Roderique**  
- Member

Paul has worked in the Customer Owned banking sector for the past 24 years both in New Zealand and Australia. He was the youngest Credit Union CEO in Australasian history and was rewarded with nomination as world young credit

union person of the year in 2003.

He currently works as the Business Retention Manager for Beyond Bank, one of Australia's largest customer-owned banks.

Paul joined the board of SIDS and Kids Hunter Region in 2012 after being a supporter via the Beyond Bank community programme and has been chair for the past 18 months, joining the national council at that time.



# ACTIVITY REPORT: SIDS AND KIDS NATIONAL SCIENTIFIC ADVISORY GROUP 2014/15

The SIDS and Kids National Scientific Advisory Group (NSAG) is a multidisciplinary group of health professionals and researchers who promote and support the SIDS and Kids agenda in research, community and health professional education, and bereavement care. In particular, NSAG is responsible for ensuring that information provided to parents and health professionals is based upon the best available evidence and meets the needs of parents and carers living and working in contemporary Australian society.

This financial year the group have met face-to-face or by teleconference in May, August and November of 2014, and in February 2015. A review of the Terms of Reference is scheduled for April 2015.

A key responsibility of the group is to support SIDS and Kids in its role of facilitating the translation of scientific evidence into evidence-based infant care advice for health professionals and parents which influences practice, in addition to actively engaging with services for the maintenance of policy and standards. This participation has included:

- Liaison with the ACCC, the Office of Fair Trading's Department of Product, Safety Standards Australia and INPAA representatives to inform present standards, investigations and recommendations that relate to safe infant sleeping environments and infant products to ensure consistency of messaging to the public. This work included:
  - o the Office of Fair Trading's community education relating to infant slings;
  - o Feedback relating to hammock safety for infant sleep;
  - o Use of teething necklaces during infant sleep.
- Active dissemination of safe infant sleeping messages through lobbying and support of professional groups, state and territory health departments, and community interest groups. This support specifically includes contributions as key stakeholders in development of position statements that relate to public health issues (e.g. the Australian College of Midwives Draft Statement of Co-sleeping; the Victorian Government Safe Sleeping guidelines; Primary Health Care Strategy). The Group also feeds back to professional groups relating to parent advice and engagement with product companies to promote consistency of advertising messages with the 'Sleep Safe, My Baby' recommendations.
- Revision of Position Statements relevant to the 'Sleep Safe, My Baby' recommendations. This year, NSAG undertook a review and revision of current position statements: Sleeping with a baby, Breastfeeding, Dummy Use, Immunisation,

Infant Wrapping, Gastroesophageal reflux and sleeping position for babies, and Smoking. The development of a new statement relating to 'Illicit drug use and risk for babies' is currently in development. The Safe Sleeping resource 'Frequently asked questions' is reviewed several times per year, in response to new evidence, standard development and parent queries.

## ADDITIONAL ACTIVITIES UNDERTAKEN BY NSAG THIS YEAR INCLUDE:

- Establishment of the Stillbirth Awareness and Prevention Working Group who will meet regularly in 2015-2016 to review current literature and develop an evidence-based resource for parents relating to stillbirth risk reduction appropriate for preconception, early and late pregnancy. The first meeting occurred in 2014. The key purpose of activity is to develop a health promotion program to raise awareness of the risk factors associated with stillbirth and explore ways to communicate with health professionals regarding stillbirth, particularly unexplained deaths.
- Development of a survey for Coroners to evaluate processes in all Australian jurisdictions relating to SUDI investigation. The aim is to determine conformation with international standards, and identify areas for improvement, particularly in regard to parent experience, and quality and completeness of data relating to investigation of infant deaths.
- Collaborative sharing of relevant policies and procedures developed by each state and territory which assists in highlighting areas of need (e.g. development of Victorian Safe Sleeping guidelines – feedback provided to draft document)
- Advocacy and response for parents and family members seeking further information about systems, processes and responding to recommendations for improvements (e.g. support of parents involved in Coronial Inquests)
- Response to government reports and processes which impact on safe infant sleeping messages. SIDS and Kids responded to the federal government proposal to set up new arrangements to ensure continued adherence to the Marketing in Australia of Infant Formulas Agreement (MAIF) by calling for a reinstatement of the panel overseeing the MAIF agreement. Senator Fiona Nash responded to the request, and ongoing lobbying in collaboration with other key stakeholders will continue.



