# sidadkids<sup>®</sup> Republic to saving the lives of babies and children during pregnancy, birth, infancy and childhood and supporting bereaved families.

### **SIDS AND KIDS AUSTRALIA**

1227 Malvern Road Malvern VIC 3144 P 03 8888 1600

**F** 03 8888 1691

E national@sidsandkids.org

www.sidsandkids.org www.rednoseday.com.au www.sidsandkidsshop.org

ABN 55 050 464 616



- 4 CHAIRMAN'S REPORT
- 5 CHIEF EXECUTIVE OFFICER'S REPORT
- 6 VISION, MISSION AND BACKGROUND
- 8 WHAT WE DO NATIONALLY
- 11 ACHIEVEMENTS
- 14 SIDS AND KIDS NATIONAL SCIENTIFIC ADVISORY GROUP
- 16 HEALTH PROMOTION AND BEREAVEMENT SUPPORT
- 19RED NOSE DAY 2013
- 23 AMBASSADORS
- 26 SIDS AND KIDS PARTNERS AND SUPPORTERS
- **30 TRUSTS AND FOUNDATIONS**
- 31 SIDS AND KIDS SHOP ONLINE
- 32 COMMONWEALTH GOVERNMENT FUNDING
- 34 MEDIA
- 36 SOCIAL MEDIA AND WEBSITES
- **37 COMMITTEE REPORTS**
- 39 AN OVERVIEW OF CHILD DEATH IN AUSTRALIA
- 46 **REFERENCES**

# Chairman's Report

The past year, like most years, had its challenges but also saw some new and important developments which I believe will be crucial to our continued viability as an organisation. For a long time the National Council has sought a better way of working with our member organisations to maximise the impact we can have on education and research into SIDS, SUDI, SUDC and stillbirth and to deliver the best standard of bereavement support and services to those who seek our help. We have recently joined with the largest of our members, SIDS and Kids NSW-Vic Inc., to implement a new joint management structure which will see the National Council with its central role of fundraising, education and research facilitation and NSW-Vic with its strong focus on service delivery, run as one organisation under the leadership of the National CEO Leanne Raven. The potential for better utilisation of our resources and reduction of duplication of effort will lead to financial benefits which we can apply to our frontline services. Even more important, in my view, is the opportunity it provides us to develop a single sense of purpose in what we do. Other member organisations have expressed interest in joining the scheme and the focus of the board in the coming year will be to make this new venture a success.

The past year had some low points, chief of these being the Product Recall we undertook together with the ACCC due to a manufacturing defect in some of our Red Nose Day products. While this certainly costs us some revenue we can thankfully reveal that we had no reports that any child suffered any harm from this unfortunate circumstance. Despite this setback we managed to meet our budget targets and the Council looks forward to the new year in a sound financial position.

Finally I must thank the CEO and staff of the National Council for the excellent work they have done during the year. Thanks are also due to the members of the National Board who gave their time and valued advice to the furtherance of our mutual goals.

#### **Graham Henderson**

Chairman

EVEN MORE IMPORTANT, IN MY VIEW, Is the opportunity it provides Us to develop a single sense of Purpose in what we do.



MR GRAHAM HENDERSON – CHAIRMAN
MR CRAIG HEATLEY - DEPUTY CHAIRMAN
MR ANDREW KENNEDY – TREASURER
PROF PAUL COLDITZ
MS SHERI NORTON
MR MARK SHEEHY
MS CHRISTINE PAYNTER
MR KEN RAMSAY
MS JENNY GODDARD
MR PAUL RODERIQUE

# Chief Executive Officer's Report

This year has been one of considerable change and achievement at SIDS and Kids Australia. We have ventured into new ground at the same time increasing our funds to support bereavement services nationally. The bravery of the families who have experienced the death of a baby or child is truly remarkable and it is a privilege to work within an organisation where this courage is made visible in the hope that we can increase our knowledge about prevention of sudden and unexpected child death.

Our achievements this year have resulted in the development of new 'Sleep Safe, My Baby' resources, a news SIDS and Kids Online Shop, new corporate partnerships, a new service for member organisations and an increased awareness with a stronger media presence.

It is clearly understood that the delivery of our public health promotion programs and bereavement services rely on the dedication and commitment of all SIDS and Kids volunteers and staff within Australia. The passion, time, effort and depth of their commitment to the purpose of SIDS and Kids is unstinting and truly remarkable. We know that throughout the year over 1,400 new referrals for bereavement support have been made to SIDS and Kids. Our efforts nationally have focussed on providing assistance where we can to add value to the delivery of public health programs, increased funding for bereavement support services for families and funding of research programs that are consistent with our purpose.

In February 2014 we forged an exciting new partnership with CUA, Australia's largest customer- owned financial institution, which will provide valuable financial support for our work at SIDS and Kids. As a part of this partnership CUA staff has been provided the opportunity to spend one day each year as a volunteer with SIDS and Kids. Other new supporters include Sheridan Australia and Red Nose Kids Cuts which opened a children's hairdressing salon on the northern beaches of Sydney in late 2013. Without the continued support of our financial sponsors including our donors, Trusts and Foundations and the Commonwealth Department of Health we would not be able to achieve as we have throughout this year.

Our financial result for the year has been solid and positive. Annual revenue increased by 12.4% on the previous year and we made a surplus of \$121,593. Our Asset: Liability ration sits at 10:1 and company equity increased by 11% on previous year result.

The Red Nose Day Campaign with its "Wild and Silly" theme received strong support from the public nationally even with the voluntary recall of some of the plush toys. All of our retail partners have stood by us during this process and we have received considerable support from our suppliers who have gone to great lengths to ensure these quality problems do not occur again. Many thanks to our Red Nose Day supporters who returned requested stock for destruction.



Earlier in the year we were asked to manage the financial accounting and reporting function of our largest member -SIDS and Kids NSW and Victoria. This transition has worked well and we will be moving in the next year to broadening that support in providing full management services. This new service to member organisations will produce multiple benefits with the primary one focusing of cost savings. A better and more effective use of the donor dollar is an important responsibility for a non-government organisation that receives considerable community support.

The national team is comprised of a small number of people who give more than one would ask for in terms of commitment, time, energy and focus. Many thanks to all the staff for this year's efforts as we said goodbye to Deb Chen who moved to Canberra with her new husband and welcomed Carly Bourke in her new role as Red Nose Day Manager. Bill Hanlon also joined us in the corporate services division.

#### **Associate Professor Leanne Raven**

Chief Executive Officer

# Vision, Mission & Background

#### **OUR MISSION AND VISION**

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 vision through funding world class research, delivery of evidence-based education, providing bereavement support, and advocacy.

#### BACKGROUND

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 research into sudden infant death syndrome (SIDS), perinatal deaths and stillbirth.

SIDS and Kids has been largely responsible for an 80 per cent reduction in sudden unexpected death in infancy (SUDI) in Australia.

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.

Today, SIDS and Kids is a national organisation with offices in every state and territory of Australia as well as a national office in Melbourne. 80% reduction in SUDI deaths in Australia since 1989 7,990 babies' lives saved

More than \$16,000,000 spent on research and education

More than 10,000 calls for support and information annually

24 hour bereavement support line

More than 1,400 new referrals for bereavement support annually

1,400,000 safe sleeping brochures and resources distributed annually

1,500 enthusiastic volunteers SIDS AND KIDS IS DEDICATED TO Saving the lives of babies and Children during pregnancy, Birth, infancy and childhood and Supporting bereaved families.





SIDS and Kids provides national public health promotion programs that reduce infant and child mortality, funding for bereavement support and research.

#### THE FIVE KEY AREAS OF RESPONSIBILITY INCLUDE

Advocating nationally for and funding research into stillbirth prevention and other areas of sudden and unexpected child death.

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.

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. Providing funding and resources for bereavement support and counselling to families who have experienced stillbirth or the sudden and unexpected death of a child, regardless of the cause.

Facilitate sharing of information with the public and SIDS and Kids organisations.

#### **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.

#### **HEALTH PROMOTION**

'Sleep Safe, My Baby' is an evidence-based public health campaign developed for health professionals, childcare workers, new and expectant mothers, parents and anyone who cares for babies. The campaign has been developed in conjunction with researchers from Australasia and internationally and provides information about the evidence around SIDS risk reduction and fatal sleeping accidents. Following a review of the evidence, the revised health promotion campaign was launched in May 2012. The program was given a new name, 'Sleep Safe, My Baby', and a song dedicated to the safe sleeping message was written and performed by The Wiggles.

Resources to assist in the delivery of this program have been developed, including: 'Sleep Safe, My Baby' brochures, FAQs, Information Statements, mobile apps, and an Online Education program.

Since its inception the campaign has reduced the incidence of SUDI in Australia by 80%, saving 7,990 babies' lives. The SIDS and Kids National Scientific Advisory Group ensures recommendations provided by SIDS and Kids are based on the latest scientific evidence.

#### BEREAVEMENT

SIDS and Kids bereavement support services assist families who have experienced the sudden and unexpected death of a baby or child, during birth, pregnancy or infancy, regardless of the cause.

Our support services are available in every state and territory of Australia through our member organisations. These services 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.

#### RESEARCH

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.

