

# National Premmie Foundation



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## Message from the President



The new Committee for National Premmie Foundation was elected in late April 2009 and I am honoured to have been elected President of such an amazing Association. I am particularly grateful that I have so many wonderful women on the Committee whose passion, energy and commitment to the cause will help us continue the good work that the National Premmie Foundation has commenced.

The planning for our 3rd annual National Premmie Day, to be held on Friday 31 July 2009 is well underway and our member groups, NNICUPS, Life's Little Treasures, PIPA, Loddon Mallee Kids and Central Coast Premms are

all busily preparing local events to help celebrate this wonderful day. We also have lots of wonderful people who will be holding other events such as morning teas to help raise funds. L'il Aussie Premms will be holding an online forum on the evening of NPD and this is great for those people not able to get along to an event during the day.. Information on events will be on the website and the Facebook pages and we would love to see you at an event to help celebrate our little Aussie battlers.

Also don't forget about our Children's Rose fundraiser, purchases can be made through our website.

On a personal level, this will be my second celebration of National Premmie Day! My daughter Amy was born at 28 weeks in Nepean Hospital in April 2008. She is my strong little girl and her fight to survive and battle through the many challenges was amazing.

Words cannot describe how thankful my family and I are to the doctors and nurses who helped Amy grow strong so we could bring her home. They do amazing work that is often unrecognized and National Premmie Day is as much a day for us to thank them for their tireless work and for them to celebrate as well.

RSV is again a theme for this year. Respiratory Syncytial Virus is a serious health threat for our prematurely born infants and seriously ill infants and we are again trying to raise awareness of the signs and symptoms of RSV and some preventative measures that everyone can do to minimize the risk.

I experienced RSV first hand when Amy contracted it in early May. It was a harrowing time for all of us and so heart-breaking to see her so ill again on nasal oxygen with a collapsed lung and hospitalized for 6 nights.

[www.prembaby.org.au](http://www.prembaby.org.au)

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Approximately  
 21,000 premature  
 babies are born in  
 Australia each  
 year.



## Message from President *Continued*

It was the one thing I feared her catching when we were released from hospital after her birth and I now know why. I am pleased to say she has recovered fully.

The National Premmie Foundation has some amazing supporters of our work including Happy Baby, Earlybirds, NicePak products, ThinkTwins, Huggies, Abbott, Gaia Baby, La

Toriana and L'il Aussie Prens. We are so grateful for their generosity and we look forward to a continued association with them.

We would love to hear from anyone who has a question, comment or suggestion. You can email us on [contact\\_us@prembaby.org.au](mailto:contact_us@prembaby.org.au)

Enjoy National Premmie Day and we look forward to hearing about all the celebrations Australia wide!

Warm regards

Deanna Jenkins  
 President

## National Premmie Day

### Friday 31 July 2009

National Premmie Day is the day to celebrate the births of our smallest and most vulnerable newborns. The NPF invites all prems big and small and their parents, families and friends to help them celebrate this special day.

Each year approximately 21,000 premature babies are admitted to special and Intensive care nurseries across Australia. National Premmie Day is the day to celebrate with these Little Aussie Battlers. It is a time for the community to come together to

reflect on the journey these little ones have taken, celebrate their strengths, express our gratitude to the health professionals who have looked after them and remember the precious little ones who did not survive the journey.

The day coincides with Respiratory Syncytial Virus (RSV) season, a common virus that causes cold like symptoms. For prematurely born and seriously ill infants, RSV is a serious health threat often resulting in re-hospitalisation or forced isolation

for families.

By the age of 2 nearly all children will have been infected with RSV at least once and we want to make all parents and the general community aware of the signs, symptoms and preventative measures for RSV.

For information about National Premmie Day activities being held near you or to organise one of your own visit [www.prembaby.org.au](http://www.prembaby.org.au) or call the parent info line on 1300 773 622.

# Information about RSV

## What is RSV?

RSV is the most common cause of lower-respiratory-tract infection in infancy or childhood. RSV causes cold-like symptoms that can trigger chronic breathing difficulties if the lungs become involved. RSV occurs in seasonal outbreaks, usually through autumn to winter. In Australia the risk of catching an RSV infection is at its highest from May to October.