- Representation for SIDS and Kids as media spokespeople in their area of expertise including responses to the media in relation to Sudden Unexpected Death in Infancy and stillbirth.

## GOODBYE TO MEMBERS

Member Professor Vicki Flenady (Qld) and guest Associate Professor Adrian Charles (WA) have stepped down due to other work commitments. We thank them for the generous contributions and expertise. NSAG will actively seek to recruit members in 2015-2016 who are appropriately placed to represent the needs of Indigenous communities, general practitioners and practising midwives.

Dr Kelly Hamill, NSW, who is participating in the GP Registrar Training Program, attended the April 2015 meeting in Sydney as a guest of NSAG.

## PRIORITIES FOR 2015 TO 2016

The Group have identified the following priorities for 2015-2016:

- Actively support the work of the Stillbirth Awareness and Prevention Working Group
- Finalise the Investigation of SUDI – current Australian Coroner processes survey and distribute to participating jurisdictions through Coroner networks

## ACTIVITIES OF NSAG MEMBERS

*National recognition of NSAG members in the Queen's Birthday Honours List*

In 2013, Professor Roger Byard was made an Officer of the Order of Australia (AO) and recognised for his "distinguished service to medicine in the field of forensic pathology as an academic, researcher and practitioner and through contributions to professional committees and organisations."

In 2014, Professor Heather Jeffery was made an Officer of the Order of Australia (AO) and recognised for her "distinguished service to medicine and tertiary education in the field of paediatrics, and to improved maternal and child health in rural and remote Australia and in developing countries."

Congratulations to both of our members for their outstanding contributions and achievements.

*International Conference on Stillbirth, SIDS and Baby Survival, Amsterdam September 2014*

Representatives from SIDS and Kids and NSAG members attended and shared their research and programs with the

international community at the 2014 International Conference on Stillbirth, SIDS and Baby Survival in Amsterdam, during September 2014. This was an excellent conference, with lively discussion and debate around important issues in SUDI investigation, safe sleep recommendations and stillbirth reduction. Participation in this conference highlighted to me that Australia's research and education programs in SUDI and stillbirth risk reduction and bereavement support, led by SIDS and Kids, in collaboration with ANZSA and other key stakeholders, are world class.

*National awards for a safe sleep enabler trial*

Professor Jeanine Young and her team are currently conducting the first Australian trial of a safe sleep enabler in high risk Aboriginal families. The Pepi-Pod Program is currently operating in Queensland with 10 organisations (governmental and NGO Aboriginal controlled medical organisations) across over 20 communities from Queensland's southeast corner, to the Cape, and across to Mt Isa. Preliminary results indicate parents perceive the enabler as safe, convenient and portable. The program has picked up two national awards in 2014: the Hesta Australian Nursing Award for Team Innovation and the National Lead Clinicians Group Award for the Indigenous Maternal and Child Health Category. This program is partly supported by a grant from SIDS and Kids.

