Red Nose would like to thank the Family and Community Development Committee in allowing us to take this opportunity to contribute to the Victorian Parliamentary Inquiry into Perinatal Services.

**Background of Red Nose**

Founded in 1977, Red Nose (formerly SIDS and Kids) is a not-for-profit organisation providing health promotion and education, research, bereavement support and resources to all Australian States and Territories including Victoria. The organisation is dedicated to saving the lives of babies and children during pregnancy, birth, infancy and childhood and to supporting bereaved families. We aim for excellence in accordance with our values in the four key result areas of client services, sustainability, research and governance. Red Nose brings evidence based recommendations to parents, carers and health professionals to help prevent the sudden death of an infant. For those families that children have died suddenly and unexpectedly Red Nose brings hope, support and guidance showing that there is light in the darkness of grief, aiding in reducing mental health conditions potentially caused by unresolved grief.

**Red Nose Vision**

*A future where no child dies suddenly and unexpectedly during pregnancy, infancy or in childhood.*

**Red Nose Mission Statement**

*Saving the lives of children during pregnancy, infancy and childhood and ensuring all people affected by the death of a baby, infant or young child, are supported, cared for and connected to what they need to continue engaging with life.*

Red Nose has contributed to an 80% reduction in Sudden Unexpected Death in Infancy (SUDI) in Australia. This has been attributed to the introduction of the safe sleeping public health campaign introduced in 1991 by Red Nose and implemented in collaboration with researchers and health authorities promoting evidence-based safe sleeping practices to reduce the risks. The Red Nose ‘Saving Little Lives’ public health program is an evidenced based health promotion and education program providing new and expectant mothers, carers and health professionals with recommendations on how to sleep baby safely and reduce the risk of sudden infant death.

Red Nose and our National Scientific Advisory Group (NSAG) a group made up of experts in the fields of research, health care and midwifery are working to find answers for parents by funding and supporting vital research into Sudden Unexplained Death in Infants (including SIDS), Stillbirth and Safe Sleeping Practices.
Red Nose Grief and Loss is a bereavement support service for any person affected by the sudden and unexpected death of a baby or child. Red Nose Grief and Loss assists families who have experienced the sudden and unexpected death of a baby or child, during birth, pregnancy, infancy and childhood, regardless of the cause.

At present Red Nose receives less than 10% government funding and relies heavily on fundraising within the communities to fund our vital research and services. In Victoria, Red Nose currently only receives a small grant from the Victorian Government Department of Education for a supply of printed resources.

With reference to the Family and Community Development Terms of Reference for the Inquiry into Perinatal Services Red Nose recommends the Inquiry take consideration of the below combined response for:

Point 1 – the availability, quality and safety of health services delivering services to women and their babies during the perinatal period.

Point 3 - the adequacy of the number, location, distribution, quality and safety of health services capable of dealing with high risk and premature births in Victoria.

Point 4 – the quality, safety and effectiveness of current methods to reduce the incidence of maternal and infant mortality and premature births.

Point 5 – access to and provision of an appropriately qualified workforce, including midwives, paediatricians, obstetricians, general practitioners, anaesthetists, maternal and child health nurses, mental health practitioners and lactation consultants across Victoria.

Point 6 – disparity in outcomes between rural and regional and metropolitan locations

Tables and italic content are abstracted from the latest Consultative Council on Obstetric and Paediatric Mortality and Morbidity Victoria’s mothers, babies and children 2014 and 2015 Report

In 2015 there were 78,961 births in Victoria. Victoria’s perinatal mortality rate (9.0 per 1000 births) is the lowest in 15 years, and comparable with the most recent overall Australian rate of 9.6 per 1000 births reported for 2014. Victoria’s perinatal mortality rates for Aboriginal and Torres Strait Island babies continued to decline from 23.6 per 1000 births in 2008–10 to 13.6 per 1000 births in 2013–15. However, the gap between Aboriginal and non-Aboriginal populations remains wide (almost one and a half times).