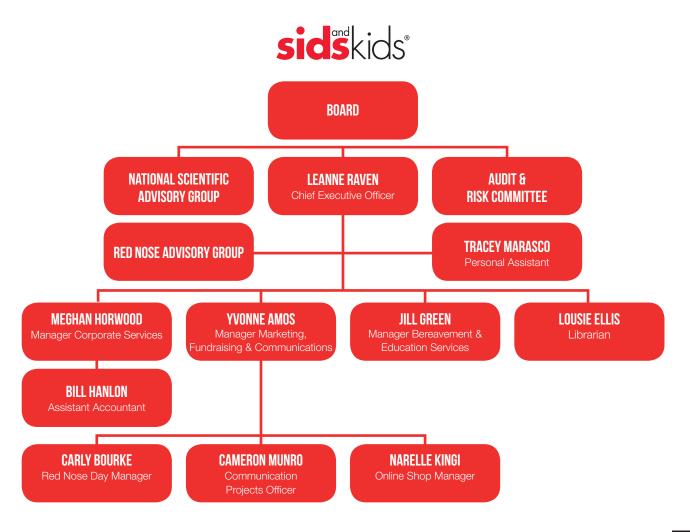
Within Australia, SIDS and Kids has established a National Scientific Advisory Group who review and recommend research development, research initiatives and public health educational campaigns that prevent child deaths.

#### **COMMUNICATIONS**

SIDS and Kids communicates to the public through its website, as well as over 1,000 media articles, plus regular electronic newsletters, including a Child Care Kit e-news for childcare centres that have purchased a 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.





# Achievements 2013/14

### NEW 'SLEEP SAFE, MY BABY' HEALTH PROMOTION RESOURCES

### INFANT SAFE SLEEPING CHILD CARE KIT FOR EDUCATION AND CARE SERVICES

The Child Care Kit was developed to inform staff and carers employed by child care services/providers, including long day care and family day care, to ensure all those who care for babies are aware of the current and evidence-based SIDS and Kids Safe Sleeping recommendations to reduce the risk of SIDS and sleeping accidents. The new Child Care Kit was released in June 2013 and more than 450 have been purchased by child care centres.

#### INFANT SAFE SLEEPING DVD

The Infant Safe Sleeping DVD was produced and is available for purchase from the SIDS and Kids website.

#### COT TO BED SAFETY

Cot to Bed Safety is a new health promotion program developed to provide information for parents on when to move a child from a cot to a bed and how to create a safe sleeping environment for a child. It is available as an online brochure and as a free app for iPhone and Android. Cot to Bed Safety has been translated into Chinese, Hindi, Vietnamese and Arabic.

#### BEDDING AMOUNT INFORMATION STATEMENT

An information statement 'Bedding amount recommended for Safe Sleep' was added to the 16 other information statements, which can be downloaded from the website.

#### **NEW SIDS AND KIDS ONLINE SHOP**

After months of development, a new SIDS and Kids Online Shop website was launched in July 2013 with a much-improved design and a greater range of products. In October, SIDS and Kids Chief Executive Leanne Raven received the Business Innovation Award at the 2013 Telstra Victorian Business Women's Awards partly in recognition of her online store innovation.

#### **NEW CORPORATE PARTNERSHIPS**

SIDS and Kids has formed new partnerships including:

- CUA in January 2014
- Sheridan Australia in early 2014
- Red Nose Kids Cuts in October 2013

#### **NEW SERVICE FOR MEMBER ORGANISATIONS**

As of 1 July all of the financial processing and reporting will be undertaken by SIDS and Kids Australia for SIDS and Kids NSW and Victoria. Commencing in the next financial year this service will extend to full management.

### INCREASED AWARENESS WITH STRONGER MEDIA PRESENCE

Editorial value and television advertising for the Red Nose Day Campaign increased in value in 2013/14. Our social media presence on Facebook and Twitter is also on the rise.

#### **RESEARCH PROJECTS FUNDED**

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

### 1. UNDERSTANDING THE MECHANISMS MEDIATING SUDDEN AND UNEXPECTED DEATH IN CHILDHOOD

This study aims to better understand the underlying mechanism mediating sudden and unexpected death in childhood. In order to achieve this goal, researchers from around the world are uniting to form effective collaborative networks.

One of the greatest human tragedies is the sudden unexpected death of a child – when that death remains unexplained, it is even more devastating for the parents, the family, and society at large. Fortunately, the sudden unexplained death of a child (SUDC), which is defined as the sudden and unexpected death of a child over the age of 12 months which remains unexplained after a thorough case investigation is conducted, is rare – occurring mainly in toddlers with an incidence of 1.2/100,000 in the United States.

Yet, it is this very rarity that makes research into the causes and mechanisms of SUDC almost intractable. Indeed, it is virtually impossible for any one investigator to accrue a sufficient number of cases to determine commonalities among them – the critical clues that lead to testable hypotheses and evidencebased scientific inquiry necessary to determine the ultimate means of prediction and prevention. Thus, it is essential that investigators come together to pool their ideas, drive, and resources and study SUDC in a concentrated worldwide effort.

The Cooper Trewin SUDC Research Fund, in partnership with SIDS and Kids, announced its support of the development of an international initiative between Australia (Dr Jhodie Duncan, Florey Institute of Neuroscience and Mental Health) and the United States (Professor Hannah Kinney, Children's Hospital Boston/Harvard) to perform SUDC research through the organising leadership of the SUDC program at Children's Hospital Boston.

This initiative involves support in the transition and infrastructure-building period, as well as support for shared research studies into potential brain mechanisms underlying SUDC. The project also includes investigation of a new research program that explores the link between SUDC and potential serotonergic brainstem pathology as seen in Sudden Infant Death Syndrome, that is, is death in SUDC cases mediated by the same factors as SIDS but occurs at a later time point in life?

Thus this project represents a critical opportunity to rethink and reshape the direction of SUDC research and to build into it for the first time the infrastructure for international collaborative endeavours with Australian and overseas researchers.

The overriding goal is to identify why children, who seem normal and healthy, may die suddenly and unexpectedly and is this related to abnormalities in the brain. The next step would be to implement intervention strategies to prevent an adverse outcome.

#### 2. SUDDEN UNEXPECTED EARLY NEONATAL DEATH OR COLLAPSE IN PREVIOUSLY HEALTHY TERM INFANTS IN THE FIRST 7 DAYS OF LIFE.

The study aims to establish the current incidence of sudden unexplained death or collapse in the early neonatal period (first 7 days of life) in Australia.

The incidence of sudden unexpected and unexplained death or neonatal collapse is reported as between 0.035/1000 to 0.4/1000 live births. Greater than half of these infants die.

There is currently no national system available in Australia for investigating and reporting these cases.

The study also aims to document the risk factors and outcomes for such cases in Australia, as well as preventative strategies.

In the reported literature many of these infants are found face down on the mother's breasts suggesting that airway compromise may be a contributing factor. Other risk factors include maternal analgesia, bed-sharing and prone sleeping.

Examination of neonatal sudden unexplained death in infants in NSW has found that the history, examination, and the death scene investigations are incomplete and under-investigated.

A recent study using the British Paediatric Surveillance Unit showed that in 30 of 45 cases there was no identified underlying disease/abnormality, but in 24 there was clinical or pathological evidence of airway obstruction while breastfeeding or in a prone position. The authors called for development of guidelines for safe postnatal care of infants, especially for new mothers.

The failure to register on a population wide basis means national guidelines for safe sleeping are inadequate especially in this early postnatal group, as most definitions of SIDS commence after day 7 or 28 days of life.

It is anticipated that the information obtained as a result of this study will lead to the development and initiation of policy directives aimed at safe postnatal management of healthy newborns. Preventative strategies including education programs for parents and carers are important in reducing the incidence of these conditions.

### THUS, IT IS ESSENTIAL THAT INVESTIGATORS Come together to pool their ideas, DRIVE, and resources and study sudc In a concentrated worldwide effort.

### 3. UNDERLYING MECHANISMS OF SIDS - INVESTIGATION IN TO THE EFFECTS OF INTRAUTERINE GROWTH RESTRICTION ON THE HEART AND CIRCULATION

SIDS and Kids has awarded a three-year PhD scholarship to Dr Emily Cohen to pursue research into the underlying mechanisms of SIDS.

Emily started medical school at Maastricht University in The Netherlands in 2006 and as part of her degree she undertook a research elective at The Ritchie Centre, Monash University in 2011. Her project was supervised by Prof Rosemary Horne and Dr Stephanie Yiallourou, who have an international reputation in research which aims to understand the physiological mechanisms which underlie the known risk factors for SIDS such as sleeping infant on their tummy and being exposed to maternal smoking.

After completion of her medical degree in 2012, Emily commenced working in the paediatric and neonatology department of the St. Antonius Hospital in The Netherlands. Emily has been able to return to The Ritchie Centre this year to pursue a PhD with the SIDS and Kids scholarship. In collaboration with Utrecht University she will be 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.

In the course of the next three years 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 "fetal 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.

### Activity Report for the SIDS and Kids National Scientific Advisory Group 13-14

### **PROFESSOR JEANINE YOUNG, CHAIR**

The period 2013-2014 has been another productive year for the SIDS and Kids National Scientific Advisory Group. This multidisciplinary group of health professionals and researchers, from all over Australia, works with SIDS and Kids to ensure that information provided to parents and health professionals is continuously reviewed and based on best available evidence.

During this financial year the group has met face-to-face or by teleconference in May and August 2013 and February 2014 and has conducted the annual review of our Terms of Reference. Our plan for a May meeting in Perth was delayed to November 2014 and the group will meet next in June 2014.

In particular, the group has succeeded in supporting 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 engage 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:

- The ACCC investigation of convertible prams and pushers;
- the voluntary standard for cot mattresses (AS/NZS 8811.1:2013 Methods of testing infant products Sleep surfaces Test for firmness);
- The Office of Fair Trading's safety investigations into infant slings and infant bean bags;
- Feedback relating to hammock safety for various models.

The Group continues to actively lobby for consistency in safe infant sleeping messages by supporting and informing 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 safe infant sleeping, e.g. the Australian College of Midwives Draft Statement of Co-sleeping (risk minimisation approach consistent with SIDS and Kids); the Victorian Government Safe Sleeping guidelines; National Aboriginal and Torres Strait Islander Health Plan. The Group also feedbacks 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.



