



# Austprem Ink

## AT A GLANCE

**Austprem Inc. is a major national self-help Internet based support group which now has well over 700 members!**

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## Volume 5 Issue 3

## Premature birth, babies and beyond

### A Parent's Instincts

**Lisa Reid**

**F**rom the moment our boys were born our world changed forever. This was a much longed for pregnancy and had taken eight years of IVF. I had absolutely no idea how quickly things could change. At 24 weeks and 3 days gestation I was diagnosed with premature labour and despite the best efforts of the hospital staff our boys arrived three days later.



*Mitchell Reid*

This was just the start of our often tumultuous journey. So when we finally left the NICU after almost five months we thought the worst was behind us. I am sure people warned us of the ongoing impacts of prematurity, but this faded into the background as we took Mitchell and Harrison home for the first time.



*Harrison Reid*

The first few months rushed past in a blur of doctor's appointments, community nurse visits and night feeds. Our first physiotherapy visits provided me with small signs of potential problems. Both boys were considered low tone and were quite floppy. They took a long time to learn to lift their heads and they could only tolerate very short periods of stimulation. At this stage it was too early for any definitive diagnosis. As the boys gradually learnt to crawl (at 10 months) and walk (at 24 months) I learnt to push my nagging doubts aside. After all our family would tell us how well the boys were doing. But there was always the follow-up...



*Mitchell and Harrison are almost three years old now.*

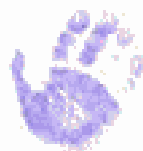


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comment, "Considering how prematurely they were born." Each time we had a physiotherapy appointment or saw the neonatologist I would always ask about Cerebral Palsy – and after a long time of being told that there were no signs I started to relax.

Then several months ago our world collapsed. On our final visit to the neonatologist he commented on the boys' strange gait and the lack of improvement. So I asked once again, "Is this Cerebral Palsy?" And back came the words that I had dreaded for so long, "It looks like Cerebral Palsy." Somehow I maintained my decorum, thanked the neonatologist and left his office. It was only when I arrived home that I collapsed. A million thoughts flooded in. Would the boys live independently? Would they have intellectual impairments? Where would we go from here? Eventually, after a horror weekend, my husband and I reconciled ourselves to the fact that whatever the diagnosis Mitchell and Harrison were still our precious, beautiful little boys and nothing had really changed.

After a week we visited a Cerebral Palsy specialist who acknowledged the boys' low tone, but was cautiously optimistic that the boys didn't have Cerebral Palsy. However, something had changed... the security we had felt for so long had been torn away. If this could happen, what else may happen in the future? And now I find myself battling with those old fears once again. All I can do is face every challenge as it arises and try not to look too much into the future. Who knows what the future holds for our beautiful boys. All we can do as their parents is love them, teach them and provide them with every opportunity to become kind and loving men. And one day, maybe one day, I will look at them and those old fears will be long gone...



## Moment by Moment™

a journey of a premature baby



Moment by Moment was born from experience and was passionately founded by the family of a 27weeker.

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[www.momentbymoment.com.au](http://www.momentbymoment.com.au)

## Waves of Anxiety

**Kirsten Burkitt**

Most people would acknowledge that having a baby is both a happy and stressful time for any couple. When the baby arrives ahead of schedule, there are often more feelings of anxiety, and fewer of happiness and there is certainly a lot more stress for the parents.



Austprem members often report that while their baby is on the roller coaster ride of the NICU they usually manage to deal with day-to-day life, but once their baby is more stable, often the smallest things become great hurdles. Other members find that the first few years are manageable but once life is seemingly under some sort of control, the anxiety and stress of the first few months and years really affects them.

A quick look at research over the last ten years or so shows that much has been done in terms looking into the stressful experiences of mothers of preterm infants, and the long term implications of this. Research clearly shows that the mothers of preterm infants recorded significantly higher values for traumatic experience, depressive symptoms and anxiety<sup>1,2,6</sup>. It is also shown that emotional support for the mothers is necessary even 14 months after the birth<sup>1</sup>.

Other research<sup>3,6</sup> showed similar results, but also looked at what could be done. Conclusions reached included higher maternal education and increased perception of support from nursing staff had positive effects and that policies covering family centred care should be developed and implemented in the neonatal care environment, as well as intervention with specific programs aimed at reducing anxiety.

