

Submission to the Senate Select Committee on Stillbirth Research and Education

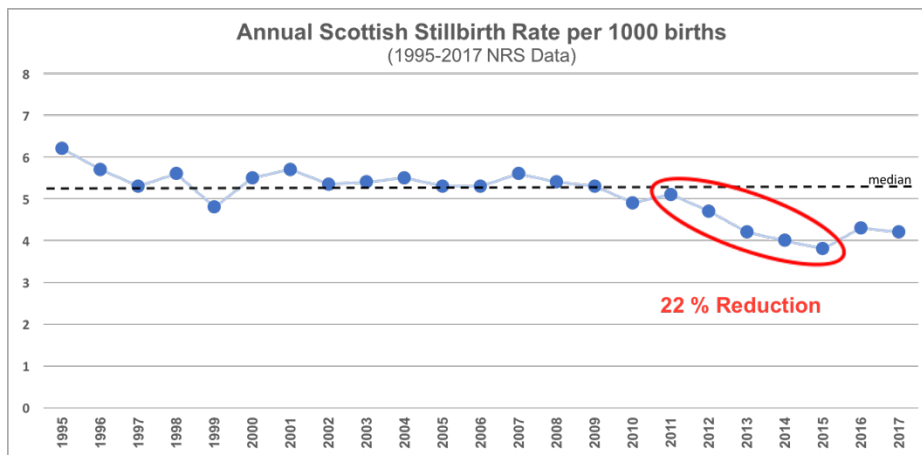
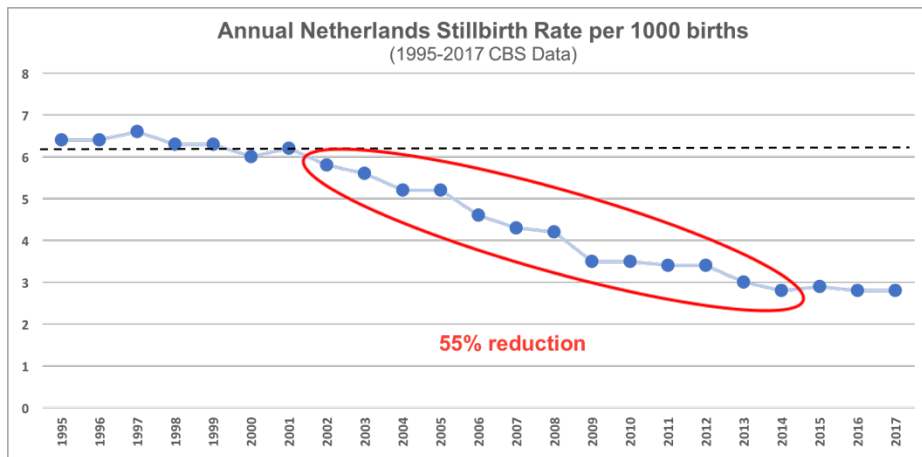
It is a *tragedy* each year that **2200 babies** are stillborn each year.

It is a *tragedy* that most people believe there is nothing that you can do to reduce stillbirth.

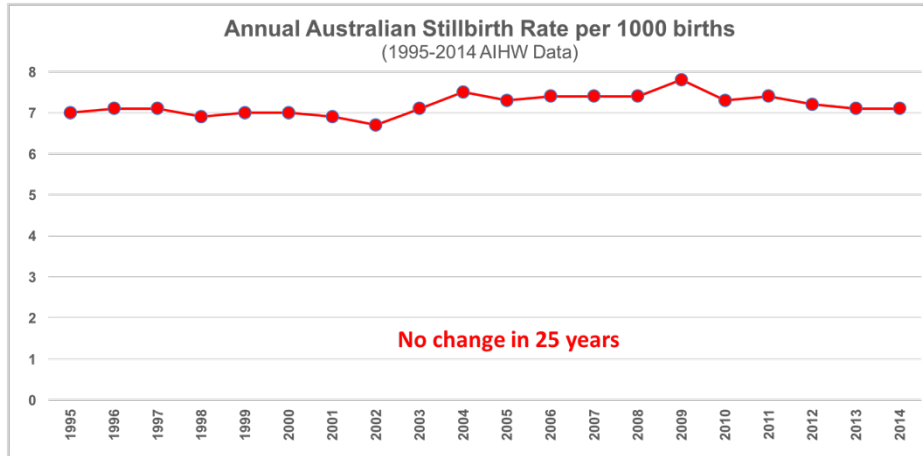
It is a *tragedy* that most do not know that a substantial proportion of stillbirth is preventable.