#### **CORE BUSINESS OF THE GROUP INCLUDED**

- SUDI Position statements: revision of current position statements (Smoking, Breastfeeding, Dummy Use, Immunisation, Sleeping with a Baby); finalisation of new statements (Sleeping position for babies with gastrooesophageal reflux, Soft toys in the cot, Pillow use), and the development of new statements (How much bedding to use?).
- The Safe Sleeping resource 'Frequently asked questions' is reviewed periodically throughout the year, in response to new evidence, standard development and parent enquiries: inclusions made about bassinets and breathability zones; Mattress firmness referencing of new AS/NZS 8811.1 in Australian Product Standard
- 'Cot to Bed' Brochure developed by Jill Green, National Educator, in response to a toddler accident and coronial enquiry with group feedback
- Child Care Kit update was completed by Jill Green, National Educator, with group feedback



L to R: NSAG Members: Dr Susan Arbuckle, Prof Gay Edgecombe, Ms Belinda Jennings, Assoc Prof Leanne Raven, Dr Susan Beal and Nixon, Prof Roger Byard, Prof Jeanine Young, Dr Janet Vaughan, Associate Prof Jane Freemantle, Prof Heather Jeffery, SIDS and Kids Team: Jill Green, Louise Ellis. Not shown: Dr Jackie Scurlock, Dr Vicki Flenady, Prof Rosemary Horne, Prof Sandra Eades and Dr Jodie Duncan.

- Progression of the Stillbirth agenda in collaboration with ANZSA through supporting and lobbying for
  - > Further funding for the IMPROVE program,
  - My Baby's movements mobile phone application (improving awareness of decreased fetal movements)
  - Writing to Coroners regarding systems for use for investigations used in autopsy
- Collaborative sharing of relevant policies and procedures developed by each states and territory which assists in highlighting areas of need
- Advocacy and response for parents and family members seeking further information about systems, processes and responding to recommendations for improvements
- 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. One highlight was a segment on the Today Show in June 2013, as part of the Red Nose Day celebration to highlight safe sleeping messages.

#### **GOODBYE TO MEMBERS**

Professor Sandra Eades and Dr Janet Vaughan due to other work commitments. The group will actively seek to recruit an NSAG member in 2014-2015 who is appropriately placed to represent the needs of Indigenous communities.

#### PRIORITIES FOR 2014 TO 2015

The Group have identified the following priorities for 2014-2015:

- Progression of the Stillbirth Health Promotion Program Steering / Reference Group in collaboration with ANZSA, with the purpose of developing 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.
- Continue to revise and develop Sleep Safe, My Baby resources.
- Progress National Safe Sleeping statement to promote consistency of safe sleep messaging in each state and territory, particularly around infant care practice issues including sharing sleep with a baby, dummy use and infant wrapping.
- Collaborate with Coroners regarding systems used for SUDI investigations across each state and territory in order to identify areas for improvement to promote consistency and completeness of information.

Several of the National Scientific Advisory Group members will be presenting their work as representatives of SIDS and Kids at the 2014 International Conference on Stillbirth, SIDS and Baby Survival in Amsterdam, September 2014. We look forward to returning invigorated, refreshed and prepared to innovate.

I would like to extend a heartfelt thankyou to my National Scientific Advisory Group 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.

# Health Promotion & Bereavement Support

Each year in Australia over 300,000 families await the safe arrival of their baby. In most cases this event has been highlighted by a time where parents plan and prepare to bring their baby home. Sadly, in Australia each year over 3,500 families experience the sudden and unexpected death of a baby or child, from stillbirth, SIDS, or sudden unexpected death in pregnancy, birth, infancy and childhood.

Last year over 1,400 new families contacted SIDS and Kids for bereavement support. SIDS and Kids is the largest provider of grief counselling support for sudden and unexpected death of babies and children in Australia. Given 60 people are impacted by the death of one child, a minimum of 210,000 people are impacted every year.

#### SIDS AND KIDS BEREAVEMENT SUPPORT

SIDS and Kids has a strong commitment to self-help and ensures that services and programs are developed in response to the emerging needs and interests expressed by families, and families are involved in their implementation as much as possible. This keeps the service fresh and responsive.

Our support services are delivered at a local level by our member organisations and are available to families free of charge.

In particular, the SIDS and Kids national 24 hour 1300 line received over 10,000 calls last year for bereavement support and information. The main focus of the calls to the 1300 line was from parents seeking guidance, support and someone to listen to.

SIDS and Kids has also collaborated with the Pregnancy, Birth and Baby free telephone helpline to ensure confidential, professional information and counselling is available for women, their partners and families in Australia relating to issues of conception, pregnancy, birthing and postnatal care. The helpline and website are for pregnant women and new parents who have a baby up to 12 months of age. Call 1800 882 436 or visit www.pregnancybirthbaby.org.au.

SIDS and Kids has a suite of bereavement literature designed to support families who have experienced the sudden and unexpected death of a baby, toddler or child regardless of the cause. These booklets are available from our offices in each state and territory or can be downloaded free from our website www.sidsandkids.org/bereavement-support/ bereavement-support-literature.

#### **OUR BEREAVEMENT SERVICES**



#### A SIDS AND KIDS PUBLICATION

#### **HEALTH PROMOTION**

#### 'SLEEP SAFE, MY BABY' HEALTH PROMOTION PROGRAM

Given that infants sleep for an average of 11 to 14.5 hours a day for the first year of their life, and SIDS and fatal sleeping accidents remains the main cause of sudden and unexpected death between the ages of one month and one year of age, where we sleep our babies and the sleep practices we adopt must be a priority.

The key focus areas within our health promotion program are to promote safe sleeping through information, education, and advocacy and by building supportive networks for families to ensure consistent and evidence-based safe sleeping messages are given. Our work spans the continuum of individual to population-based approaches providing opportunities to support parents, other carers and health professionals caring for families and their children and to allow for informed choices.

SIDS and Kids, supported by our National Scientific Advisory Group, has developed many resources to present some guidance for parents and carers of infants and help address some of the myths and misinformation in the public domain about the safest way to sleep babies. These resources are available on our website www.sidsandkids.org.

#### NEW RESOURCES FOR THE 2013/14 YEAR INCLUDED:

#### Infant Safe Sleeping DVD



**Information Statements.** There are 17 information statements covering a broad range of topics. These statements have been primarily designed for health professionals and individuals wanting to research a particular topic related to infant safe sleeping and health related topics. A new Information Statement *Bedding amount recommended for safe sleep* has been added to the suite in response to many calls and queries from parents, carers and health professionals.

#### Cot to Bed Safety

**brochure.** The new Cot to Bed Safety brochure and free app provide information on when to move a child from a cot to a bed, what type of bed to use, and how to provide a safe environment for a child moving out of the cot. It is currently available as a PDF and as an app for iPhone and Android and can be used in five languages: English, Chinese, Vietnamese, Hindi and Arabic.



#### SIDS and Kids Infant Safe Sleeping Child Care Kit.

The new SIDS and Kids Infant Safe Sleeping Child Care Kit was released in June 2013. Resources in the new kit include:

- Self-assessment and reflective tools to measure baseline knowledge and to assist educators and the service to ensure best practice standards are employed
- Guidance on developing a safe sleeping policy, including a sample policy and a supporting checklist and guidelines for Education and Care Services
- Further information and resources for educators including background information, brochures, information sheets, an FAQ, and DVDs
- A safe sleeping checklist to be used during enrolment and orientation of families
- Information for families including posters for display and ongoing education
- Emergency response and bereavement support

Each kit includes a new Safe Sleeping DVD.

Purchasers of the Child Care Kit also receive regular email newsletters including news relating to the contents of the Child Care Kit and safety news relevant to Education and Care Services.





#### Other information and services

SIDS and Kids offers individual advice and information through our telephone service, email and social media.

SIDS and Kids provides leadership in developing many networks to support families in their communities. SIDS and Kids has facilitated advocacy roles and public education in the healthcare sector, across sectors and among the general community and the media.

SIDS and Kids plays an integral role advocating for policy and guidelines to be developed into the practice of all professionals that care for families and their infants within the scope of:

- Emergency response to a sudden and unexpected death of a baby, infant or child
- Bereavement support
- Reducing the risk of SUDI and Stillbirth

SIDS and Kids' advocacy role is to influence a broad range of issues facing parents' ability to successfully adopt safe sleeping practices, particularly in the area of health policy and practice and product safety. SIDS and Kids is currently working on a range of projects and building partnerships and collaborating with analogous organisations and safety groups.

Continuing opportunities for education and ensuring ongoing support and resources for professionals are available is an integral component of the health promotion team's priority.

CONTINUING OPPORTUNITIES FOR EDUCATION AND ENSURING ONGOING SUPPORT AND RESOURCES FOR PROFESSIONALS ARE AVAILABLE IS AN INTEGRAL COMPONENT OF THE HEALTH PROMOTION TEAM'S PRIORITY. CONGRATULATIONS AND THANK YOU TO EVERYONE WHO SUPPORTED RED NOSE DAY THROUGH EVERYDAY HERO.

# Red Nose Day 2013

Red Nose Day in its 26th year remains a prominent fundraising event for SIDS and Kids and is well supported by the Australian community.

The Red Nose Day 2013 campaign was held throughout the month of June with events and activities culminating on Red Nose Day, Friday 28 June 2013. The arrival of the Carnival Spirit into Sydney Harbour on the morning of Red Nose Day was a magnificent sight with many supporters alongside Circular Quay to welcome the vessel. The *Today Show* made Red Nose Day a key feature of their morning program.

The Red Nose Day campaign included product that was sold nationally through our retail partners including Target, Big W, Best & Less, Supercheap Auto and many others. The theme for the campaign was "Go Wild and Silly this Red Nose Day", which was supported by a range of products including plush toys, pens, wristbands, key rings and more.