I would like to express my gratitude to my NSAG colleagues and the SIDS and Kids Board for their support of the valuable work that this group does in facilitating the provision of parents and health professionals with evidence-based information to facilitate the best possible outcomes for Australian families. Together, we are looking forward to progressing the SIDS and Kids education, service and research agenda in 2015-2016

*Written by*

## PROFESSOR JEANINE YOUNG

*FACN, PhD, BSc (Hons)  
Nursing, Adv. Dip Nursing  
Care RGN, Reg Midwife,  
ENB 405 & 998*

*Chair of SIDS and Kids  
National Scientific Advisory  
Group*





# OVERVIEW OF CHILD DEATH IN AUSTRALIA 2014/15

## - LOUISE ELLIS, LIBRARIAN

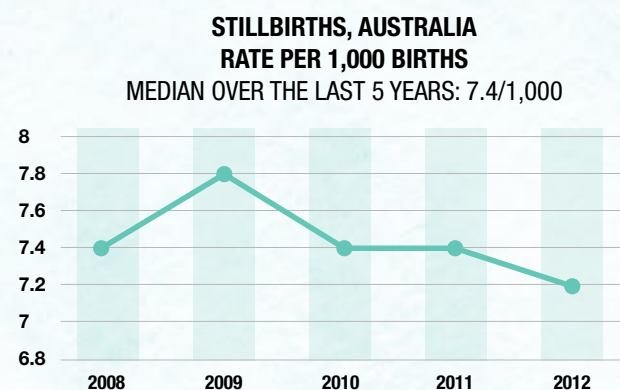
This overview of child death in Australia covers the categories of perinatal death, Sudden and Unexpected Death in Infancy (SUDI), Sudden Unexplained Death in Childhood (SUDC), suicide and bereavement. It includes data released in 2014/2015, with reference to earlier data for comparative purposes.

*Around the time of birth (Perinatal) (Hilder et al 2014)*

### INCIDENCE

Australia's *Mothers and Babies 2012* was released in December 2014, reporting that there were 2,255 stillbirths in 2012, resulting in a rate of 7.2 per 1,000 births, and 737 neonatal deaths, giving a rate of 2.4/1,000 live births. There were 2,992 perinatal deaths reported for 2012, giving a rate of 9.6 perinatal deaths per 1,000 births (9.3 in 2010). Of these, 75.4% were stillbirths.

The rate of stillbirths has declined in Australia over the past five years.



Stillbirths, Australia. Rate per 1,000 births. Median over the last 5 years: 7.4/1,000

### CAUSES:

- congenital abnormalities (anomalies) (27.1%)
- unexplained (20.4%),

### FOCUSING ON GESTATIONAL AGE:

- almost half (49.2%) the foetal deaths of babies from 37 weeks gestation were unexplained

### STILLBIRTH RESEARCH IN AUSTRALIA:

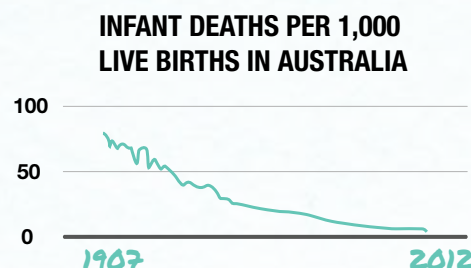
#### *Understanding risk factors for stillbirth*

Unexplained late stillbirth<sup>1</sup> is a devastating event that is difficult to study due to the lack of clues. To make progress towards predicting and reducing unexplained late stillbirth, a triple risk model for unexplained late stillbirth was proposed (Warland & Mitchell 2014): (1) maternal factors (such as maternal age, obesity, smoking), (2) fetal and placental factors (such as intrauterine growth retardation, placental insufficiency), and (3) a stressor (such as venocaval compression from maternal supine sleep position, sleep disordered breathing). Risk factors within each group in themselves may be insufficient to cause the death, but when they interrelate may produce a lethal combination.

#### *Reducing the incidence of stillbirth among high-risk infants*

Addressing the fact that twins have a higher rate of stillbirth than singletons (Hilder et al 2014), Roberts and colleagues (2015) showed that twin pregnancies that continue to 36 weeks of gestation and beyond and are delivered after labor, compared with delivery by prelabor caesarean delivery, have significantly increased risks for adverse outcomes including perinatal death and death up to 5 years of age.

#### *Infant mortality (AIHW 2014)*



3.3 was the number of infant deaths per 1,000 live births in Australia in 2012. This represents a decline of more than 95% since 1907, an important improvement in Child health, development and wellbeing.