Other countries have *decided* that reducing stillbirth is a National issue.

1. The **Netherlands** initiated a Nationwide wide stillbirth initiative in 2001 resulting in a **55% reduction** in stillbirth over 14 years.
2. The Chief Medical Officer of **Scotland** initiated a government led, Nationwide, stillbirth initiative in 2011 resulting in a **22% reduction** in stillbirth over 5 years; their next target is a 35% reduction.
3. The United Kingdom has initiated a Nationwide stillbirth initiative in 2018; their target for 2025 is a 25% reduction in stillbirth.

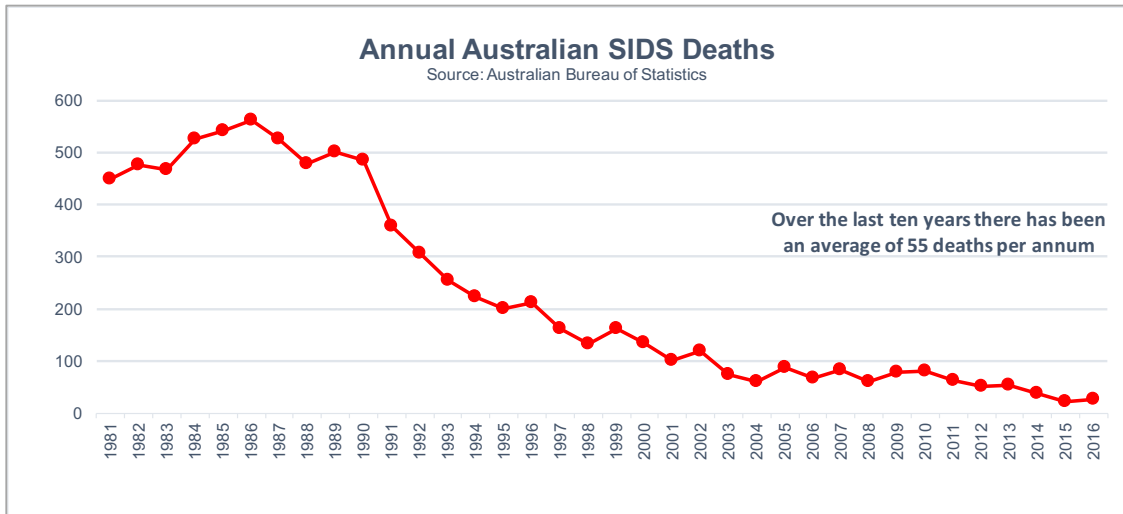


Red Nose believe that it is time for the Australia to decide that reducing stillbirth is a National issue.



It is a tragedy that the rate of stillbirth in Australia has not changed in 25 years.

In 1990, the rate of SIDS deaths was approximately 500 per year and had not changed for 10 years. Through research, education and advocacy, Red Nose worked to reduce the rate of SIDS by 85%. This was one of the most successful public health campaigns in Australia.



Red Nose has 40 years of experience, a national network, and a proven formula that resulted in one of the most successful public health campaigns in Australia. With a strong organisational structure, capacity to scale quickly, and our evidence-based approach, Red Nose can influence health practitioners and new parents. As industry leaders in child safety, we inspire people to fundraise given the trust and familiarity our brand built up over 40 years.

**Red Nose are the National leaders in infant and child safety.
We can bring change to the problem of stillbirth in Australia.**

The National Scientific Advisory Group (NSAG) of Red Nose have been actively working with the Chief Medical Officer of Scotland, Dr Catherine Calderwood, to develop the most efficient and effective approach to implement the successful Scottish Program (Maternity Care Quality Improvement Collaborative) in Australia. The **Red Nose Stillbirth Prevention Program** will be developed over the next six months by the Red Nose NSAG in collaboration with the team that developed and implemented the Scottish initiative as well as the NHMRC Stillbirth Centre of Research Excellence (CRE). The Red Nose vision is a future where no child dies suddenly and unexpectedly during pregnancy, infancy or in childhood. This program is one step closer to achieving our vision.