Highlights of the campaign included our Red Nose Me campaign, which urged supporters to upload photos of themselves and family members, including their pets, and tag the images with a "wild and silly" nose. The winning entry received a holiday on board the Carnival Spirit.

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.

#### **RED NOSE DAY EVERYDAY HERO FUNDRAISING**

Our community supporters nationally once again got behind Red Nose Day by setting up their own fundraising accounts with Everyday Hero. Our supporters raised a total of \$70,762, which was an amazing effort and could not have been achieved without the support of their families, friends, work colleagues and local communities.

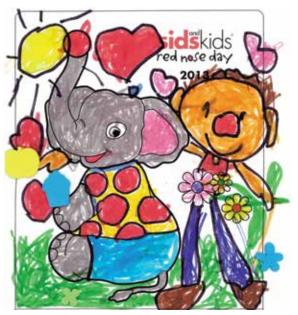
Once again we thank and congratulate Clare Field on being our number one fundraiser through Everyday Hero, raising over \$11,000 in 2013. This is the third year Clare has been crowned our number one fundraiser and we thank Clare and her support base, including The Wiggles, for their ongoing support.



#### **RED NOSE DAY COLOURING IN COMPETITION**

The Red Nose Day Colouring in Competition saw over 1,000 entries received from across the country, which was an amazing effort! There were three age groups for the competition including Under 5s, 5-9 years and 10 years and over. With so many entries it is hard to feature them all but we have included some of our winners who received our giant 1 metre plush toys and prize packs donated by The Wiggles. Thank you to everyone who entered the competition.

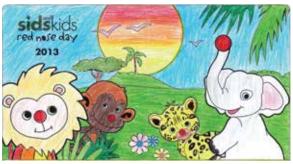




**Under 5 winner** – Benjamin aged three from Hawthorn East in Victoria



5-9 winner – Shaun aged nine from Karama in the Northern Territory



**10+ winner** – Emily aged 13 from Murrumba Downs in Queensland



#### **RED NOSE DAY RETAIL PARTNERS**

#### TARGET

Target has been a major supporter of SIDS and Kids since 2009 and proudly sells Red Nose Day promotional



merchandise in all stores during the campaign month of June. In just five short years they have raised more than \$1.1 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 \$940,000 for Red Nose Day since 2008.

#### BEST & LESS

Best & Less has been proudly supporting Red Nose Day since



2002. Best & Less stores nationally sell Red Nose Day merchandise during the month of June. Red Nose Day has been a much-loved event by Best & Less staff and customers with many getting behind the event by wearing red to work. The generosity of Best & Less customers and staff across Australia has raised over \$1.5 million since 2002.

#### 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 \$600,000 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. The winnings stores were: Townsville, QLD; Penrith, NSW; Horsham, VIC; Enfield, SA; Darwin, NT; and Midland, WA.





ON BEHALF OF THE NATIONAL BOARD, CEO AND STAFF of SIDS and Kids, 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.

#### **CARNIVAL CRUISE LINES**

For 2013 SIDS and Kids entered into a new partnership with Carnival Cruise Lines to promote Red Nose Day.



On Red Nose Day, 28th June, the cruise ship Carnival Spirit sailed into Sydney Harbour wearing a giant 7m diameter illuminated red nose on her bow. This striking sight attracted media attention across the country, with every commercial TV station covering the story. The story was also picked up by many newspapers and news websites.

The crew of Carnival Spirit also got into the spirit of Red Nose Day by creating a myriad of onboard Red Nose Day activities for guests, including fundraising activities, red nose food items, walks onboard and a 'hand wall' from the children. More than \$5,000 was raised through donations by guest and crew.

Carnival matched these donations and generously donated a cruise on Carnival Spirit as a promotion on the www. rednoseme.com website. Red Nose Day supporters were urged to upload photos of themselves and family members, including their pets, and tag the images with a "wild and silly" nose to be in the running. The Carnival Facebook page encouraged followers to enter the competition and reached 144,000 people with one post promoting the competition. The competition received more than 3,000 entries.

#### 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 2013, Red Nose Day received \$770,370 of in-kind support from this partnership.

#### SPARK COMMUNICATIONS

Spark Communications was engaged by SIDS and Kids to



implement a public relations campaign for Red Nose Day 2013. Spark helped Red Nose Day achieve more than 1,000 media hits across TV, radio, print and online and secured three new Red Nose Day ambassadors.

#### 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.

#### 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 look forward to our continued partnership.

#### 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.

#### BENCH

Bench Creative is a graphic design studio with over 15 years experience in the print



designing business growth™

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.

#### 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.

### SIDS and Kids Ambassadors 2013

#### **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. For Red Nose Day 2013 The Wiggles also performed at Knox Westfield on Red Nose Day.

The Wiggles have also written a song about Safe Sleeping titled 'Sleep Safe, My Baby' which you can view on You Tube or the SIDS and Kids Website.

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 through Australia during that time.

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









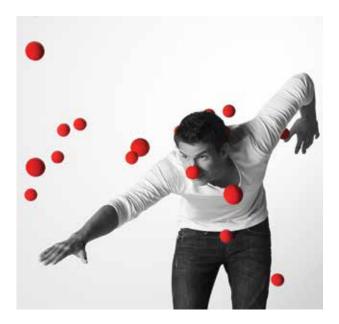
#### **DEBORAH THOMAS**

Deborah Thomas, Director Media, Public Affairs and Brand Development at Bauer Media, 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's passion for the SIDS and Kids cause is due to the death of a close friend's son to SIDS at only 22 months. Eamon believes no family should have to experience the pain his friend has felt, and so he is dedicated to raising awareness and funds for SIDS and Kids.



#### **RED NOSE DAY AMBASSADORS 2013**

#### DAN AND MARNI EWING

Dan and Marni Ewing approached SIDS and Kids directly to become Red Nose Day ambassadors following Dan's portrayal of a parent who experienced a SIDS death in TV show *Home and Away*. In early 2013 they held a fundraiser for SIDS and Kids called 20 To Go, which raised more than \$5,000. For Red Nose Day 2013 they were a fantastic asset to the campaign, appearing in *Woman's Day* and *New Idea* and were always happy to assist.



#### LAUREN PHILLIPS

Television host and presenter Lauren Phillips featured in a *Today Show* weather cross, was interviewed in *Total Girl* and promoted Red Nose Day through her Twitter account. Always happy to help and changing her schedule to assist with the weather cross, she was a delight to work with.

#### **FIFI BOX**

As a new mum radio broadcaster and television presenter Fifi Box was a perfect fit for Red Nose Day. The arrival of her new baby limited her involvement, but she was able to participate as an ambassador by appearing in *Who* magazine and showing her support through her Twitter account.



#### DAMIEN BODIE

Winners & Losers star Damien Bodie provided Red Nose Day with one of its biggest print media hits by wearing a red nose for a photoshoot in *TV Week*.



DEBORAH THOMAS, DIRECTOR MEDIA, PUBLIC AFFAIRS AND BRAND DEVELOPMENT AT BAUER MEDIA, HAS ASSISTED IN BUILDING THE PROFILE OF SIDS AND KIDS TO CORPORATE BUSINESSES, SUPPORTERS AND THE AUSTRALIAN COMMUNITY.

# SIDS and Kids Partners and Supporters

#### CUA

In February 2014, SIDS and Kids formed a very important corporate partnership with CUA, Australia's largest customerowned financial institution.

CUA will provide financial support for the vital research SIDS and Kids undertakes into finding the cause for and minimising the risk of Sudden Unexpected Death in Infancy and Stillbirth and together we will raise even greater awareness of the invaluable services and activities provided by SIDS and Kids.

CUA will also be supporting Red Nose Day in a number of ways, including:

- Distributing and selling Red Nose Day merchandise throughout CUA branches and encouraging donations
- Creating awareness of Red Nose Day through social media
- Supporting the Red Nose Day Colouring in Competition, including accepting entries at CUA branches.

CUA will also offer its staff the opportunity to spend one day each year as a volunteer with SIDS and Kids. It is a privilege for SIDS and Kids to work alongside CUA and we look forward to doing everything we can to make this partnership a great success. CUa Life rich banking



CUA's Chief Executive Officer, Chris Whitehead, signing the partnership agreement with Leanne Raven, Chief Executive of SIDS and Kids.



CUA's Executive Management Team, L to R: Sue Coulter, Scott North, Jason Murray, Tony Taylor, Chris Whitehead, David Gee, John George, Darrin Northey and Dawn Tsoubos.

#### PLUM

Plum has been a proud supporter of SIDS and Kids National Safe Sleeping education campaign since 2011. Plum works closely with SIDS and Kids to assist us in delivering our Safe Sleeping education messages to the community. Plum also supports the printing of our Safe Sleeping brochure suite including our Safe Sleeping, Tummy Time and Safe Wrapping brochures along with posters and other support materials for our state and territory offices. This is vital support for our organisation and the Australian community when it comes to reducing the risk of SIDS and fatal sleeping accidents.



#### **AUSSIE WIPES**



Aussie Wipes and SIDS and Kids launched Red Nose Baby Wipes in January 2013 with SIDS and Kids benefiting from the sale of every pack of Wipes sold nationally.

The Red Nose Baby Wipes range includes scented,

unscented, travel, flushable and medico medical grade wipes for the home. Our scented and unscented bulk packs of baby wipes and our travel wipes are environmentally sustainable and are the only baby wipe available in Australia with FSC® certification (FSC® licence code: FSC-C 113129). To find out more about Forrest Stewardship Council Certification visit http://ic.fsc.org. Aussie Wipes and SIDS and Kids have ensured our baby wipes have been developed to the highest standard and are dermatologically tested and approved, pH balanced and hypoallergenic, so they are soft and gentle on baby's skin.