RSV is highly contagious. Approximately one-half of all infants are infected with the RSV during the first year of life and nearly all children have been infected at least once by the time they reach their second birthday.

Up to 90 per cent of bronchiolitis hospitalisations and up to 50 per cent of hospital admissions caused by winter pneumonia are caused by RSV.

Diseases of the respiratory system account for the highest proportion of all admissions to hospital in children aged 1-14 years, according to the latest data from the Australian Institute of Health and Welfare.

Babies born prematurely as well as those with chronic lung disease or congenital heart disease are at the highest risk of severe disease and hospitalization due to RSV. While adults and healthy children can normally cope with the mild cold-like symptoms of an infection, at risk infants are at a high risk of being admitted into hospital. In babies who are born prematurely or who have lung or heart complications, RSV may cause life-threatening conditions requiring intensive care.

Pre-term infants are at the highest risk for serious RSV infection and related hospitalisation. Premature infants have underdeveloped

lungs, which can be a contributing factor to increased risk for RSV disease and cardiopulmonary complications.

Infants with a congenital heart disease (structural or functional defect in the heart that is present at birth) or a chronic lung disease are also at increased risk of developing severe RSV disease, hospitalisation and death.

Other risk factors for severe RSV disease include low birth rate (less than 2500 grams or 5.5 pounds) and a compromised immune system.

Other contributing factors are exposure to tobacco smoke, having school aged siblings, attending day-care and living in crowded conditions.

## Effects on Families

Parents of infants born preterm experience an enormous amount of emotional trauma, stress and grief dealing with the complications surrounding the early arrival of their child and the lengthy hospital stay that follows. The average duration of hospitalisation for these premature infants is seven weeks. In addition they have to live with ongoing health concerns and problems with their children. The readmission of the at risk infant due to RSV presents considerable further burdens, both emotionally and financially, to these families; and to the public health system. These infants are at risk of intensive care admission, long term lung damage and in rare cases death. For families in regional areas the cost of readmission is considerably higher. Thus they live in fear of their child being readmitted to hospital and isolate their child from the rest of the community to prevent this occurring. For those with other children another hospital stay will mean more disruption for the whole family with siblings often failing to understand why mum is

away so much of the time.

Susan, mum to Connor born at 26 weeks and now 2 years old explains "I am at the doctors with Connor whenever he has the slightest cough to ensure that he is okay and live in constant fear of him being sick. I have become germ phobic and very aware of sick people in shopping centres etc. – I have never placed Connor in a shopping trolley and I keep antibacterial handwash in my purse at all times. I tend to keep Connor more isolated during the winter / flu season which is detrimental to him both developmentally and socially. I know the majority of people think I am overly protective but any mum in a similar position would do the same to protect their child. The greatest issue to our family has been the isolation factor and watching Connor having to miss out on many fun events and parties. This just breaks my heart."

## What can parents do to prevent RSV?

There are simple steps parents can take such as:

- \* Washing hands with soap and water before touching your baby
- \* Avoiding people with a cold or fever
- \* Using a tissue when you cough or sneeze, and dispose of it immediately
- \* Keeping your baby away from other people with coughs and colds, particularly during the RSV season.
- \* If your child is at high risk, try to avoid crowded environments
- \* Washing toys used by children who have symptoms of a cold. Viruses can live on the surfaces of tables and toys for several hours.
- \* Discourage other people from kissing your baby
- \* Not exposing your baby to a smoky environment from cigarettes, either in your home, or outside
- \* Seeing your doctor if symptoms persist.

## A Mum's Story

**Karen Maree Messmer born at 26 weeks and infected with RSV 8 months after being discharged from hospital after premature birth**



At 22 weeks into my second pregnancy I experienced complications, haemorrhaging and premature labour. As a result I found myself transferred from Rockhampton to the Mater Mothers, Brisbane. This was a very scary time. Not only was I worried about my baby but I also had my young son Caleb to look after.

Karen was born at 26 weeks weighing 824 grams.

She spent just over 16 weeks in hospital. Seeing your baby lying there with all the tubes and wires attached is a very scary event and it is one that I would never wish on anyone. However it is a lot more common than people realise.

The hardest part is sitting beside your child's bed wishing you could bring them home and wondering if they will actually get out of hospital.