### SUDDEN AND UNEXPECTED DEATH IN INFANCY (SUDI):

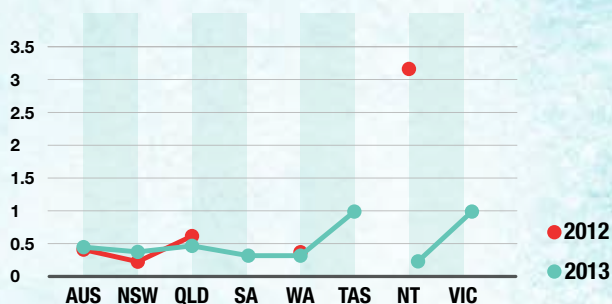
#### *Incidence (ABS 2015):*

In 2013, 117 infants died suddenly and unexpectedly, a rate of 0.4 per 1,000 live births.

As indicated in the chart below, this was equal to the previous year.



**SUDIs**  
RATE PER 1,000 LIVE BIRTHS  
ABS DATA



## SIDS

Among the 117 babies who died suddenly and unexpectedly in 2013, the cause of 54 deaths was identified as SIDS. This was a rate of 0.2/1000.

For the past 10 years, more males have died from SIDS than females. This trend continued in 2013, as SIDS accounted for 33 male and 21 female deaths.

What is being done to reduce the incidence of SUDI?

## SUDI RESEARCH IN AUSTRALIA: HIGH RISK INFANTS

Prone (tummy) sleeping is a major risk factor for SIDS and preterm infants are at significantly increased risk. In term infants, prone sleeping is associated with reduced mean arterial pressure (MAP) and cerebral tissue oxygenation index (TOI). Fyfe and colleagues (2014) examined TOI and MAP in preterm infants after term-equivalent age, during the period of greatest SIDS risk and found that cerebral oxygenation is reduced in the prone position in preterm infants and is lower compared with age-matched term infants, predominantly in the prone position when MAP is also reduced. This may contribute to their increased SIDS risk.

## BACTERIA

To examine the role of bacteria in the causation of SIDS, the gut microflora in SIDS were compared with live comparison babies by Highet and colleagues (2014). Gut colonisation of the babies with various bacteria was analysed in relation to age, gender and type of feeding; and for SIDS babies sleeping position. The study results gives an insight into differences in the gut bacterial microbiome of SIDS babies compared with healthy babies. These differences could be important

in contributing to a baby's susceptibility to infection and therefore to SIDS. The association of *S. aureus* colonisation with prone sleep position supports the hypothesis that prone sleep position could increase the risk of ingestion/inhalation of bacteria contaminating the sleeping surface and could account for the increased risk of SIDS in babies who are put to sleep prone (on the tummy).

## STUDY OF THE BRAIN

Jensen and colleagues (2014) studied the presence and distribution of a protein called - amyloid precursor protein (APP) in the brains of babies that had died from head trauma, infection, drowning, asphyxia and SIDS and found that the APP staining of SIDS are remarkably similar to those of children who died of accidental asphyxiation. This very important result helps to show that asphyxia rather than infection or trauma is more likely to be involved in SIDS deaths. The APP staining by itself does not necessarily tell the cause of death, but it can help to clarify the mechanism<sup>2</sup>.

## SUDDEN UNEXPLAINED DEATH IN CHILDHOOD (SUDC)

SUDC occurs in children over the age of 12 months and is a diagnosis of exclusion assigned when all known causes of death have been ruled out. In 2013 the incidence of SUDC in the US was 1.4 deaths per 100,000<sup>3</sup>. SIDS is 45 times more common (US data)<sup>4</sup>.