A multidisciplinary approach between obstetricians, paediatricians and psychiatrists is needed to detect and manage the many issues facing parents of preterm babies<sup>4,5</sup>, and to develop interventions that to help diminish the long-term impacts.

A longer-term study<sup>7</sup> found that parents of very low birthweight (VLBW, <1500g) babies were more likely to feel stressed than those of full term parents. Mothers of high risk VLBW infants had similar scores to those of low risk VLBW infants at 12 months, but by 24 months, the scores of the mothers of low-risk VLBW infants were similar to those of full term babies.

*Continued Page 4*

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The mothers of high-risk infants, however, were still reporting psychological stress. By the time the children were 3 years old, the difference had diminished, and the three groups of mothers' scores no longer differed significantly. A link between psychological stress and depression in the mother, and lower child developmental outcomes was also shown, making early intervention to support these mothers critical to both the wellbeing of mother and child.



There are no real "rules" about when someone will find the stress, anxiety, depression or trauma resulting from having a baby born early will hit. Finding someone to help if it does is very important. Sometimes sharing with other parents, through a group such as Austprem, and finding out that your feelings are shared by others is enough, other times a chat with your doctor or a therapist or counsellor might be required.

Enjoy your babies (and children)!

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## How does your baby grow?

A number of Austprem members have submitted their children's weight and length data at various ages so that we can all gain some perspective on how premature babies grow.

You can see the resulting chart at  
<http://www.austprem.org.au/journey/home/growth.shtml>

Further contributions most welcome!







## Sponsor Feature Product



These tiny hand signs **'Please wash your hands before you touch mine'** are proudly brought to you by **Moment By Moment**. They are made from a washable weather-proof silicone material and are ideal for almost any pram, stroller, car seat or baby carrier. The bright colour and stop sign shape make it almost impossible for anyone to miss—making everyone think twice before touching the baby! And at just **\$12.95**, they are one accessory you can be assured of getting value for your money! One customer said,

*I am the proud mother of twin boys who spent 96 days in the NICU. They were born at 25 weeks and only weighed 1 lb. 8 oz. and 1 lb. 6 oz. They are healthy 10 pounders now, but your sign has been such a help. It makes it so much easier to let the sign do the talking for you."*

Visit [www.momentbymoment.com.au](http://www.momentbymoment.com.au) — and don't forget to ADD 'Austprem' at the checkout!

## Pre Eclampsia Awareness Week 19th-25th August 2007



An association offering  
supporters and pregnant  
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For more information visit  
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Visit the  
**Austprem**  
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<http://www.austprem.org.au>

Contact Us:

[austprem@austprem.org.au](mailto:austprem@austprem.org.au)



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recipient at Step 5 when you order.

<http://www.toysandmore.com.au>

## Joining Austprem

Austprem is an Internet based support group.

To join Austprem Inc., you will need to go to

<http://www.austprem.org.au/join.html>

and fill out the online membership form. To access the online forums and chats (where most of the Austprem “action” happens), you will also need to follow the steps at

<http://www.austprem.org.au/forums.html>

to register with mc2 and subscribe to an Austprem group.

**Join now - it is a great opportunity to share with others who have “been there” and who can understand your experiences.**

## Membership is FREE!

Any information provided to Austprem is held in confidence and will not be used for any other purpose or given out to any third party without your permission.



PremiePress

PremiePress is a publication for those who are interested in the development of premature infants and prematurely born children.

For further information and subscription details please contact:

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## Austprem Forums / Message Boards

### → [Austprem - Forum](#)

Austprem provides a forum for Australian and N.Z. parents and caregivers of premature (or preterm) babies to discuss the issues and experience of prematurity in a local context. We welcome parents, extended family, NICU and MCH nurses and any interested health professionals. Through Austprem, families who have experienced the complex challenges of parenting a premature baby, reach out to other families facing this journey and offer friendship, information and support. Medical professionals are encouraged to participate in the discussions both to learn about the parental experience of prematurity and to offer insight and understanding.

### → [Austprem - Pregnancy Support Group](#)

The Austprem – Pregnancy Support Group has been set up for those who are contemplating or experiencing a pregnancy following a preterm birth, and for those at risk of giving birth prematurely.

Everyone is welcome to join Austprem – Pregnancy Support Group. You might be pregnant again, you might just be thinking about another pregnancy or you might have already completed a subsequent pregnancy and want to support someone else who is just starting on the journey. Sharing your thoughts and experiences might just help another mother, and support is what Austprem is all about.