Then just after Karen's first birthday when she was 81/2mths corrected, I felt these feelings rushing back again. When Karen first got sick I originally thought it was from her teething. She had a clear runny nose and a slight temp. Nothing to worry about, I thought. Then it changed to a green runny nose and a slight cough. After every meal she was throwing up and was having trouble keeping her bottles done. I took her to the doctors and they prescribed some antibiotics. However that didn't help at all. Later that night while she was asleep her breathing became laboured and she was going blue

around the lips. I contacted the ambulance and they took her to hospital. We saw a doctor who said she had bronchiolitis and was RSV positive. We were then admitted to hospital. The first day she wasn't too bad. As the days progressed she got worse. She wasn't eating, or what she did eat she threw up. She was placed on a drip and oxygen. I said to the nurse, "She's getting worse not better." They said "That is how this virus works; it can take up to five days for them to improve."

So I was back to sitting beside Karen's bed wondering if she would get back. I would cry myself to sleep wondering WHY this happened. She's been through enough and didn't deserve it.

On about day 4 the paediatrician came in and said if she doesn't improve we may have to ventilate her and send her back to Brisbane, I just shook my head and thought this can't be happening again. Luckily Karen didn't need to be ventilated and got better. It took her some time to fully recover. She was keeping down most of her feeds by the time she was discharged.

I was glad to be home after 10 days in hospital. All I could think about was that it was going to happen again. I didn't know what to do. Every snuffle or cough, found me running to the doctors. Luckily I had a great doctor who understood. He did, however, say you were never this bad with Caleb. I said yes I know but he wasn't 14 weeks preemie.

RSV is a terrible illness that is very traumatic, not only for the child but on the whole family. When Karen was admitted back to hospital with drips and oxygen it took me back to the first 16 weeks of her life when she was in the NICU.



# Meet the new NPF Board

On 30 April 2009 the members of the National Premmie Foundation elected a new Board. The women who make up the new Board bring a variety of skills and experience to the NPF. One thing they all have in common is that all agree that they have big shoes to fill following the excellent work of the founding committee of the NPF.

## **Deanna Jenkins President**

Deanna is from Sydney and is the mother of two. Her youngest, Amy was born at 28 weeks in April 2008. Deanna saw the opportunity to become involved in the NPF as a way of being able to give back and help others on their journey following premature birth. She hopes that her corporate experience, strong leadership skills and ability to get things done will be put to good use in her new role as President of the National Premmie Foundation.

## **Vanessa Neilson Vice President**

Vanessa is from Burnie in Tasmania. She is the mother of five, four of whom were born premature. As well as being a busy mum Vanessa is also a registered nurse working in the operating theatre of her local hospital. She has recently been blessed with a new addition Toby, who was born at 24 weeks in May.

## **Elizabeth Crocker Secretary**

Liz is from Sydney and is mum to premmie twins Zara and William born at 29 weeks. Liz assisted in last years National Premmie Day promotion. She is eager to do more to assist other prem parents especially those who have experienced the joys and stresses of multiple birth.

## **Eileen Cooke Treasurer**

Eileen is from Brisbane, Qld. Her first son was born in 1996, 11 weeks premature. Since that time she has been an active volunteer and board member of the Preterm Infants Parents Association (PIPA). She was instrumental in the formation of the National Premmie Foundation and has been a member of the NPF Board since it's inception in 2007. She is also is a consumer representative on a number of Queensland Health and hospital base committees Eileen is passionate about improving the conditions and services available to parents of infants born premature.

## **Julia Toivonen Website/Public Officer**

Julia resides in Victoria and is mum to two sons. Ronan, her eldest, was born at 27 weeks. As a founding committee member of the National Premmie Foundation she played a key role originally in establishing and now maintaining the NPF website. As the owner of L'il Aussie Prems, Australia's largest online premmie support forum,

Julia has been able to fulfil her passion of helping families through the difficult journey of parenting a prem..

## **Rebecca Waterhouse Newsletter and Publicity**

Rebecca (Bec) is from Brisbane Qld and is mum to her daughter who was born at 26 weeks. After the birth of her daughter Bec decided that she'd like to do something to help other prem parents. She developed her own website to share her experience with other and is excited about the opportunity to become involved with the National Premmie Foundation. She hopes that, through the NPF and its associated support network, premmie parents all over Australia will find themselves better supported through their NICU/SCN and premmie journey.