*"SUDC can occur throughout childhood. 'It's a tragedy that most people are unaware of.' states Laura Crandall, President and Cofounder of the SUDC Foundation who lost her 15 month old daughter. Maria to SUDC. 'We hear about sudden infant death and how to reduce the risk by having your baby sleep on their backs and other safe sleep measures - but no one seems to talk about sudden unexplained deaths after the first birthday. These are thriving, happy children whose deaths shock everyone around them and this shock is only worsened when a lengthy investigation yields no further understanding.'"*

**SUDC Foundation press release,  
USA, Nov 2014 <sup>5</sup>**



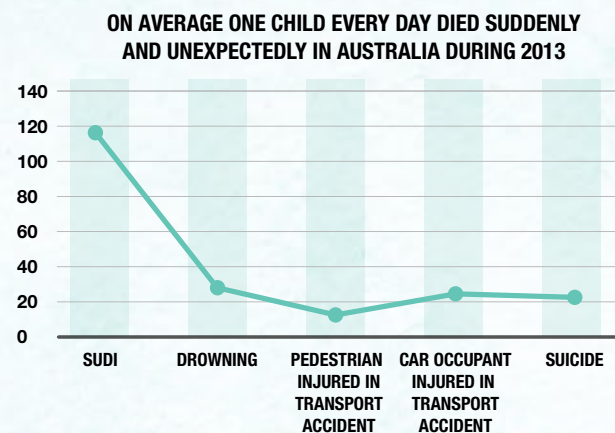
# OVERVIEW OF CHILD DEATH IN AUSTRALIA 2014/15

## - LOUISE ELLIS, LIBRARIAN

### RESEARCH

SUDC researchers have examined the possible association of a personal and/or family history of seizures with a fever and hippocampal abnormalities (Kinney et al 2009). In a recently published book chapter, Henry Krous stated that although there is insufficient information at this time to provide definitive general recommendations to the public that might reduce the overall incidence of SUDC, available data do suggest the importance of careful evaluation and consideration of prescription of antipyretics<sup>6</sup> to toddlers with a fever and who have a personal and/or family history of febrile seizures (Krous 2014).

### SUDDEN CHILD DEATHS, AUSTRALIA



*Sudden child deaths, Australia, 2012. Select causes, 0-14 years of age. (ABS 2014).*

### DROWNING (RLSSA 2014):

There were 20 children between the ages of 0 and 4 years who drowned in Australia between 1 July 2013 and 30 June 2014 (36% less than the ten year average and a continuation of the downward trend in child drowning deaths in Australia after a spike in 2012/13).

Males accounted for 70% of drowning deaths in the 0-4 year's age group in 2013/14.

Swimming Pools continue to account for the largest proportion of drowning deaths in this age group, representing 70% of all drowning deaths in children aged 0-4 years, more than 4.5 times that of any other location. All locations for drowning deaths in children aged 0-4 years reduced this year when compared to the 10 year average. Most notably, there was a 40% reduction in Bathtub/Spa Bath drowning deaths.

Falls into water accounted for the vast majority of drowning deaths in children aged 0-4 years, representing the activity being conducted immediately prior to drowning in 85% of cases. This was followed by bathing which accounted for 15% of all drowning deaths in children under five.

### DROWNING PREVENTION RESEARCH AND EFFORTS IN AUSTRALIA:

The authors of a systematic review of studies of interventions designed to reduce drowning events including fatalities among children categorised interventions into three themes: Education, Swimming Lessons and Water Safety, and Pool Fencing. The authors found that are possible effective strategies to prevent children from drowning, particularly young children aged 2-4 years, but noted a need for rigorous, well-designed studies that use consistent terminology to demonstrate effective prevention solutions (Wallis et al 2014).

Rural water safety programs and the erection of farm-safe barriers have been identified as risk reduction strategies to address the increased rate of child drownings in rural settings (Hannah's Foundation 2015).

The Australian Government is investing around \$1 million a year to produce, develop and distribute water safety messages, DVDs and educational material targeting more than 1.5 million Australian children aged up to four years (Dutton 2014).

### CHILD SUICIDE

There were 22 suicide deaths of children under the age of 15 in 2013 and 70 during 2009-2013 (ABS 2015).

