



# Noseletter

July 2020 | Issue 8

## Your supporter update

There's no doubt that nothing could have prepared us for the challenges and chaos of 2020.

The number of calls from anxious new parents seeking life-saving Safe Sleeping advice soared whilst the number of distressed parents seeking bereavement support reached levels never seen before.

Like most, we are constantly trying to do more with even less, *and we couldn't do it without you.*

**Your generous support has made sure that not one single call for help from a parent in need went unanswered.**

It's often when we feel the most vulnerable that we are able to truly appreciate the generosity of those around us and I couldn't feel more grateful for your support during this challenging period. Thank you so much.

Please enjoy this issue of *Noseletter*, knowing that you make all this possible.

**Keren Ludski**  
CEO, Red Nose Australia



## I love you

By  
Melanie Manning

In her family drawing, Paisley represented Mylee as a baby even though Mylee is her older sister. The sad reality is all of our memories are of Mylee as a baby because we never got to see her grow up.

Paisley said "I liked drawing Mylee in our family because she is my family and when we're all together it makes me happy."

**Although Paisley never got to meet her older sister Mylee, she's still a large part of her life.**

"I wish she would come back because then we could play and it would be really really fun."

"I would hug her if she came back, I'd be so happy to have my family all together, but she does make nice rainbows in the sky for us to see."



Paisley, 6yrs old



# He's with us in spirit

By  
Marnie Petkovski

'SUDC'  
Sudden  
Unexpected  
Death in  
Childhood

It was just a normal Thursday night when our little boy Lukas Joseph Petkovski died of Sudden Unexpected Death in Childhood on the 9th of February 2012.

I remember it like it was yesterday. We had gone through our normal night time routine: bath, book, bed and Lukas went to sleep easily.

When I went to check on him, I took one look and I knew something wasn't right.

Nik and I called the paramedics while my sister performed CPR. I am not sure how long it took for them to arrive – but it seemed like forever.

The rest of the night went by in a blur. We went into shock.

The police were called, they spoke with us and took photos of his bed and bedroom. They bagged his blanket and pillow, as well as what he was wearing.

We wrapped him in a quilted blanket that my sister had made.

**Leaving him at the hospital alone was the most horrific moment for me. This broke my heart as it was my job to look after him, yet I had to leave him by himself.**

Sometime throughout the next day Red Nose rang to offer their condolences and talk about the services they offered. They were very kind.

The first year was hard. I remember just going through the motions to get through each day – but it was exhausting.

The first anniversary of Lukas' death was awful. We went on a train ride because Lukas liked trains.

**In the carriage was another family with their little son, about the same age as our Lukas – and his name was Lucas as well.**

Nik and I sat in silence.

In hindsight, I'm sure it was our Lukas' way of letting us know he was still with us in spirit.

**This month Lukas would have celebrated his 10th birthday.**

In just a few weeks it will be Red Nose Day and we plan to donate and purchase merchandise to support Red Nose in Lukas' memory.

Early on in my journey, I attended a one-on-one and a group counselling session with Red Nose, and our family went on a Remembrance Walk.

It is important to support Red Nose, so that all grieving families can access support when they need it most.



If you would like to read more of Marnie's journey, visit [rednose.org.au/news](https://rednose.org.au/news)

# Counselling during COVID-19

By  
Rachel Ficinus



As the Clinical Manager Bereavement Services I wanted to say a very warm **thank you**.

This year we've all been hit hard by the COVID-19 crisis, often in ways we didn't expect.

As you can imagine, we've had to adapt very quickly to make sure we had the technology and systems for our counsellors to be able to work from home and maintain vital contact with grieving families.

With the implementation of physical and social restrictions over the past few months, feelings of emotional isolation have been overwhelming for many grieving families.

**Throughout this crisis we've received over 40% more calls for help than ever before.**

The Grief and Loss team has worked hard to provide around the clock support with our 24/7 Support Line as well as one-on-one

counselling over phone or via video chat. We've even been able to hold online group activities and supports.

It is absolutely vital that families are able to connect with those who understand their journey, and are able to walk alongside them through their grief.

"I'm ringing to say thank you for being there for us. Our son was born still six weeks ago and we were struggling to get out of bed. A friend gave us your number. It still hurts like hell, but we're getting up and getting dressed each day and that feels good. I don't know how to say thank you."

**Thanks to your generous support Red Nose Bereavement Services have been able to run throughout the pandemic, so that every family has support when they need it most.**

**“Our son was born still six weeks ago and we were struggling to get out of bed ... It still hurts like hell, but we're getting up and getting dressed each day and that feels good ... Thank you.”**

For the *diary*

**RED NOSE DAY  
FRIDAY 14 AUGUST**

**It's time to get silly for a serious cause.**

The money that you help raise on Red Nose Day funds research and education, and helps ensure the Red Nose support network is always available to families in need.

From volunteering to fundraising to buying a red nose – we need your help!



So what are you waiting for? Get involved today, visit [rednoseday.org.au](http://rednoseday.org.au)

**red nose day**  
friday 14 august

# The future of SIDS research

By  
Professor Roger Byard AO PSM



In the past we considered SIDS to be a disease with a single cause. Nowadays we understand that it is really the end result of the interaction of certain babies with their environments.

By understanding that SIDS is a complicated disorder, we have been able to understand it better and take very successful steps to reduce the number of these tragic deaths.

**While it is likely that certain genetic factors play a role in contributing to some SIDS deaths. We do know that there is no 'SIDS gene'.**

Repeated deaths in a family could well be due to genetic factors, but these are more likely to be inherited cardiac conditions or a rare metabolic illnesses.

**The next important area of SIDS research involves studying the brainstem – the part of the brain that controls our breathing and heart rate.**

Exciting research in this area in recent years has focused on a chemical called serotonin which appears to be reduced in certain SIDS babies.

This means that they are not able to respond to environmental challenges as quickly or as well as normal babies.

Perhaps even more exciting is our own work in collaboration with Harvard University looking at a chemical called substance P.

We have found that this can be significantly reduced in areas of the brainstem that control head and neck movement.

This could explain why babies who die of SIDS in the face down position have not just moved their heads to a safer position on the side – they may have been not be able to.

The future of research will involve examining brainstem chemicals more clearly and determining whether deficiencies are linked to genetic markers.

**It may then be possible to test for these specific genetic defects in babies to help us identify those who have a much higher risk of SIDS.**

## Professor Roger Byard AO PSM

Founder of Red Nose's National Scientific Advisory Group, Prof. Byard has been associated with Red Nose for over 30 years. He works as a researcher, pathologist, advisor and counsellor to families who have lost children to SIDS.

## Because of you...

**\$17 million** has been invested into research to end SIDS and stillbirth

**250,000** parents and carers are taught about Safe Sleep each year

**10,857** babies have been saved since 1989

SIDS has **reduced by 85%**

## Thank you

### Grief & Loss Support Line

1300 308 307 (available 24/7)  
rednosegriefandloss.org.au

### Safe Sleeping & Safe Pregnancy Advice Line

1300 998 698 (business hours)  
education@rednose.org.au

### Make a donation

1300 998 698 (business hours)  
donate.rednose.org.au

To read Professor Byard's full research update, visit [rednose.org.au/news](https://rednose.org.au/news)

[rednose.org.au](https://rednose.org.au)