**The Red Nose vision is a future where no child dies suddenly and unexpectedly during pregnancy, infancy or in childhood.
The Red Nose Stillbirth Prevention Program can reduce the rate of stillbirth in Australia by 20% in five years.**

RED NOSE

Prior to the inception of Red Nose, various “SIDS & Kids” organisations were formed by parents who had suffered loss; they decided they wanted to understand why, find answers, make a difference and drive change. It was these talented, committed, highly passionate and often entrepreneurial parents who stated, ‘we want to make a difference’.

The formula the founders created in the early years was a simple one: ask lots of questions; drive research; get answers; turn those findings into advocacy and education; provide support for families affected; and inspire people to help raise funds. To date, Red Nose has managed to raise \$17M for much needed research thanks to the generous support of the Australian community. This formula helped SIDS & Kids to reduce SIDS deaths by 85% in Australia.

Eighteen months ago, most of the previously independent (but loosely confederated) Australian SIDS & Kids organisations came together as one organisation. We rebranded the new organisation as “Red Nose”, given the public’s significant recall and trust for that brand asset in the Australian market. Red Nose emerged stronger than ever before. As part of the merger, the mission remit of the new organisation was broadened to include any sudden death of a child from mid pregnancy to four years of age. In Australia, that is currently around 3200 deaths per year; that is nine deaths per day.

We see the Red Nose ‘formula’, developed over almost 40 years, as relevant to bringing change in the rates of stillbirth, sudden unexpected death of an infant (SUDI), perinatal death, child accidents, just as it did originally for SIDS. While work continues to further reduce the rate of SIDS, we recognise that of the 3200 deaths of babies and children per year, 2200 are stillborn. Understandably, stillbirth is now a major area of focus for Red Nose.

That Red Nose formula includes research, education, advocacy and bereavement services. In pursuit of our core aspiration of significantly reducing the 3200 families impacted by loss, Red Nose has quadrupled its annual spend on research. Further, we have developed of a very formidable advocacy machine and now provide meaningful interaction with families impacted by death 24 hours per day, anywhere in Australia.

Red Nose today is a highly diverse and unique organisation; it has sizeable staff comprised of bereavement counsellors, educators and managers. Further it has a Board that are highly committed and passionate and a vibrant National Scientific Advisory Group (NSAG). This group advises management and the Board on science agenda, research appropriation, and translation of research to education. With the inclusion of stillbirth and other causes of childhood death in our mission remit, Red Nose is regenerating its science agenda and scientific advisory group. A step on the change journey, the Red Nose Board has recently appointed Professor Craig Pennell to chair our NSAG. Professor Pennell is now working through aligning the group's agenda with the strategic direction of our Board.

SUCCESSFUL SCOTTISH PROGRAM - MATERNITY CARE QUALITY IMPROVEMENT COLLABORATIVE (MCQIC)

The Scottish initiative to reduce the rate of stillbirth and neonatal death by 15% was based on the successful program implemented nationally in the Netherlands in 2001. The initiative is based on the concept that whilst the risks of stillbirth are well known, 70% of mothers of stillborn babies have no significant medical condition, 60% have not had any previous pregnancy complications, 90% began antenatal care before 20 weeks, 66% never smoked and 48% were in their first pregnancy. Stillbirth can happen to anyone; however, many stillbirths are preventable.

There are five elements to the MCQIC stillbirth prevention package:

1. A tailored patient education campaign with clear messaging that stillbirth can happen to anyone and some are preventable
2. Implementation of a new package to reduce smoking in pregnancy across all maternity units in Scotland
3. Raise awareness for reduced fetal movement
4. Risk assessment and fetal surveillance for fetal growth restriction
5. Implementing a new Perinatal Mortality Review Tool

Many elements of this package are unique. The **second module** is a quit smoking element that involved every patient undergoing breath testing for carbon monoxide (CO) at their first antenatal visit and each subsequent visit. Those who had positive results were referred to smoking cessation services where they were provided with a tailored package of care. Regular CO testing at antenatal visits improved compliance rates with smoking cessation. Successful implementation of the package required greater than 90% of women with raised CO levels being referred to smoking cessation services.

Smoking is the single largest risk factor for stillbirth. If all smoking women ceased smoking by 16 weeks' gestation, the rate of stillbirth would be reduced by 25%. The most recent Cochrane review 'Psychological interventions for supporting women to stop smoking in pregnancy' (Syst Rev 2017 CD001055) clearly demonstrated that smoking cessation interventions with feedback (CO testing at visits) were the most effective techniques in pregnancy.