Aussie Wipes are 100% Australian owned and operated with world class manufacturing and warehouse facilities in Victoria and corporate headquarters in North Sydney.

Aussie Wipes supports Australian manufacturing through the sourcing of supplies locally and employees over 60 people in both their manufacturing plant and head office.

For more information on Red Nose Baby Wipes visit www.sidsandkidsshop.org.

#### **RED NOSE KIDS CUTS**

Owners Tony and Kelly Stoker opened the first

salon in Dee Why NSW in

Red Nose Kids Cuts is a new children's hairdressers helping to save babies' lives by donating a percentage of its sales to SIDS and Kids.



October 2013. After friends and family experienced the death of a child, Kelly and Tony became very fond of the work SIDS and Kids does in the community to "save babies' lives" and the bereavement programs they offer families who have experienced such tragedy. Kelly and Tony have three children of their own and felt it important to help SIDS and Kids with their mission. Tony says: "Life is so precious and to be involved with such a worthy charity sits deep in our hearts. We love SIDS and Kids and love being involved in such a

#### ZYCIA

worthy charity."

Zycia have been in partnership with SIDS and Kids since 2011 with SIDS and Kids benefiting from the sale of every bottle of Zycia Natal Nutrients, a multivitamin and mineral supplement for conception, pregnancy and breastfeeding.

Tasha Jennings launched Zycia Natal Nutrients in October 2011 with the product developed according to current research into the nutritional needs of mother and baby.

We thank Zycia for their support of SIDS and Kids.



#### **MY BUB**

Dunlop Foams and SIDS and Kids launched the My Bub Nursery range in 2011. My Bub is made here in Australia and provides support for both mother and baby with an extensive range of products



that include back support cushions, angled nursing and pregnancy support pillows and more.

My Bub is available at Clark Rubber and Amart stores nationally as well as the SIDS and Kids Shop Online at www.sidsandkidsshop.org.



#### **PROTECT-A-BED**

Protect-a-Bed and SIDS and Kids have forged a partnership to develop a range of support materials



Every Mattress Needs Protection"

to provide mothers with information on how to transition their toddler from a cot to bed. The Cot to Bed Safety brochure and free app for iPhone was launched in 2013 and they have been translated into four languages. The Protect-a-Bed range of Cot Mattress Protectors are also available through the SIDS and Kids Shop Online. We thank Protect-a-Bed for their support of SIDS and Kids.





#### **SHERIDAN**

In early 2014 Sheridan became the first Australian bed linen partner of SIDS and Kids when the two organisations formed a partnership around Sheridan's new Baby Collection. Sheridan baby products are displayed in stores with the SIDS and Kids Friendly logo, and safe sleeping and safe wrapping practices are promoted on the Sheridan website. The Sheridan Baby Collection is available from selected Sheridan boutiques, David Jones stores and online.

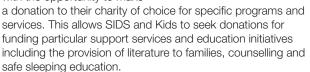
### SHERIDAN



#### **ONLINE FUNDRAISING**

#### KARMA CURRENCY

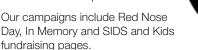
Karma Currency is a notfor-profit foundation that provides the community, businesses and corporates with the opportunity to make



The site has provided vital funding for these areas and we are pleased to be a member of Karma Currency. To find out more about SIDS and Kids and Karma Currency visit www.karmacurrency.com.au/charity/SIDS-and-Kids.

#### EVERYDAY HERO

Everyday Hero is an online site that supports not-for-profit organisations' fundraising through a range of events and activities. SIDS and Kids has been a member of Everyday Hero since its inception.



For the past three years Red Nose Me has been supported by Everyday Hero. Red Nose Me is a site where Red Nose Day supporters can upload their image and "red nose" themselves.



THE COT TO BED SAFETY BROCHURE AND FREE APP FOR IPHONE WAS LAUNCHED IN 2013 AND THEY HAVE BEEN TRANSLATED INTO FOUR LANGUAGES.

# Trust & Foundations

During the year SIDS and Kids gained support from a number of Trusts and Foundations who supported vital projects in the areas of Safe Sleeping and Bereavement.



# SIDS and Kids Shop Online

The SIDS and Kids Shop Online, www.sidsandkidsshop.org, offers an extensive range of products for babies, toddlers and children along with gifts for the whole family. It has become an important source of funds for SIDS and Kids, with a minimum of 30% of sales donated to support our education and support services.

In July 2013, following an extended period of redevelopment, SIDS and Kids launched a new retail platform for our online shoppers. Our new website has made it much easier for customers to access our site with a much improved shopping experience. There are many new features on the site and the addition of PayPal has been well received by our supporters.

The reach of the Shop Online continues to grow along with our return customers clearly demonstrating an increasing loyalty to the shop. Coupled with this is continued growth in the number of orders received each month.

During the period the SIDS and Kids Shop Online has secured a Google Grant for a monthly advertising spend which has also increased the shop's online presence and extended our reach to new customers and supporters.

SIDS and Kids Shop Online welcomed some new partners and products to the site including Bonds, Ripe Maternity, OiOi, and The Wiggles. We will be increasing our range of products over the coming 12 months as well as working with existing partners to expand current ranges.

Congratulations to our Chief Executive Leanne Raven who received the Business Innovation Award at the 2013 Telstra Victorian Business Women's Awards partly in recognition of her online store innovation.

Thank you to all of our shop partners for their support throughout the year.





# 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 continue to improve the telephone-based peer support and grief counselling available to women, their partners and families experiencing the death of a baby during pregnancy and the year following the birth.

#### THE FUNDING 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
- Education and information for health professionals, emergency responders and community groups to ensure best practice when supporting families after the death of their baby
- Bereavement booklets developed in collaboration with bereaved parents and bereavement information and resources
- Health promotion activities to provide evidence-based information, resources and education to ensure babies, infants and young children are slept in a safe sleeping environment to reduce the risk of SIDS and fatal sleeping accidents.

This funding also supports SIDS and Kids to grow strong linkages with the National Pregnancy, Birth and Baby Helpline and to build network capacities with other analogous peer support organisations. This ensures the streamlining of referral processes and consistent care, support and information can be given to bereaved parents and their families.

SIDS and Kids acknowledges that the death of a baby or child is incomparable and is known as the 'ultimate tragedy' for families. SIDS and Kids relies on ongoing financial support to provide national bereavement services to families who have experienced the sudden and unexpected death of a baby or child during pregnancy, birth, infancy and childhood.

Thank you to the Department of Health for their support to assist our mission and vision.









Wiggles on red alert in battle against SIDS



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### Motherhood after SIDS



Melbourne mum AVRYL ZANGALIS lost her son, Zachary, to SIDS in 1999. With SIDS and Kids fundraiser Red Nose Day being held for the 26th year on Friday, she reflects on how far she's come

Y twin boys, Zachary and Marcus, were born on February 12, 1999, weighing seven pounds, six ounces-tion of the seven pound of the seven the seven were born. Marcus were an usabed to diagnosed with transposition of the great arteries, a rare and life-threatening condition where the aorta and paimonary artery are reversed in the heart. A week later, be underwent nice-hour open-heart surgery, followed by months of recovery in and out of houghtal, with his dad, Steven, and I by his side. When the boys users fire weeks old, Marcus came houghtal visits dramatically decreased. We fell like everything weap seried and we finally had our holy boys together under the out ond. One night when they were nearly seven months fold I checked on them, going over to Zach first. He nocked like doil in the bed. Looking back now, it was like than in dramm. I very calmby and slowly went to Steven at the other end of the house and asid. "There's something wrong with Zachary."



SAFE SLEEPING TO REDUCE SIDS RISK

- . Sleep baby on the back from birth, not on the tummy or side.
- · Sleep baby with head and face uncovered.
- . Keep baby smoke-free before birth and after.
- Provide a safe sleeping environment night and day.
- Sleep baby in their own sleeping place in the same room as an adult care-giver for the first six to 12 months.
- · Breastfeed baby. Source: SIDS and Kids

### ON TELEVISION, RED NOSE DAY FEATURED ON POSTCARDS, THE FOOTY SHOW, TODAY SHOW, THE PROJECT AND WEATHER CROSSES.

# Media

#### **RED NOSE DAY 2013**

SIDS and Kids thanks Spark Communications and the print, radio and television media for their continued support. The families who publicly tell their stories are to be applauded for their bravery.

At the beginning of the campaign a media release was distributed to long lead media for inclusion in 'what's on' or regular news sections. This included information on this year's 'Wild & Silly' theme and how people could get involved to support the day. Pic-ops using the new theme appeared in newspapers including the *Herald Sun*, *Northern Territory News*, *Hobart Mercury* and *Adelaide Advertiser*.

For radio, SIDS and Kids Australia CEO Leanne Raven was interviewed for a series of pre-recorded grabs distributed nationally to radio stations ahead of Red Nose Day. Leanne did further interviews that ran on Gold FM, Vision Australia, 2HQ, 2UE and ABC Breakfast Tasmania.

On television, Red Nose Day featured on *Postcards, The Footy Show, Today Show, The Project* and weather crosses.

SIDS and Kids' partnership with Carnival Cruise Lines achieved national media coverage for Red Nose Day when the cruise ship Carnival Spirit entered Sydney Harbour on Red Nose Day sporting a seven metre wide illuminated red nose.

Long term supporters of SIDS and Kids, The Wiggles, showed their support with their new line up. They were interviewed by Gold FM and appeared with red noses on Channel 7 and in the *Herald Sun*. New ambassadors for 2013 were Fifi Box, Lauren Phillips and Damien Bodie.

The PR campaign also focused on Safe Sleeping, with a media release relaying SIDS and Kids' Safe Sleeping guidelines. A revised media release included updated guidelines for safe mattresses. Coverage was achieved on *Nine News, Today Show* and *Mother & Baby*.