### → [Prematurity in the Press](#)

This Austprem group is an online forum where summaries/abstracts of articles in journals, print/online media and book reviews etc that feature issues about prematurity are posted. Where possible links to the full text of the article will also be included, but this depends on the availability of the article and Copyright. This group is a semi-public group, non-members are able to read forum, but only members can post articles to the group and join in any subsequent discussions.

Take a look at

<http://www.austprem.org.au/forums.html>  
for information on how to join any of these Austprem Forums

## The Great Race

**Catrin Pitt**

I'm normally a strong person. Words like assertive, confident, calm describe me. So why am I a quivering mess?

My child, my prem baby is about to run his first race. He's tiny, standing in amongst the 'big boys,' but he's a big boy too. He's five. Or he will be next week, or in three months time, depending if you take his actual birth or his due date.

The school has taken his actual birth year. The system doesn't care that he was born 14 weeks early, that he should have been born the following year. The system says he has to run with all the boys born in the same year. Some of them were born at the beginning of the year, there's twelvemonths difference between my boy and them (taking his due date). It's not fair. I fought it, I complained, but to no avail. So my boy stands on the line with boys bigger than him, stronger than him, older than him. He looks so small, smaller now than when he was born. Then everyone was the same size, or smaller.

I want to protect him, to wrap him in bubble wrap, like he was for those first few days. But I want him to do his best, not to hold him back. What if he does well? What if he fails? What if?

The race starts whilst I'm in such turmoil, I don't get a chance to rush up and take him out. He's last to start, his learning difficulties mean his reactions are slower. He doesn't run fast, but he runs. He runs a steady pace, everything at his pace. Slowly he passes some kid, then another, and another. Slowly the boys in front stop and walk. My boy doesn't. Like his time in hospital, one step forward, followed by another. Unlike then, there are no steps backwards, just forward.

I count boys as they cross the finish line, "One, two, three, and four..... nine..." Then there is my boy. He's tenth! He is tenth out of over fifty. Fifty boys born in the same year as he was. Fifty boys who were born full term. Forty of them are not as good as my boy. He walks up to me, his grin matching my own. I believe that if the sun disappeared today, his smile would light up the world.



## Great Resource!

### Parenting Your Premature Baby and Child

The price remains at \$44.95 (including delivery to your door)!

To order your copy, please email [austprem@austprem.org.au](mailto:austprem@austprem.org.au)

or visit <http://www.austprem.org.au/promotion/books.shtml>





## The Roses Are Still Red

*Jacqui Dalling*



Born at 27 weeks following an APH, Marshall almost made it out of ICN with the all clear. On the day he was being transferred to Special Care, we received the devastating news that PVL had showed on his brain ultrasound. The Neonatologist in Charge of ICN actually showed me the scans. There were two small flecks in the white matter. So small that you had to squint to see them. Small but present. And that was what announced Marshall's eventual diagnosis of cerebral palsy.



In some ways I think we were lucky for those small dots to have been spotted. His next brain scan, a month later, was all clear. Those two dots had caved in and the white matter looked normal. I know of many children who left ICN with the all clear, only for it later to be found not to be the case. Apparently the scan has to be done at the right time for the damage to show.

I have learnt that "all clear" doesn't really mean "all clear" in the ICN. But sometimes the one thing that you fear most of all, is something that isn't as bad as you imagine.



If you had have told me that I was going to have a child with a disability, I would have scoffed at you. There is no way that I would have thought that I could handle it. And yet, that is exactly what I do each and every day.

Life is frantic. But it is also good. A steep learning curve. Sometimes incredibly frustrating (particularly when dealing with government departments). And yet, the small things no longer get overlooked. I appreciate life just that little bit more. The roses smell very fine indeed.

It hasn't always been that way though. I've read a few papers on the grieving process involved in having a child with a different life to the one you expected. The experts go on about your (the parent's) lost dreams. In the long run, I don't think your dreams are lost. They are just changed. Altered. And I can tell you that they get changed when you have neurotypical kid too.

My 15 year old is the perfect example of this. The life I thought he would have and the life he wants to have are completely different. And yet, that is still fine by me. You cannot live your life through your child. It just doesn't work that way. Maybe when you have a different child that realisation comes a lot quicker. Or maybe that was just my realisation.