**Counselling combined with feedback is associated with a fourfold reduction
in smoking rates during pregnancy
RR 4.39 17.4% to 4.0%**

The Department of Health has policy responsibility for the health warnings on tobacco products. Health warnings first appeared on tobacco product packaging in Australia in 1973. Since that time, they have been an important part in the Australia wide effort to reduce the rate of smoking. In 2006, the current system of warnings were initiated which include 14 health warnings comprising graphics, warning statements and explanatory messages. These 14 warnings are divided into two rotating sets of seven health warnings that are alternated every 12 months. The warning statement 'Smoking harms unborn babies' is part of Set B. **Due to the 12-month rotation, more than half of pregnant women who smoke will not see this warning whilst pregnant.** Given the growing evidence that smoking has a major role in stillbirth, and the observation that those with the lowest access or utilisation of health service have higher rates of smoking, Red Nose recommends the warnings on cigarette packages are updated.

**Ceasing smoking in early pregnancy reduces the rate of stillbirth by 25%.
'Smoking harms unborn babies' should be replaced with 'Smoking causes stillbirth'
Pregnancy warnings should be in both Set A and Set B**

Raising awareness of reduced fetal movement is the **third** element of the MCQIC stillbirth prevention package. This education package is the same as that used in the *Affirm* trial that will be published in the *Lancet* in coming weeks. This package includes:

1. Patient information material (written and electronic); and a
2. Compulsory education package for all maternity staff (medical and midwifery) requiring proof of completion.

Complete implementation of this module required confirmation that 90% of patients have a documented discussion about reduced fetal movements in their clinical record in the third trimester.

The **fourth** element of the MCQIC stillbirth prevention package involves confirming that each maternity site was adhering to the Royal College of Obstetricians and Gynaecologists (RCOG) guidelines for fetal growth monitoring. The Scottish implementation team found this module the most difficult to implement as it was dependent on imaging resources available at each site. The NSAG of Red Nose will work in collaboration with the Scottish implementation team, the NHMRC Stillbirth CRE, the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and the RCOG guidelines to develop an implementation package that is suitable for high and low resource facilities in Australia.

The **fifth** module of the MCQIC stillbirth prevention package is the implementation of a Perinatal Mortality Review Tool that was developed by the Scottish and Welsh Governments. This tool was commissioned by the Healthcare Quality Improvement Partnership. This tool contains five key elements:

1. Parent participation in perinatal mortality review. Parents are made aware that a local review is taking place and they are invited to participate in accordance with their wishes. Specifically, parents are asked what questions they would like answered, both during their admission and approximately one month post-delivery. These questions are discussed at the formal perinatal mortality review and answers are provided to the parents during a consultation after the formal review.
2. Two step perinatal mortality review process: the first review is complete within 48 hours and the second six to eight weeks after delivery when all pathology results are available. The second review is the traditional, multidisciplinary perinatal mortality review meeting where final diagnostic classification of the stillbirth is assigned.
3. The Perinatal Review Tool is an electronic database that requires entry from delivery to completion of the review process which should be within two months of delivery. This tool cost £1M to develop and provides structure and completeness to the review process.
4. External panel member for local reviews is encouraged
5. Review process focuses on systematic failure rather than individual level actions and blame to make recommendations and improve future care

In Scotland, local health authorities are responsible for addressing the recommendations from each perinatal review to improve future care. The electronic perinatal review tool returns data centrally to provide health authorities and government valuable data to plan future resource allocation. The perinatal review tool has several feedback loops; it acts, in some ways, like biofeedback devices utilised in other successful behaviour change interventions.

No single element of the prevention package will reduce stillbirth.
The COMBINED package has reduced stillbirth rates in the Netherlands & Scotland.
Full implementation of the Red Nose Stillbirth Prevention Program can
REDUCE the rate of stillbirth by 20% in five years.