Each year approximately 1 in 4 pregnancies end in miscarriage and between 2012 – 2015 there were 2074 perinatal deaths in Victoria.
Evidence shows that up to 60 people can be affected by the death of a child. Research has shown that the experience of grief and loss following the death of a child is particularly intense and can often lead to more serious mental health conditions such as depression, anxiety, post-traumatic stress and suicide ideation. Making access to bereavement counselling and support services vital for all those effected by the sudden and unexpected death of a child.

Victoria’s infant mortality rate was 3.0 per 1000 live births (2015). The main causes of death in post-neonatal infants (28 to 364 days of age) in 2015 were: – congenital anomaly (40%) – sudden infant death syndrome (18%) – prematurity (18%).

7.2 SUDI/SIDS

While there have been major reductions in sudden infant deaths in the last two decades, many unexpected infant deaths still occur, often in marginalised or disadvantaged families. Despite growing information for parents on the safest sleeping environments, infants continue to die in situations associated with unsafe sleep practices.

Co-sleeping is associated with an increased risk of death, and is not recommended. Although not all sudden and unexpected deaths in infancy (SUDI) can be eliminated, the promotion of safe sleeping for every sleep is the best way to minimise the risk. A key to further reducing preventable deaths in this category is to ensure parents and carers understand the safest sleeping environments and practices for infants, and have a safe sleep plan for every sleep.

The infants most at risk are premature or small for gestational age and those younger than three months of age. The risk is also highest where the co-sleeper is affected by sedating drugs, alcohol or is a smoker, or where the sleep surface is unsafe. Vulnerable children are at higher risk of SUDI.

There were 33 unexplained SUDI deaths in 2014–15. The majority of unexplained SUDI deaths occurred in circumstances where the SIDS and Kids Safe Sleeping message was not fully followed. Co-sleeping was a feature in almost half (48.5%) of the 33 unexplained SUDI deaths.

As referenced within both Red Nose website and Victoria State Heath Better Health Channel:

- A women who smokes while pregnant is at increased risk of experiencing a wide range of problems including ectopic pregnancy, miscarriage and premature labour
- Babies whose mothers smoke during pregnancy are at higher risk of SIDS, having weaker lungs and having a low birth weight. Low birth weight babies are at greater risk of death and are more vulnerable to infection, breathing difficulties and long term health problems in adulthood.
Below tables show the number of mothers that smoked during pregnancy during 2014 – 2015 and the number of preterm and low birth weight babies born during the same period.

Red Nose’s evidence based Safe Sleep Education supports reducing smoking during pregnancy to reduce the risks of preterm births, low birth rates and the risks of SUDI. Red Nose Safe Sleep Education also supports sleeping infants in their own safe sleep space for the first 6-12 months in the same room as the parent/carer which aids in reducing fatal co-sleeping accidents.
On analysis of the data provided, Red Nose would like to present the following recommendations to enhance the perinatal services available and further reduce the statistics outlined above.

Increase Red Nose evidence based Safe Sleep Education across Metro and Regional Victoria to Health Professionals, parents and carers during the perinatal period to aid in the further reduction of infant mortality rates.

Increase education across Metro and Regional Victoria to Health Professionals, parents and carers around risks of smoking during pregnancy and after birth to aid in the decrease in rates of preterm births, low birth rates and SUDI.

Increase education across Metro and Regional Victoria to Health Professionals, parents and carers around the benefits of breastfeeding and the association in reducing the risks of SUDI.

Provide culturally appropriate Safe Sleep education and resources to the Indigenous communities of Victoria to aid in reducing the disparity between Indigenous and non-Indigenous, smoking rates during pregnancy, pre-term births, low birth rates and infant mortality rates.

Increase awareness across Metro and Regional Victoria of Red Nose Grief and Loss Bereavement services available to all those affected by the sudden and unexpected death of a child. Bringing clinical and non-clinical support through the journey of grief and subsequent pregnancies and aid in averting potential mental health conditions and improve the overall health and wellbeing for those affected.

Increase awareness of referral pathways for Red Nose Grief and Loss services for First Responders and Health Professionals across Metro and Regional Victoria.

Increase awareness and locations across Metro and Regional Victoria of Red Nose specialised support groups targeted at those affected by the death of a child from termination for abnormalities, miscarriage, stillbirth, SUDI, subsequent pregnancy after a loss, grandparents and siblings.