The experts also talk about the seven stages of grieving. Blah! You can go through the seven stages all in one day, depending upon what is going on in your life. You can go back two stages to grief when someone calls your kid "a poor little soul". You can jump two more stages to anger when someone tells you that you have mistakenly parked in the disabled car spot. There is no exact path. No timeline. Just you.

*Continued Page 11*







Aromababy

# National Premature Birth Awareness Week IS COMING 24th-30th November 2007

# Austprem says,



## September

1 Thomas (3)	10 Olivia (7)	15 Alannah (2)	19 Deakon (1)	25 Taea (2)
2 Malachi (3)	11 Tiffany (4)	15 Justin (1)	20 Kaitlyn (2)	25 Bailey (2)
3 Sharna (14)	12 Samuel (9)	16 Meridith (9)	20 Emily (2)	26 Jolyon (2)
3 Connor (5)	12 Tavien (1)	17 Abby (7)	21 Cibella (5)	27 Skye (4)
4 April (3)	13 Aiden (4)	17 Danica (7)	21 Samantha (5)	27 Alyssa (4)
5 Finnegan (2)	13 Alexander (3)	17 Katja (1)	21 Toby (3)	27 Shantel (3)
6 Jack (5)	14 Lachlan (2)	17 Arnika (1)	23 Casey (8)	28 Joshua (6)
6 Christopher (1)	15 Nicholas (10)	18 Isabella (3)	23 Connor (5)	28 Declan (2)
6 Olivia (1)	15 Ashleigh (10)	18 Aaron (3)	23 Hayley (3)	29 Jazzmin (12)
7 Lily (3)	15 Griffin (5)	18 Kael (2)	25 Michael (11)	30 Renee (8)
9 Amelia (9)	15 Erin (4)	19 Hunter (94)	25 Camberon (10)	
9 Patrick (8)	15 Abby (4)	19 Jaiden (2)	25 Hanna (5)	

## October

1 Madeline (11)	8 Emily (4)	16 Tristan (1)	25 Connor (5)	31 Chloe (3)
2 Rhys (6)	8 Ethan (4)	17 Kayla (9)	25 Ashley (4)	31 Joshua (3)
2 Erin (1)	9 Ella (4)	18 Caitlin (5)	25 Eric (2)	31 Livi (3)
2 Tyler (1)	9 Dechlan (3)	18 Jesse (3)	25 Jade (2)	
3 Mason (7)	10 Elim (6)	19 Harrison (4)	26 Tahneisha (3)	
3 Cain (6)	10 Jaime (5)	19 Micaela (4)	26 Mark-Anthony (1)	
3 Jessica (2)	10 Charlie (5)	20 Sharn-Allen (3)	26 Ollie (1)	
4 Kevin (8)	12 Huon (8)	20 Callum (2)	28 Ryan (11)	
4 Isabelle (2)	12 Jonathan (4)	20 Louis (1)	28 Emily (10)	
4 Jayden (1)	12 Amelia (2)	21 Kaden (5)	28 Callum (4)	
5 Joshua (2)	13 David (1)	23 Jaden (6)	28 Jack (2)	
6 Vincent (13)	14 Amelie (2)	23 Maddison (4)	28 Emily (2)	
6 Liam (7)	15 Eden (7)	23 Owen (2)	28 Ryan (1)	
6 Nicoletta (4)	15 Samuel (4)	24 Liam (5)	28 Jack (1)	
7 Samuel (3)	16 James (4)	24 Stefani (5)	31 Caitlyn (4)	

## November

1 Annie (5)	9 Rebecca (9)	17 Amy (2)	25 Bradley (3)
1 Karlie (4)	9 Kade (2)	18 Emily (3)	25 Mikeal (3)
2 Oliver (3)	11 Caitlin (4)	18 Connor (2)	25 Nicholas (1)
2 Bailey (1)	11 Amelia (2)	19 Adrian (5)	26 Zachary (6)
3 Amaya (4)	11 Sophie (1)	19 Elliot (3)	26 Dante (4)
4 Benjamin (8)	12 Lewis (14)	19 Talon (3)	26 Isabelle (3)
4 Katinka (2)	12 Kyle (14)	20 Jay (4)	27 Francis (5)
5 Samuel (5)	12 Cooper (2)	20 Indyannah (2)	27 Grace (1)
5 Peter (3)	13 Isabella (4)	21 Khyle (9)	28 Madelyn (5)
5 Ethan (3)	13 Zoe (4)	21 Thomas (6)	28 Jobie (3)
7 Mitchell (5)	13 Jarred (3)	21 Finnian (4)	29 Jessica (1)
7 Grace (2)	14 Hannah (6)	22 Jorja (2)	30 Lizzie (4)
8 Lianna (5)	15 Eilish (6)	23 Jessica (9)	30 Noah (2)
8 Keeley (5)	15 Amy (5)	24 James (5)	30 Ivy (2)
8 Thomas (4)	15 Hanna (5)	24 Maxwell (5)	
8 Isaac (4)	17 Shea (5)	24 Ebonee (1)	
9 Tahlor (9)	17 Blake (3)	25 Alasdair (5)	