THE COST OF IMPLEMENTING THE SCOTTISH MATERNITY CARE QUALITY IMPROVEMENT COLLABORATIVE (MCQIC)

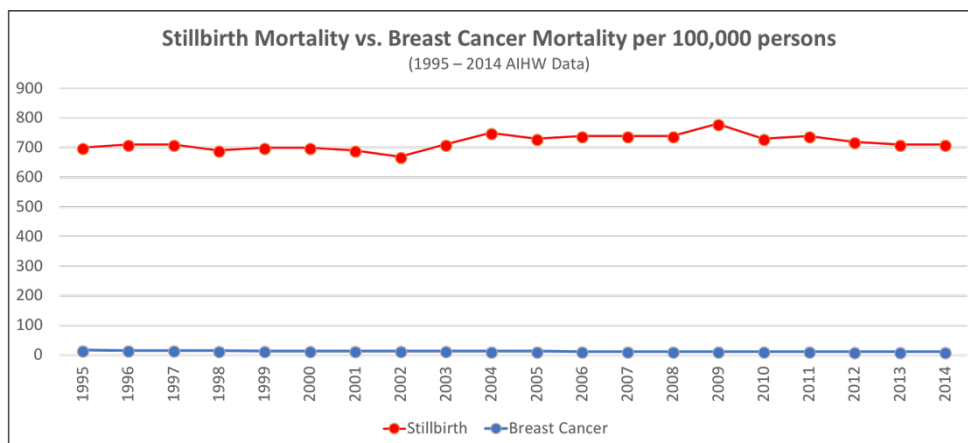
Scotland has a population of 5.4M with 60,000 births annually. These occur at 17 obstetric units that are part of 14 health boards. Government provided £1M annually for local hospital champions to implement the program. These funds were provided for four years after which funding for the initiative ended. Based on recent discussions with the Scottish Chief Medical Officer, ongoing funding is likely to be required for the local champions to maintain data entry into the perinatal review tool.

In summary, the Scottish government invested \$7.1M dollars over four years to implement a package that reduced stillbirths by 22% in a population of 60,000 births.

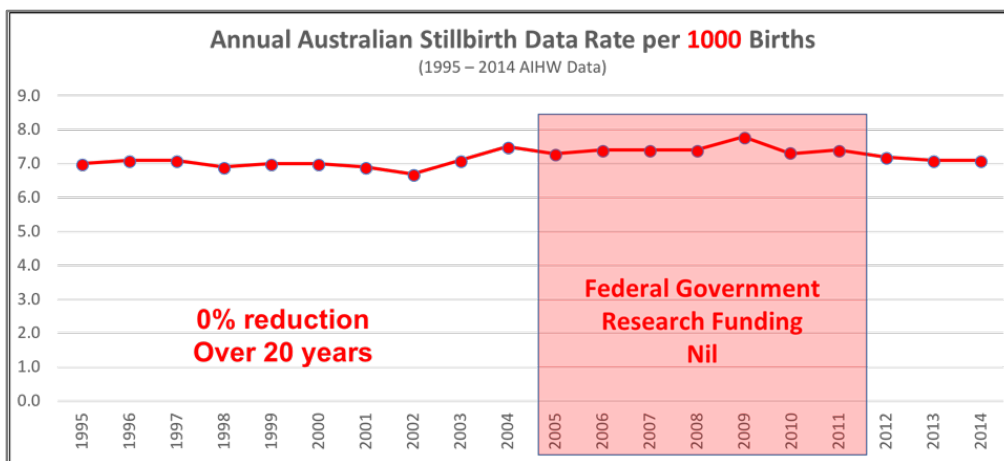
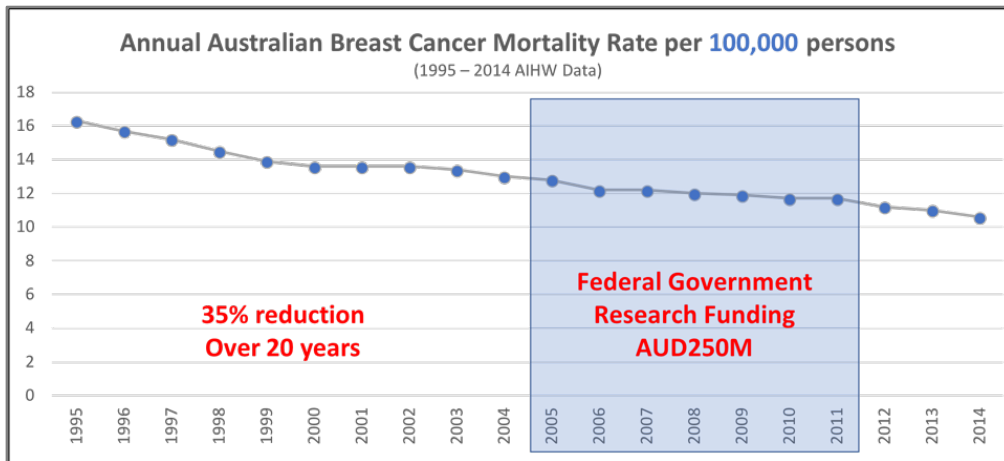
In Australia, there were 311,104 births registered in 2016. **To roll out the Scottish Package in Australia would cost \$37M over four years (\$9.3M annually).** During the roll out, 1218 babies lives would be saved during the four years; after implementation, based on data from Scotland and the Netherlands, 500 babies lives will be saved per year