Personal stories also highlighted the experiences of families whose child had died suddenly and unexpectedly, and showed the important work done by SIDS and Kids in the community.

The Red Nose Day media campaign achieved an estimated \$2,837,032 in editorial value (excluding radio release value), with 1,056 media hits, 929 radio hits (radio release), eight radio interviews, 23 TV hits, 34 print hits and 62 online hits.

Advertising for the campaign was to the value of \$770,370, including: TV \$104,955, press \$320,325, radio \$289,416, and online \$55,674.

#### SIDS, SAFE SLEEPING AND RESEARCH

Stories containing SIDS and Kids' Safe Sleeping advice were published on the Coles Baby & Toddler Club website in May 2013, in *Practical Parenting* magazine June and September editions, Medibank *be.* magazine website, and *Mother & Baby* September edition.

In May 2013, media reported on a British Medical Journal study that found babies that slept in their parents' bed were five times more likely to die from SIDS.

In December 2013, media including *The Age* newspaper reported on a Victorian Coroner's call for safety standards for single beds following an inquest into the death of a two-yearold girl.

There was significant media attention given to an article in the December 2013 issue of Pediatrics in which SIDS researchers reported that many infants dying suddenly and unexpectedly, in all kinds of sleep environments, have underlying brainstem abnormalities and are not all normal prior to death. Australian SIDS researcher and SIDS and Kids National Scientific Advisory Group member Dr Jhodie Duncan, now at the Florey Institute of Neuroscience and Mental Health, Melbourne, participated in this work during research years at Boston Children's Hospital and continues to collaborate with the team on an international initiative exploring the causes of sudden death in infants and children. The Florey produced a media release quoting Dr Duncan. The story was featured on The Project and included an interview with SIDS and Kids' Jill Green, as well as the story of Ashley and Duncan Griffiths, a couple whose son died from SIDS.

### Social Media and Websites

Throughout the year the SIDS and Kids Facebook and Twitter accounts provided useful and interesting information for expectant, new and bereaved parents, including:

- Infant safe sleeping advice
- Links to the new Cot to Bed Safety brochure and free mobile app
- SIDS and Kids Online Shop products and special offers
- The new Red Nose Kids Cuts salon in Dee Why, NSW

SIDS and Kids Facebook lifetime likes increased from 7,781 to 11,160 for the year. Twitter followers increased from 525 to 830 and SIDS and Kids tweeted 142 times.

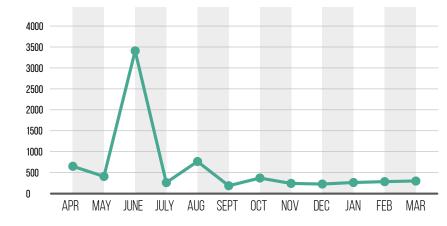
Red Nose Day social media provided information on Red Nose Day products, Red Nose Baby Wipes, media, the Red Nose Me competition, Online Shop products and more.

Facebook likes grew from 18,904 to 24,478. Red Nose Day twitter followers increased from 968 to 1292 for the year, with 157 tweets.

For the year, the SIDS and Kids website was visited over 300,000 times. The Red Nose Day website was visited over 67,000 times, including almost 29,000 visits in June.

The redesigned SIDS and Kids Online Shop website was launched in July 2013, while the new partnership with Red Nose Kids Cuts saw the launch of its website www.rednosekidscuts.com.au in December 2013.

SIDS AND KIDS FACEBOOK LIFETIME LIKES INCREASED FROM 7,781 TO 11,160 For the year. Twitter Followers increased FROM 525 TO 830.







The Red Nose Kids Cuts website was launched in December 2013



# Committee Reports

SIDS and Kids has two committees that support the organisation: our Red Nose Day Committee and our Audit and Risk Committee.

SIDS and Kids National Board would like to thank both committees for their time and dedication to their roles within their respective disciplines.

#### **RED NOSE DAY COMMITTEE**

The Red Nose Day Committee supports the planning of the national Red Nose Day campaign. The areas of expertise include marketing, public relations, product development and project management.

Over the past 12 months we have said goodbye to Cassandra Wetherspoon, Dee Taseff, and Debbie Chen, and have welcomed Michelle Bateman, SIDS and Kids WA, and Kate Middleton, SIDS and Kids Hunter, onto the Committee.

Current Committee Members include: Chair, Karen Passey, CEO, SIDS and Kids NSW and Victoria; Samantha Mead, CEO, SIDS and Kids South Australia; Janet Grima, General Manager, Fundraising and Marketing, SIDS and Kids NSW and Victoria; Yvonne Amos, National Marketing and Communications Manager; and Carly Bourke, Red Nose Day Manager.

The Committee is involved in developing the overall concept and theme for Red Nose Day.

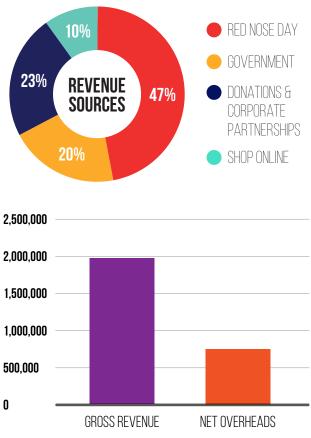
## AUDIT AND RISK COMMITTEE

The Audit and Risk Committee met four times in the last 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, Ken Ramsay, Mark Sheehy and Andrew Kennedy.

SIDS and Kids Australia finished the year in a good position with net operating surplus of \$121,593.

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



For detailed financial information please refer to our audited financial report for Year Ended 31 March 2014.



# An Overview of Child Death in Australia 13/14

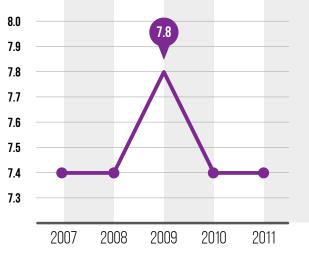
This overview of child death in Australia covers the categories of perinatal death, Sudden and Unexpected Death in Infancy (SUDI), Sudden Unexplained Death in Childhood (SUDC), suicide and bereavement. It includes data released in 2013/2014, with reference to earlier data for comparative purposes.

#### AROUND THE TIME OF BIRTH (PERINATAL) (LI ET AL 2013)

#### INCIDENCE

Australia's Mothers and Babies 2011 was released in December 2013, reporting that there were 2,220 stillbirths in 2011, resulting in a rate of 7.4 per 1,000 births, and 772 neonatal deaths, giving a rate of 2.6/1,000 live births. There were 2,992 perinatal deaths reported for 2011, giving a rate of 9.9 perinatal deaths per 1,000 births (9.3 in 2010). Of these, 74.2% were stillbirths.

With the exception of a 5.4% increase in 2009, the rate of stillbirths has remained stable 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) (26.3%)
- unexplained (21.6%),

Focussing on gestational age:

• almost half (42.3%) the fetal deaths of babies from 37 weeks gestation were unexplained.

#### PERINATAL DEATH RESEARCH OUTSIDE of Australia

Research into the possible causes of stillbirth continued with global efforts identifying possibly modifiable factors such as maternal smoking, obesity and age (Varner et al 2013, Waldenström et al 2013, Warshak et al 2013) or meteorological factors such as air pollution (Faiz et al 2013). A number of papers examined the effect of gestational age on the cause of stillbirth, such as the high proportion of infection in post-term stillbirths (Stormdal Bring et al 2013).

#### PERINATAL DEATH RESEARCH IN AUSTRALIA

#### MATERNAL FACTORS

A number of Australian research teams looked at maternal factors in adverse pregnancy outcomes. Among findings published this year were studies of the perinatal outcomes of obese women. The authors of a study of a small sample of moderate to super-extremely obese women expressed concern regarding the number of second trimester stillbirths experienced in this small sample of women; almost 2.5 times that of the Australian population (1.96% vs. 0.79%, respectively) and identified that current antenatal care provision for these women may have key deficiencies (Slavin et al 2013).

#### **INFANT/PERINATAL FACTORS**

Researchers identified high risk groups including monochorionic twin pregnancies (identical twins that share the same placenta) (Danon et al 2013). A case-control study conducted in NSW examined the possibility that low 25(OH) D serum concentrations in the first trimester of pregnancy predicting adverse pregnancy outcomes (including stillbirth) better than routinely assessed clinical and maternal risk-factor information (Schneuer et al 2013).

#### **RISK PREDICTION**

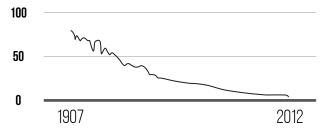
Hypoxia in utero can lead to stillbirth and while current prenatal tests can identify fetuses that are hypoxic, none can determine the severity of hypoxia/acidemia. Whitehead et al (2013) reported that measuring hypoxia-induced mRNA in maternal blood may form the basis of a test to clinically determine the degree of fetal hypoxia/acidemia while in utero.

#### EFFORTS TO REDUCE THE INCIDENCE OF STILLBIRTH

Steven Tong and Clare Whitehead of the Mercy Hospital for Women in Melbourne (see Risk prediction above) hope that the maternal blood test that may be able to determine oxygen levels in the fetus while it is still in the womb can identify fetuses' critically starved of oxygen and at peril of being stillborn. Such fetuses could be delivered – moved out of harm's way – before they are stillborn. This team are now running The FOX (Fetal Oxygenation) study, involving seven teaching hospitals, to validate a specific test for the clinic (NHMRC 2013).

"One of the most dangerous periods in one's life is their time in mum's womb. To start with, 1 in 135 will not make it out alive. Therefore, I am deeply inspired by the fact we are working to make the passage to the beginning of life safer. The implication of any discovery that diminishes the toll wrought by serious pregnancy complications is that babies saved could lead full and productive lives."