## **Sarah Peatey Fundraising and Sponsorship**

Sarah is from Middlemount in Central Queensland. She is a very busy mum to four. The youngest two, Hayden and William being born premature. This experience as made her eager to assist other prem parents. Residing in Central Queensland she has experienced first hand the difficulty of accessing maternity services and health services for children with special needs.

# Children's Rose Fundraiser



**NPF Website sponsor**



L'il Aussie Prems is an Australian website for families of premature babies . It has a free forum.

## NPF Member Groups

- \*Preterm Infants Parents Association (PIPA)
- \*Nepean Neonatal Intensive Care Unit Parents Support (NNICUPS)
- \*Life's Little Treasures
- \*Loddon Mallee Kids
- \*Central Coast Premmie & Sick Newborn Support

Contact details for the support groups are available on the NPF website

National Premmie Foundation celebrates National Premmie Day with the Children's Rose.

Purchase a rose for yourself, as a gift for a family member or friend currently in the Neonatal Intensive Care Unit or to support the work of the National Premmie Foundation. Then plant your rose and watch it flourish as it flowers and grows over the years. These special roses help raise funds to support the work of the National Premmie Foundation.

**Only \$16.00** per rose

**POSTAGE:** \$10 for 1 rose and \$4 for every additional rose

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*"Life is not measured by the number of breaths we take but by the moments that take our breath away"*



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Your support is very much appreciated and we look forward to a continued association.

# PREM Triple P: Developing a parenting program for parents of very preterm babies



Researchers at the University of Queensland, Royal Brisbane and Women's Hospital, Mater Mother's Hospital and the Queensland Cerebral Palsy and Rehabilitation Research Centre (Royal Children's Hospital) are collaborating on a project to develop and trial a new variant of the Positive Parenting Program - Triple P developed for parents of babies born very preterm. The new variant of Triple P "PREM Triple P" would be delivered to parents in group sessions while their baby is still in NICU and include individual telephone sessions after the baby has gone home. Prem Triple P would include education about positive parenting strategies, coping skills and partner support. Researchers believe that Prem Triple P will impact on the cognitive development of very preterm babies at 24 months corrected age by positively changing the parent-child relationship and parent discipline style. Researchers are also interested in Prem Triple P's effects on motor development, language skills and behaviour at 24 months corrected age. Professor Paul Colditz, director of the Perinatal Research Centre and a chief investigator on the project commented, "Parents of very preterm babies often feel uncertain about how to deal with the needs of their preterm baby as he or she grows and how to deal with the stresses. Prem Triple P is being developed to meet these needs and will be properly research tested to ensure it delivers on this aim".

Triple P is a parenting intervention that is backed by 30 years of research and is widely implemented in Australia as well as 17 other countries. The aim of Triple P is to improve children's behaviour and development through enhancing the parenting skills and the confidence of parents. Researchers in Triple

P have been extended the program to suit various parents, children and parenting issues. Professor Matthew Sanders, the founder of Triple P and a chief investigator on the project stated, "This is the first time that Triple P has been applied to parenting a very preterm baby. This is an important study that has the potential contribute to the quality of life of families of preterm babies."

This project is currently at a piloting stage and feedback is required from parents with preterm babies to ensure that PREM Triple P meets their needs. A web-based survey of parent's reaction to PREM Triple P and the parenting tasks of parents of preterm babies is currently being conducted. If you are the parent of a preterm baby aged under 24 months (corrected age) we invite you to participate. We also need parents of term babies to participate as well so we can compare the two experiences. So if you have friends or family members with a term baby please invite them to participate as well! You can find the survey at the following website: <https://exp.psy.uq.edu.au/prem>. If you would like to discuss the project please contact the study coordinator, Dr Koa Whittingham on 3636 5539 or [koawhittingham@uq.edu.au](mailto:koawhittingham@uq.edu.au). The chief investigators of this project include: Professor Paul Colditz, A/Professor Roslyn Boyd, Professor Matthew Sanders, Dr Margo Pritchard, A/Professor Peter Gray and A/Professor Michael O'Callaghan. The researchers involved would like to acknowledge a RCH Foundation grant in the funding of this pilot research.