RELATIVE INVESTMENT IN STILLBIRTH RESEARCH IN AUSTRALIA

In 2014, there were 2844 deaths from breast cancer from the Australian population of 23.5M. In 2014, there were 2225 stillbirths from 313,000 births. The relative mortality is presented below using consistent axes. Relatively, stillbirth is much more common in Australia that most are aware.



Research has played a crucial role in the reduction of mortality from breast cancer in Australia. In 2015, Cancer Australia published a report, “Cancer Research in Australia: an overview of funding initiatives to support cancer research capacity in Australia 2006 to 2011”. This report detailed government funding for research into each type of cancer in Australia. These data are presented below with a direct comparison to stillbirth research funding from the NHMRC.



Red Nose, and other researchers around Australia, are thankful that research funding from the NHMRC for stillbirth has increased, totalling \$5.4M over the last six years. This is however only a fraction of the funding investment into other causes of death in the community.

To achieve reductions in the rate of stillbirth in Australia, like those seen in breast cancer, urgent funding is required to implement programs based on existing data, such as the **Red Nose Stillbirth Prevention Program** detailed in this document. A significant increase in funding for stillbirth research is also required to develop new diagnostic tools to prevent the 75% of stillbirth cases that are most difficult to predict.

Red Nose invested \$17M into SIDS research and contributed to the 85% reduction in SIDS. Red Nose has quadrupled its investment into stillbirth research over the the last 3 years.

AUSTRALIAN COSTS ASSOCIATED WITH STILLBIRTH

There are significant costs associated with stillbirth. These include but are not limited to:

1. Direct financial costs associated with stillbirth investigations, hospital costs, and counselling,
2. Indirect costs such as funeral costs, absenteeism, government subsidies, divorce, and costs to the family, and
3. Intangible costs such as the impacts on mental well-being and relationships, and flow-on effects on family and friends. These costs and the associated economic and social impact of stillbirth in Australia are documented poorly, resulting in an under-estimation of the impact of stillbirth.

Below is a table representing the estimated direct and indirect costs of stillbirth for a five-year period from 2016-2020 across 13 different categories. The total of these costs in Australia for the five-year period were estimated by Pricewaterhouse Coopers Australia to be \$681.4 million.

COST CATEGORY	Costs Associated at the time of stillbirth	VALUE (\$ millions)	
Direct Costs	Cost of stillbirth investigation	33.3	
	Hospital fees	74.5	
	Cost of counselling	53.2	
	Cost of postnatal investigations	0.6	
	Cost of a subsequent pregnancy		
	Tests	5.6	
	Counselling	4.9	
	Sub-total direct costs		172.1
Indirect Costs	Funeral Costs	67.1	
	Absenteeism	129.4	
	Presenteeism	149.0	
	Lost Productivity from exiting the labour force	70.6	
	Cost of divorce	37.4	
	Government subsidy	36.1	
	Absenteeism (family)	19.7	
Sub-total indirect costs		509.3	
TOTAL		681.4	

Source: Pricewaterhouse Coopers Australia

These data provide no doubt of the economic value of investing to reduce the rate of stillbirth. Traditional funding models are not ideal to implement the broad package required to reduce the rate of stillbirth. Novel partnerships between the Federal Government, State Government, Academic Institutions and Philanthropy will be required to reduce the rate of stillbirth.

Red Nose recommend that the Australian Government match one-for-one philanthropic donations for stillbirth research.