> Steven Tong on what inspires him about his research field.



Infant mortality (AIHW 2013a & b). Infant deaths per 1,000 live births in Australia.

There were 3.3 infant deaths per 1,000 live births in Australia in 2012. This represents a decline of more than 95% since 1907. The decline in infant deaths is linked to:

- improved access to and quality of neonatal health care
- increased community awareness of risk factors for infant and child deaths
- improved sanitation and hygiene
- reductions in vaccine-preventable diseases through universal immunisation programs.

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

#### INCIDENCE (ABS 2014):

In 2012, 115 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 115 babies who died suddenly and unexpectedly, the cause of 50 deaths were identified as SIDS. This was a rate of 0.2/1000.

For the past 10 years, more males have died from SIDS than females. In 2012, SIDS accounted for 29 male and 21 female deaths. The majority of these deaths occurred in the period between 28 days and 1 year of age, with SIDS identified as the underlying cause of death for 47 (94.0% of SIDS deaths) infant deaths in this age group.

# WHAT IS BEING DONE TO REDUCE THE INCIDENCE OF SUDI?

#### RESEARCH

#### Research from outside of Australia included:

UK researchers examined the frequency of bed sharing in babies who died of SIDS and living control infants. Five large SIDS casecontrol datasets were combined (1472 SIDS cases, and 4679 controls). The results showed that bed sharing for sleep when the parents do not smoke or take alcohol or drugs increases the risk of SIDS. Risks associated with bed sharing are greatly increased when combined with parental smoking, maternal alcohol consumption and/or drug use. A substantial reduction of SIDS rates could be achieved if parents avoided bed sharing (Carpenter et al 2013).

US researchers looked at the relationship between the presence of potentially asphyxia conditions in the sleep environment and brainstem abnormalities in infants dying suddenly and unexpectedly. The researchers found that brainstem abnormalities were associated with both asphyxia-generating and non-asphyxia generating conditions and concluded that heeding safe sleep messages is essential for all infants, especially given our current inability to detect underlying vulnerabilities (Randall et al 2013).

A couple of reviews from the US included one review of the aetiology of SUDI that looked at various risk factors including the prone sleeping position, overheating by excessive bundling, viral upper respiratory tract infections, parental smoking at home, and birthing injury resulting in an insult to the inner ear and central chemoreceptor zone, and an immaturity that involves CO2 chemoreceptors that regulate respiratory control. The authors also looked at neurological risk factors for SIDS (Rubens & Sarnatt 2013). Another US review looked at SIDS as a disorder of autonomic regulation. Although SIDS is most likely defined by complex multifactorial genetic and environmental interactions, it is also thought to result from central deficits in the control of breathing and autonomic regulation. The article reviewed the current understanding of these autonomic disorders and discussed the influence of this information on clinical practice and future research directions (Rand et al 2013).

Researchers from France evaluated the influence of ambient temperature on autonomic nervous activity during sleep in preterm neonates and found that an elevated ambient temperature was associated with a higher basal heart rate and lower short- and long-term variability in all sleep stages, together with higher sympathetic activity and lower parasympathetic activity. Their results showed that modification of the ambient temperature led to significant changes in autonomic nervous system control in sleeping preterm neonates. The latter changes are very similar to those observed in infants at risk of SIDS, thus their findings may provide greater insight into the thermallyinduced disease mechanisms related to SIDS and may help improve prevention strategies (Stéphan-Blanchard et al 2013). German researchers studied channelopathic heart arrhythmias and dysfunctional autonomic regulation of respiration and arousal based on defects in the brainstem as they are assumed to be involved in the pathogenesis of SIDS. The results of their casecontrol study showed a significant upregulation of heart specific miR-1 and brainspecific let-7b in SIDS compared to control cases. Their pilot study is first to analyse differential miRNA expression in SIDS and their findings suggest that organ specific miRNA dysregulation may be associated with SIDS pathogenesis and establishes the feasibility of miRNA analysis in different kinds of preserved and archived SIDS tissues (Courts et al 2013).

#### SUDI research in Australia:

**Genetic factors:** Australian researchers reviewed SIDS deaths and performed genetic analysis in key genes that may contribute to sudden death. In a subgroup of 226 SIDS cases (n = 46), genetic analysis identified 2 likely pathogenic variants. The researchers concluded that mutations in cardiac ion channel genes including rare nonsynonymous HCN gene variants may play a role in the pathogenesis of some SIDS cases.(Evans et al 2013).

**Maternal factors:** Researchers from Curtin University in WA investigated the association between maternal alcoholuse disorder and SUDI in their evaluation of nearly 78,000 live births from 1983 to 2005. They found nearly 22,000 of the mothers had an alcohol diagnosis such as acute alcohol intoxication or dependence and found that the highest risk of SIDS occurred when a maternal alcohol diagnosis was recorded during or within 1 year postpregnancy. An alcohol diagnosis recorded during pregnancy more than doubled the risk of infant deaths (excluding SIDS) and maternal alcohol-use disorder is attributable for at least 16.41% of SIDS and 3.40% of infant deaths not classified as SIDS. The team concluded maternal alcohol-use disorder is a significant risk factor for SIDS and infant mortality excluding SIDS (O'Leary CM et al 2013).

## **HIGH RISK INFANTS**

Researchers from Monash Medical Centre (Victoria) looked at autonomic dysfunction, either sympathetic or parasympathetic, as an explanation for the increased incidence of SIDS among preterm infants. The team found that with maturation, in preterm infants, parasympathetic modulation of the heart increases while sympathetic modulation of blood pressure decreases. Compared to term infants, preterm infants exhibit lesser parasympathetic modulation of the heart along with greater respiratorymediated changes and lower sympathetic modulation of blood pressure. Impaired autonomic control in preterm infants may increase their risk of cardiovascular dysfunction later in life (Yiallourou et al 2013).





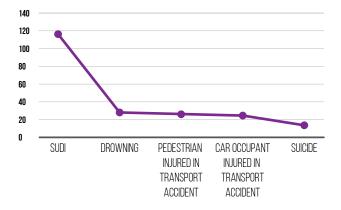
#### SUDDEN UNEXPLAINED DEATH IN CHILDHOOD

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 2009 the incidence of SUDC in the US was 1.4 deaths per 100,000<sup>1</sup>. SIDS is 45 times more common (US data)<sup>2</sup>.

#### RESEARCH

Researchers interrogated the database of the National Sudden Infant Death Register (NSIDR) in Ireland to compare cases of SIDS and SUDC over a fifteen-year period (1995-2009). Based on their findings the researchers recommended referral of all SUDC cases to specialist centres for optimal autopsy examination and investigation, and that cases of sudden unexpected death in children over 1 year of age are investigated according to the same guidelines as are used for unexpected death under one year of age (Treacy et al 2013).

Researchers from the UK looked at the prevalence of vitamin D deficiency (VDD) in cases of sudden death in infancy and childhood. Among 25 cases of unexplained death in the cohort, 76% had inadequate vitamin D levels. A significant proportion of infants and children who died suddenly and unexpectedly had inadequate levels of vitamin D. The researchers called for further multicenter studies to confirm their findings and explore possible associations between VDD and other known risk factors for sudden unexplained death in infancy and childhood (Cohen et al 2013).



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

1. Retrieved from http://www.sudc.org/ MedicalForensicInfo/SUDCStatistics.aspx

2. Retrieved from http://www.sudc.org/ Advocacy/MediaEducation/FactSheet.aspx

## **DROWNING (RLSSA 2013)**

There were 31 children between the ages of 0 and 4 years who drowned in Australia between 1 July 2012 and 30 June 2013 (6% less than the ten year average however a disturbing reversal of the consistent downward trend observed in the previous 4 years). In particular, it is a 48% increase on 2011/12 figures for this age group.

Males accounted for 65% of drowning deaths in the 0-4 years age group in 2012/13.

Swimming Pools continue to account for the largest proportion of drowning deaths in this age group, representing 61% of all drowning deaths in children aged 0-4 years. Swimming Pools are also the only location which has increased this year when compared to the 10 year average.

Falls into water continue to account for the majority of drowning deaths in children aged 0-4 years, representing the activity being conducted immediately prior to drowning in 81% of cases. This was followed by Bathing which accounted for 13% of all drowning deaths in children under five.

#### **DROWNING PREVENTION**

 Interim figures released by Royal Life Saving Society - Australia 4/01/2014 showed that 47 people have drowned since the start of December in Australian waterways. With every drowning preventable, Royal Life Saving urges all Australians to be safe when enjoying the water ... Royal Life Saving's CEO Justin Scarr said "We traditionally see a spike in drowning's across the warmer months and the holiday period when more people are recreating around water.. Royal Life Saving is aware of 11 non-fatal drowning's of children under the age of 10 in swimming pools. Royal Life Saving urges all Australians to ensure young children are always actively supervised and are within arms' reach at all times. Ensure you have a correctly installed and regularly maintained pool fence with a self-closing and self-latching gate...Royal Life Saving is also aware of 11 non-fatal drowning's in children under the age of 10 in swimming pools across the same period to date. Almost two-thirds of these were children under five in home swimming pools.

"Children drown quickly and silently, it is important that children are actively supervised within arms' reach at all times. Ensure the home swimming pool is fenced with a correctly installed and regularly maintained pool fence with a self-closing and self-latching gate. Every year in Australia, children drown in unfenced pools or pools where gates have been propped open."

Supervision of young children is also key at BBQs and social gatherings. "Young children have drowned when their parents mistakenly thought someone else was supervising. Parents and carers of young children should always KEEP WATCH, ensure there is a designated adult supervisor watching at all times and to ensure the person supervising has not been drinking alcohol".