Increase training for health professionals and community services across Metro and Regional Victoria in grief and bereavement communication skills.

Increase in distribution of both Red Nose Saving Little Lives and Red Nose Grief and Loss resources across Metro and Regional health and community facilities.
Red Nose Services

Red Nose can offer the following established services to the Victorian communities, but to be able to provide the quantity required to cover the entire state it would be crucial for Red Nose to secure additional funding to increase current staffing levels and produce the required quantities of resources. As previously noted Red Nose currently only receives a minor financial grant from the Victorian Government Department of Education for a supply of printed resources.

Red Nose Safe Sleep Education Services

Safe Sleep Education

Red Nose Educators across Australia deliver evidence based education sessions to health professionals, parents and carers about ways to reduce the risks of SUDI. The education is based on the information that has been developed and reviewed by Red Nose NSAG our content experts in the area of optimal infant care practices and strategies to reduce SUDI. The education is available via face to face sessions or through video link.

Reducing the Risks of SUDI in Aboriginal Communities (RROSIAC) program

The Red Nose RROSIAC program seeks to reduce unacceptably high risk Aboriginal infants dying of SIDS and fatal sleep accidents. The program has been successfully operating throughout WA since 2005. A cultural and clinical delivery of SUDI evidence based information identifying the risks associated with sleep accidents and education on ways to reduce the risks of SIDS.

Safe Sleep eLearning

Red Nose Safe Sleep eLearning courses are currently under review and due for release in 2018. The courses are aimed at Health Professionals, Early Childhood Educators, Community Services, Parents and Carers.

Smart Phone Applications

Safe Sleeping application provides evidence-based education on Safe Sleeping, Tummy Time and Safe Wrapping in five languages including English, Chinese, Vietnamese, Hindi and Arabic. Available for iOS and Android.

Red Nose Safe Sleeping Brochure and information suite

Printed resources are available to order through the Red Nose website in a variety of languages along with downloadable evidence based Information statements on a range of related topics.
Red Nose Grief & Loss Services

24 Hour Bereavement Support Line 1300 308 307

All calls to the Bereavement Support Line during business hours are taken by Service staff. All calls to the Bereavement Support Line after business hours and across the weekend are taken by trained Red Nose Grief and Loss Counsellors or Telephone Support Workers. All Telephone Support Workers are trained Parent Supporters who have undertaken further training for the afterhours bereavement support line.

Intake

The centralised Intake Service for all bereavement calls to Red Nose Grief and Loss was introduced on 1st July 2014 (2016 in NSW, VIC, WA, ACT, Hunter and QLD). This service operates during business hours out of the Sydney office. All intake staff are fully qualified to provide bereavement support, information, resources and referral.

Our Online Professional Referral Form (OPRF) is located on our website and acts as a simple and effective way of ensuring that any bereaved parent requiring support is linked as quickly as possible to our support services.

Red Nose intake support pathway has been designed in order for the caller to access the services that best meet their needs.

Professional Counsellors

Available at Red Nose Grief and Loss offices located in Docklands, Victoria and nationally. Counselling services can be either face to face, by phone, video link or live chat. All counselling staff are fully accredited, appropriately trained and highly professional with many years’ experience and include Registered Psychologists, Social Workers and Counsellors.

Trained Parent Supporters

Peer/Parent Supporters play a vital role in the delivery of our services. After a period of 18 months into a client’s grief journey they have the option to become a Peer / Parent Supporter. Potential Peer/ Parent Supporters then go through a rigorous training program to ensure they are well positioned to support newly bereaved families and friends.

Trained Peer/ Parent Supporters offer a very special and personal service that can only be delivered by those parents who have directly experienced or been impacted themselves by the loss of a baby or child.
Red Nose Peer Support Training enhances and builds upon the existing knowledge and skills (experiential learning) acquired by those who have experienced the devastating impact of the death of a child.

Trained parent supporters are matched with clients who have had a similar experience and supported by our professional counsellors.

**Support Groups**

The counselling staff at Red Nose Grief and Loss facilitates a range of monthly Support Groups in each location. There are also a range of groups that are supported by Red Nose Grief and Loss, which are run by trained Red Nose Grief and Loss parent/peer supporters. Specialised groups are available for those affected by the death of a child from termination for abnormalities, miscarriage, stillbirth, SUDI, subsequent pregnancy after a loss, grandparents and siblings.