RED NOSE HOSPITALS – IMPLEMENTING THE RED NOSE STILLBIRTH PREVENTION PROGRAM

The National Scientific Advisory Group (NSAG) of Red Nose have been actively working with the Chief Medical Officer of Scotland, Dr Catherine Calderwood, to develop the most efficient and effective approach to implement the successful Scottish Program (Maternity Care Quality Improvement Collaborative) in Australia. The **Red Nose Stillbirth Prevention Program** will be developed over the next six to twelve months by the Red Nose NSAG in collaboration with the team that developed and implemented the Scottish initiative as well as the NHMRC Stillbirth Centre of Research Excellence (CRE).

The initial program has five modules which have previously been described in detail:

1. Patient education campaign about stillbirth
2. Implementation of a new package to reducing smoking in pregnancy
3. Raising awareness for reduced fetal movement
4. Risk assessment and fetal surveillance for fetal growth restriction
5. Implementing a new Perinatal Mortality Review Tool

Red Nose have secured matching funds from three partners, The University of Newcastle (\$100K), the Hunter Medical Research Institute (\$100K) and the John Hunter Hospital (\$100K) in Newcastle. We seek to partner with government (\$300K) to allow our team to immediately:

1. Develop and enhance each of the five modules for implementation with the following additions:
 - a. Tailored modules focusing on migrant women who suffer significantly higher rates of stillbirth in their first ten years in Australia
 - b. Tailored approach for our indigenous community
2. Develop all media tools required to for effective implementation
3. Implement the five modules into John Hunter Hospital
4. Perform an economic evaluation of implementation of each module
5. Develop the process for implementing the modules across the 17 hospitals that feed John Hunter Hospital (Hunter New England Health Region)

Red Nose have been graciously offered the new Perinatal Mortality Review Tool to evaluate at John Hunter Hospital and within the Hunter New England Health Region. This tool has been utilised in Scotland for several years and has been recently adopted by the United Kingdom. This tool cost £1M to develop. The opportunity to evaluate this tool in our clinical setting is a unique element of this proposal. If the tool is effective, purchase of the tool is possible; if ineffective, we will be well positioned to develop a tool suitable for Australian hospitals.

The completion of this project will allow all five modules to be developed and their implementation costed; information that will be required for national roll out of this initiative. Information gained in this project will be invaluable for Red Nose, Government and Health Regions.

Each year on Red Nose Day, people, cars, buses, and ferries wear Red Nose's to celebrate the success of Red Nose in reducing the rate of SIDS by 85%. **Our new vision is to develop Red Nose Hospitals.** The process for a hospital to become a Red Nose Hospital will be similar to the process hospitals follow to become 'Breast Feeding Friendly Hospitals'; it will require implementation of all five modules and a site visit from an external review team. The details of this process will be developed with the assistance of Pricewaterhouse Cooper who are strong supporters of Red Nose.

The Red Nose vision is a future where no child dies suddenly and unexpectedly during pregnancy, infancy or in childhood.

The Red Nose Stillbirth Prevention Program can reduce the rate of stillbirth in Australia by 20% in five years.

CONCLUSION

The establishment by the Senate on 27 March 2018 of a Select Committee to inquire and report on the future of stillbirth research and education in Australia was a **momentous step towards reducing stillbirth in Australia.** The initiative and drive demonstrated by Senator the Honourable Kristina Keneally in this process has encouraged researchers, clinicians and families to believe that reducing the rate of stillbirth in Australia is a real possibility.

There is no doubt that we can reduce the rate of stillbirth in Australia. This will require investment into implementation of existing knowledge and investment into discovery research to develop tools to identify pregnancies at highest risk of stillbirth.

The future of national initiatives to reduce stillbirth through implementation science will require novel partnerships between Government, Philanthropy, Academic Institutions and Health Districts. It will also require local, national and international collaboration.

Red Nose believes that it is time for the Australia to decide that reducing stillbirth is a National issue. The organisation has 40 years of experience, a national network, and a proven formula that resulted in the most successful public health program in Australia reducing the rate of SIDS by 85%.

Red Nose has developed the **Red Nose Stillbirth Prevention Program** and the concept of **Red Nose Hospitals** to take the first step in reducing stillbirth in Australia through implementation of a program that is designed to scale up to a national level. Through international collaboration, we have greatly reduced the costs of developing this initiative and our partnership with The University of Newcastle, the Hunter Medical Research Institute, the John Hunter Hospital and Government will afford us the opportunity to rapidly develop this program for implementation in 2019.

To reduce the rate of stillbirth in Australia will require a National program, driven by local Champions, and supported by researchers, clinicians and families who believe that reducing stillbirth is possible.