# THERE WERE 14 SUICIDE DEATHS OF Children under the Age of 15 in 2012 and 57 during 2008-2012

## **CHILD SUICIDE**

There were 14 suicide deaths of children under the age of 15 in 2012 and 57 during 2008-2012 (ABS 2014).

# 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. While not separately tabulated, it should be noted that of the 57 deaths by suicide of children and young people under the age of 15 from 2008 to 2012, 15 deaths (26.3%) were of Aboriginal and Torres Strait Islander Australians (ABS 2014).
- Adolescents within the welfare system, indigenous, rural and refugee youth, along with same sex attracted young people often need very careful monitoring and support. Young men continue to take their lives more frequently than young women. (McNamara 2013).
- Results from an online survey conducted at the University of Newcastle in NSW showed differences between suicide-risk in heterosexuals and non-heterosexuals (lesbian, gay, bisexual, and questioning: LGBQ). LGBQ participants reported significantly greater suicide-risk than heterosexuals. LGBQ participants were more likely to report suicide attempts, disclose suicidal intentions, and predict future suicide attempts. The LGBQ group also indicated greater likelihood of going online to develop new personal relationships. (Harris 2013).
- Research from the University of Western Sydney noted that high suicide rates were evident in Australian young adults during an epidemic period in the 1990s, a period that coincided with changes in employment patterns in Australia. Under-employment rates (those employed part-time seeking additional hours of work) and unemployment rates (those currently seeking employment) for the latter part of this time series (1978-2010) were also examined and compared with periodand cohort-specific trends in suicide. Increases in male cohort-specific suicide rates were significantly correlated with increases in cohort-specific under-employment and unemployment rates. (Page et al 2013).

#### CHILD SUICIDE RISK PREVENTION STRATEGIES

- Prevention programmes in Australia aim to develop resilience in young people, families and communities that can serve as protection against self harm and suicide. The improvement of mental health literacy, a fostering of adolescent self-efficacy and better access to early intervention strategies are currently privileged in national and state policies related to young people in Australia. More work is needed, however, to achieve a well integrated mental health framework capable of effectively addressing adolescent suicide prevention into the twenty-first century (McNamara 2013).
- Indigenous peoples of Canada, United States and New Zealand experience disproportionately high rates of suicide. As such, the methodological quality of evaluations of suicide prevention interventions targeting these Indigenous populations should be rigorously examined, in order to determine the extent to which they are effective for reducing rates of Indigenous suicide and suicidal behaviours. A systematic review that aimed to: 1) identify published evaluations of suicide prevention interventions targeting Indigenous peoples in Australia, Canada, United States and New Zealand; 2) critique their methodological quality; and 3) describe their main characteristics. Among the nine evaluations of suicide prevention interventions identified were three targeting Aboriginal Australians. The main intervention strategies employed included: Community Prevention, Gatekeeper Training, and Education. Only three of the nine evaluations measured changes in rates of suicide or suicidal behaviour, all of which reported significant improvements. The team concluded that there is an urgent need for an increase in the number of evaluations of preventive interventions targeting reductions in Indigenous suicide using methodologically rigorous study designs across geographically and culturally diverse Indigenous populations. Combining and tailoring best evidence and culturally-specific individual strategies into one coherent suicide prevention program for delivery to whole Indigenous communities and/or population groups at high risk of suicide offers considerable promise (Clifford et al 2013).
- The LGBQ online survey participants indicated greater likelihood of going online to develop new personal relationships. Multiple regression modeling was conducted to guide outreach and support efforts, revealing unique factors predicting help-seeking denial of suicide-risk LGBQ. Implications include the importance of online support and considering sexual minorities not just as a potential high-risk group, but also as a population with unique suicide risks and behaviours (Harris 2013).

#### **BEREAVEMENT SUPPORT**

#### RESEARCH

#### Australian published research included:

Support of bereaved families:

**Perinatal death:** A study from the University of Minnesota, Minneaplis, and the University of South Australia presented secondary analysis of data from parents who, 50 to 70 years ago, birthed stillborn babies or babies with lethal anomalies and from adult children born after these losses. The stories reflect a time in history when parents were "protected" from seeing or holding their babies and mothers were unable to attend the funeral. There was no understanding by society or caregivers for parents' need to process the loss or resources to build memories. They provide a strong argument for health care providers to offer such resources to parents today and offer grief support (O'Leary & Warland 2013).

Suicide: Researchers from the Australian Institute for Suicide Research and Prevention at Griffith University. Queensland, noted that suicide is a unique type of death, a deliberate act of taking one's own life with the intention to die. The authors questioned if this means that suicide causes different reactions in the people who are left behind or if suicide grief is different. Although this question is popular in the literature, there is still a lack of empirical research on the topic. The authors described the empirical evidence on suicide grief in existing studies using other modes of deaths as control or comparison groups, considering factors such as the influence of the quality and characteristics of the relationship between the survivor and the deceased survivors' reactions to suicide, as well as the vulnerability or resilience of the survivor. For example, a study by Mitchell, Sakraida, Kim, Bullian, and Chiappetta (2009) showed that people in a close relationship (spouses, parents, and children) had significantly higher levels of depression and anxiety, and lower levels of quality of life, following a suicide than more distant people such as in-laws and friends. Furthermore, there are differences between close relatives. Reed (1998) showed that adult children had significantly lower levels of grief than parents, spouses, and siblings. To facilitate a comparison between studies, this chapter has been divided into subsections according to the kinship between the grieving and deceased persons-widows, parents, and children-as well as studies with mixed samples (Kõlves & Leo 2014).

#### SOCIAL SUPPORT

 Also from the Australian Institute for Suicide Research and Prevention, as co author with a researcher from Center for Crisis Psychology in Bergen, Norway, was a study of the effect of social support of people who live through the experience of extreme psychosocial stress due to the loss of a child, spouse, parent or sibling. With good social support, they may have better physical and mental health than those who do not have such support. They live longer, are more protected from disease, and if they get sick, they can recover faster than survivors who are not backed up by a good network of relatives and friends (Dyregrov & Dyregrov, 2008). As positive effects of support are highlighted, the literature also discusses the negative effects attributable to the lack of it. For example, inadequate or poor support can lead the person who needs help to a worsening in their management of the problem, alienating their relationships with their helpers, or triggering stress-related illnesses (Greene & Burleson, 2003). It is obvious that some people are more capable than others in arranging that their support have a positive impact; on the other hand, there are individuals who are unable to obtain significant results, despite their best intentions (Dyregrov et al 2014).

- A study from La Trobe University, Victoria, identified and explored the informal social supports that bereaved parents found helpful following the death of their primary school-aged child. Among the results of the interviews of the ten participants were the existence of novel informal supports that enrich contemporary literature. Nine common characteristics of helpful support emerged from the analysis; the specifics of each depended on congruence with parents' unique framework of meaning. Parents also identified five ways to strengthen informal social support. Implications for health promotion research and practice in parental bereavement are discussed (Gear 2014).
- Researchers from the University of Melbourne noted that exposure to natural and human-made disasters is associated with long-term health consequences, including for mental health. Parents who have lost children, particularly their only children, in any circumstances are also at increased risk of developing mental health problems. The aim of their study was to review the available evidence about the psychological and social consequences for parents who had faced these circumstances simultaneously through losing children in a disaster. The results showed that bereaved parents had more mental health problems than bereaved spouses and non-bereaved parents, and mothers appeared to be more vulnerable to mental health problems than fathers. Potential protective factors for bereaved parents' mental health included having psychological interventions, having adequate social support, seeing their children's bodies and having a subsequent baby. Although the literature was modest and methodologically diverse, there was a consistent finding that parents who have lost children in disasters were at high risk of suffering mental health problems, especially bereaved mothers. As there was little evidence, further studies are needed to understand the best advice and interventions to offer bereaved parents and provide enhanced mental health care of such bereaved populations after disasters (Xu et al 2013).

See page 46-47 for references.

THE RESULTS SHOWED THAT BEREAVED PARENTS HAD MORE MENTAL HEALTH PROBLEMS THAN BEREAVED SPOUSES AND NON-BEREAVED PARENTS, AND MOTHERS APPEARED TO BE MORE VULNERABLE TO MENTAL HEALTH PROBLEMS THAN FATHERS.



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# SIDS AND KIDS AUSTRALIA

ABN 55 050 464 616 1227 Malvern Road Malvern VIC 3144

P 03 8888 1600 F 03 8888 1691 E national@sidsandkids.org

www.sidsandkids.org www.rednoseday.com.au www.sidsandkidsshop.org

## SIDS AND KIDS ACT

The Chifley Health and Wellbeing Hub Unit 10/70 Maclaurin Crescent Chifley ACT 2606 P 02 6287 4255 F 02 6287 4210

# **SIDS AND KIDS HUNTER REGION**

78 Stewart Avenue Hamilton South NSW 2303 P 02 4969 3171 F 02 4696 3170

# SIDS AND KIDS NSW AND VICTORIA

Level 1, Building 125 Cnr Church & Glover Streets Lilyfield NSW 2040

P 02 9818 8400 F 02 9818 4555 1227 Malvern Road Malvern VIC 3144 P 03 8888 1600

**F** 03 8888 1691

# **SIDS AND KIDS NT**

19, Rapid Creek Shopping Centre Trower Road Rapid Creek NT 0810 P 08 8948 5311 F 08 8948 5244

# SIDS AND KIDS QUEENSLAND

68 Creek Road Mt Gravatt QLD 4122 P 07 3849 7122 F 07 3849 7121

# SIDS AND KIDS SA

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# SIDS AND KIDS TASMANIA

36 Strahan Street South Burnie TAS 7320 P 03 6431 9488 F 03 6431 6081

# SIDS AND KIDS WA

33 Sixth Avenue Kensington WA 6151 P 08 9474 3544 F 08 9474 3636