Each school holiday period, Children’s Groups are held for bereaved siblings. Ages generally range between 5 years up to 12 years and are run by our professional counsellors.

**Treasured Babies’ Program (TBP)**

TBP provides gifts for families whose baby has died in the perinatal period. The gifts contain beautiful and specially designed handmade clothing, literature and naming certificates. The TBP also supplies Angel boxes for burial, Memory boxes in which to keep precious items, Remembrance boxes for early losses and Comfort shawls for the bereaved family members. Families receive the TBP gifts free of charge. The program is fully funded by donations and sponsorship. All materials used have been kindly donated. The TBP packs can reduce some of the stress for parents at a time that is already very difficult.

**Bereavement Support Education**

Ongoing education is provided to health professionals, community groups, emergency personnel and the workplace to assist these groups in supporting bereaved families following the death of a baby or child. Red Nose specialist training and education sessions are designed to increase awareness of common reactions and responses to the death of a baby or child and assist with developing skills in supporting others who are affected, while managing your own reactions and responses. De-briefing sessions are offered to professionals and groups of people who have been affected by the death of a baby or child.
Current Education/De-brief sessions -
- Health and Community Service Providers
- Community Information Session
- Workplaces affected by the death of a baby or child
- Service provider De-brief session
- Community group De-brief session

ELearning courses covering the above bereavement support education will be available in 2018.

**Literature and Resources**

Red Nose Grief and Loss printed brochures and information provides an outline of services/resources available through our service and gives phone and website contact details so that people can engage further if they wish.

Current brochures and printed information -
- Bereavement services brochure
- Bereavement services postcard
- Health professional’s brochure

A variety of booklets and articles relating to different aspects of grief and written in collaboration with bereaved parents, children and health professionals are available. These can be also found on our website for downloading with topics including:

- Miscarriage
- Choices in arranging a child’s funeral
- Sudden Unexpected Death of an Infant (SUDI) - including SIDS
- Stillbirth
- Termination
- Having another baby
- Grandparent grief
- Sibling grief
- Relationships
- Men’s grief

These are available to all newly bereaved families through Intake, counselling staff, Hospital Social Workers or via the Red Nose Grief and Loss website.
Bereavement Website

Red Nose Grief and Loss Website has been developed in collaboration with bereaved families to offer information and further accessibility to our support services. The website has sections for Parents, Family/friends, Professionals and Parent Supporters. There are many specific sub-sections including information for Bereaved Dads, Grandparents, Siblings, Employers and Colleagues.

Examples of supporting articles available on the Red Nose Grief and Loss Website;


Library

A library of bereavement and support literature and books is available at our head office in Docklands, Victoria and all offices of Red Nose Grief and Loss.

Newsletter

Red Nose Grief and Loss publishes a newsletter, ‘Guiding Light’, three times a year. This ties in with Mothers’ Day, Fathers’ Day and Christmas. These newsletters are designed to provide information on grief & loss, bereavement services available, suggestions on how to deal with anniversaries and important dates.

Memorial/Remembering Services

Memorial/Remembering services are conducted each year by every office of Red Nose Grief and Loss. These services are scheduled to align with Red Nose Day activities or Christmas time. These services provide the opportunity for bereaved parents, families and friends to pay tribute to the baby or child who has died.

Advocacy

Red Nose provides free, confidential and professional support and service to anyone impacted by grief and loss due to the sudden and unexpected death of a baby or child during pregnancy, birth, infancy and childhood.
Summary

Red Nose welcomes the opportunity for the Family and Community Development Committee to engage and consult with our industry leading highly skilled team in the development of a Model of Best Practice.

Red Nose would like to thank you for your consideration of our submission and praise you for reviewing the current perinatal services available to the Victorian community. Red Nose looks forward to working collaboratively with you to enhance the Perinatal Services in Victoria.

Kind regards,

Theron Vassiliou
Chief Executive Officer
Red Nose

17/75 Lorimer St,
Docklands, VIC 3008