### HIGH RISK GROUPS AND CHILD SUICIDE RESEARCH FROM AUSTRALIA:

- It is recognised that the death rate from suicide differs between Aboriginal and Torres Strait Islanders and non-Indigenous Australians. During 2009-13, Australian jurisdictions with data available (NSW, Qld, SA, WA, NT) reported a rate of suicide among Aboriginal and Torres Strait Islander children aged 5-17 years of 8.2 per 100,000 whereas non-Indigenous children's rate for the same period was 1.7/100,000 (ABS 2015).
- Children living outside of the main cities of Australia were at a higher risk of suicide (1.7/100,000 compared with 2.6/100,000) (ABS 2015).



A study of the demographic, psychosocial, and psychiatric factors associated with child suicides (Soole, Kölves & De Leo 2014) between 2004 and 2012, found that the gender asymmetry was less evident in child suicides and suicides were significantly more prevalent in indigenous children. Children residing in remote areas were significantly more likely to die by suicide than other external causes compared with children in metropolitan areas. Types of precipitating events differed between children and adolescents, with children more likely to experience family problems. Disorders usually diagnosed during infancy, childhood, and adolescence (e.g., ADHD) were significantly more common among children compared with adolescents who died by suicide. The authors concluded that psychosocial and environmental aspects of children, in addition to mental health and behavioral difficulties, are important in the understanding of suicide in this age group and in the development of targeted suicide prevention.

Schools are the likely centre of effective working with children to prevent child suicide (Graham 2014), coupled with adequate staff members sufficiently well trained to understand the power of Mental Wellness in undermining development of ill health.

### **CHILD SUICIDE RISK PREVENTION STRATEGIES: HIGH RISK GROUPS**

A review assessing suicide prevention programs that have been evaluated for indigenous youth in Australia, Canada, New Zealand, and the United States found that despite culturally appropriate content, the results of the review indicate that more controlled study designs using planned evaluations and valid outcome measures are needed in research on indigenous youth suicide prevention. Such changes may positively influence the future of research on indigenous youth suicide prevention as the outcomes and efficacy will be more reliable (Harlow Bohanna & Clough 2014).

Lesbian, gay, bisexual, and other same-sex attracted young people have been shown to be at a higher risk of mental health problems, including depression, anxiety, suicidality, and substance abuse, compared to their heterosexual peers. Homophobic prejudice and stigma are often thought to underlie these disparities. The relationship between such experiences of social derogation and mental health and substance use in same-sex attracted young people was examined among same-sex attracted men and women aged 18-25 years living in Sydney, Australia. The authors found that chronic social stress due to sexual orientation is associated with poorer mental health. The high rates of mental health and substance use problems in the current study suggest that same-sex attracted young people should continue to

be a priority population for mental health and substance use intervention and prevention (Lea, de Wit & Reynolds, 2014).

Understanding the extent to which suicide is associated with childhood sexual abuse (CSA) exposure can help inform prevention strategies. A review of literature on CSA exposure showed that it is associated with suicide attempts when a range of different confounders are controlled for, but the temporality of the association is not well established, and the association is highly heterogeneous (Devries, Mak, Child et al 2014).

### **BEREAVEMENT SUPPORT RESEARCH**

Australian published research included:

#### **SUPPORT OF BEREAVED FAMILIES:**

The death of a child around the time of birth is not uncommon, but social stigma and negative attitudes are inextricably linked to underreporting of babies' deaths, leading to disenfranchised grief and diminished preventive efforts to reduce stillbirth and neonatal deaths. Australian authors called for acknowledging these deaths to bring them 'out of the shadows' and compassionate, respectful care for parents suffering perinatal loss (Flenady, Boyle, Koopmans et al 2014).

Stillbirth, among the most distressing experiences an adult may face, is also a time when parents must decide whether an autopsy or other post-mortem examinations will be performed on their baby. Autopsies can reveal information that might help explain stillbirth, yet little is known about how people make this difficult decision.

A study examining the influences on decisions about autopsy after stillbirth among Australian parents showed that they shared the decision making. The authors concluded that parents need factual information about autopsy procedures, recognition that there might be fear of blame, an environment of trust, and health services and professionals prepared and skilled for difficult conversations (Horey, Flenady, Conway et al 2014).

With a long history of supporting families following the sudden and unexpected death of a child, the majority of families supported by SIDS and Kids NSW and Victoria in recent years have experienced a perinatal loss, particularly stillbirth, neonatal death or medical termination. Counsellors and trained bereaved parents work together in supporting families. One study described the typical responses of parents after the death of their baby and how perinatal death has unique



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consequences. The author drew on feedback from parents as to how this affected their key relationships, how they helped themselves to strengthen these, and what support enabled them to begin to heal and work through their grief. Support is provided via counselling (couple and individual), “Parent Supporters”, self-help resources, support groups, internet forum, and our weekend workshop “PEP” (Personal Enrichment Program) (den Hartog, 2014).

One article discussed a study which identified and summarized the hospital-based bereavement services to families following the death of a child. The study focused on the provision of transitional bereavement support for the whole family including parents, siblings, and grandparents. Bereaved families described the need for access to a combination of formal assistance (professional) and informal support (social network) following the death of a child, with researchers affirming that both forms of help are required, as they meet different needs. Contemporary models of loss and grief suggest acknowledgement and support of anticipatory grieving prior to the death of a child may ensure improved outcomes for grieving parents in the longer term (Donovan, Wakefield, Russell et al 2015).

Prolonged grief disorder (PGD) is a potentially disabling condition that affects approximately 10% of bereaved people. Grief-focused cognitive behaviour therapy (CBT) has been shown to be effective in treating PGD. Although treatments for PGD have focused on exposure therapy, much debate remains about whether exposure therapy is optimal for PGD. Twenty-five participants who experienced the death of a child were among patients with PGD attending a University of New South Wales clinic that were studied. The results showed that facilitating emotional responses to the death may promote greater changes in appraisals about the loss, which are associated with symptom reduction. The authors called for the promotion of emotional processing techniques in therapies to treat patients with PGD (Bryant, Kenny, Joscelyne et al 2014).

Continuing bonds (CBs) expression appears especially prevalent among bereaved parents. One study examined the relationship between CBs and grief outcomes for bereaved parents recruited from Facebook bereavement support groups, 42% of whom were Australian. The results showed clear links between internalized bonds and a more positive grief status; externalized bonds showing an opposite relationship. Weaker effects were found for child's age, time since death, and type of death (Scholtes & Browne, 2015).

When relationships hurt, too: The impact of grief on parents' relationships after the sudden death of their child was written

by Petra den Hartog, in collaboration with bereaved parents. The three-part booklet focusing on many facets of the grief journey that families face after the death of a child was reviewed in 2014. The reviewer described being given a sense of hope, as all aspects of grief were covered, from guilt and shame to anger and blame – in essence, normalising grief responses by not typecasting grief. (Butera 2014).

<sup>1</sup> stillbirth at or beyond 28 weeks gestation

<sup>2</sup> University of Adelaide. 'New insight into SIDS deaths points to lack of oxygen'. Media release, 15 April 2014.

<sup>3</sup> Retrieved from <http://www.sudc.org/MedicalForensicInfo/SUDCStatistics.aspx>

<sup>4</sup> SUDC Foundation (2013) Newsletter, September 3: 1

<sup>5</sup> SUDC Foundation (2014) 'The SUDC Foundation applauds the Health, Education, Labor and Pensions (HELP) Committee' Washington DC, 14 November

<sup>6</sup> Such as paracetamol or ibuprofen. Source: Department of Health, Government of South Australia (2015, February). South Australian Paediatric Practice Guidelines: Management of fever without focus in children (p. 7). Retrieved from <http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/clinical+topics/paediatric+clinical+guidelines>







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