*Our Angel Jaxon  
born 7th September  
2004*



*Our Angel Lauryn  
born 8th November  
2004*



*Our Angel Cassie  
born 11th November  
1993*



*Our Angel Jack  
born 14th November  
2001*



*Our Angel Tainn  
born 17th November  
2002*



*Our Angel Jessica  
born 21st November  
2001*



From Page 8

Everyone handles it differently. Just as your family will handle the realisation differently.

Say for example my husband and his parents. Hubby thought diagnosis was rubbish for the first year. Then when Marshall's limitations became so in your face and obvious to strangers, he eventually conceded that there was indeed a problem.

My parent-in-laws on the other hand - well they still can't even pronounce cerebral palsy, let alone tell you what type of CP Marshall has. They won't admit that he has anything wrong with him and believe that he will just catch up in his own time. Never mind that he is now 3 years old and can't sit up on his own. My mother-in-law takes him to spiritual healers cause that's what she believes in. They all tell her that he will walk because that is what she wants to hear. She isn't ready to accept anything different. But this is her process, not mine. I'm sure she will get there in the end, even if her "there" isn't the same place as my "there" is.

My mother, as another example, is supportive - so long as her hands are not the ones getting dirty. She once told me that *we were going through this together*. Funny thing is, it feels to me like I'm the only one in the trenches, fighting the good fight. Everyone else is hiding behind a bush saying *I'll be there in a minute*.

As hard as this is, it is the way my Mum handles having a disabled grand-child. And who am I to criticise?

Right here. Right now. For me and for the family, the roses are still red and they smell divine. We don't dwell on the negatives because if you do, they will consume you. So, the sun is still shining and everything is going to be okay in the end.

Because, if it's not okay, then it's not the end.

## Austprem Inc.

### Official Notice is given of the Annual General Meeting

to be held on  
Sunday 26<sup>th</sup> August 2007

at 6:30pm (WA) / 8:00pm (SA & NT) /  
8:30pm (AEST)

in the Austprem Chat Room  
(if you are not a member of the  
Austprem Forum on mc2, you will  
need to join before the meeting to  
access the Chat Room there)

All nominees for positions, as well as  
those wishing to nominate someone or  
to vote in any election, must be  
registered members of Austprem Inc.

To register, if you haven't already,  
please complete the form at

[http://www.austprem.org.au/about/  
membershipform.shtml](http://www.austprem.org.au/about/membershipform.shtml)

This must be done by  
**5:00pm, Sunday 19th August 2007.**

Further information regarding  
nominations will be posted to the  
Austprem Forum prior to the Meeting.

## Celebrating Birthdays

If you would like your children (full term and prem) listed in the *Austprem Ink* newsletter, or to be added to the Birthdays page at <http://www.austprem.org.au/journey/superheroes/birthdays.shtml> please email [kirsten@austprem.org.au](mailto:kirsten@austprem.org.au)





## Feel like chatting with members of Austprem?



Chats are a great way to get to know other members better. They are usually held on Thursday (not in January) and Sunday nights. A reminder is usually posted to the Austprem Forum the day before a chat, so check there for the exact time. The chats are held in the Austprem Chat Room on the mc2 site, so only Austprem members are able to attend. Chats times (for Thursday and Sunday nights):

7:00pm	WA
8:30pm	NT, SA
9:00pm	VIC, TAS, ACT, NSW, QLD
11:00pm	NZ

*These times may change, so please check the Forum for reminders and updates.*

# Austprem Inc.

Premature birth,  
babies and beyond



## You Name It Labels Fundraiser

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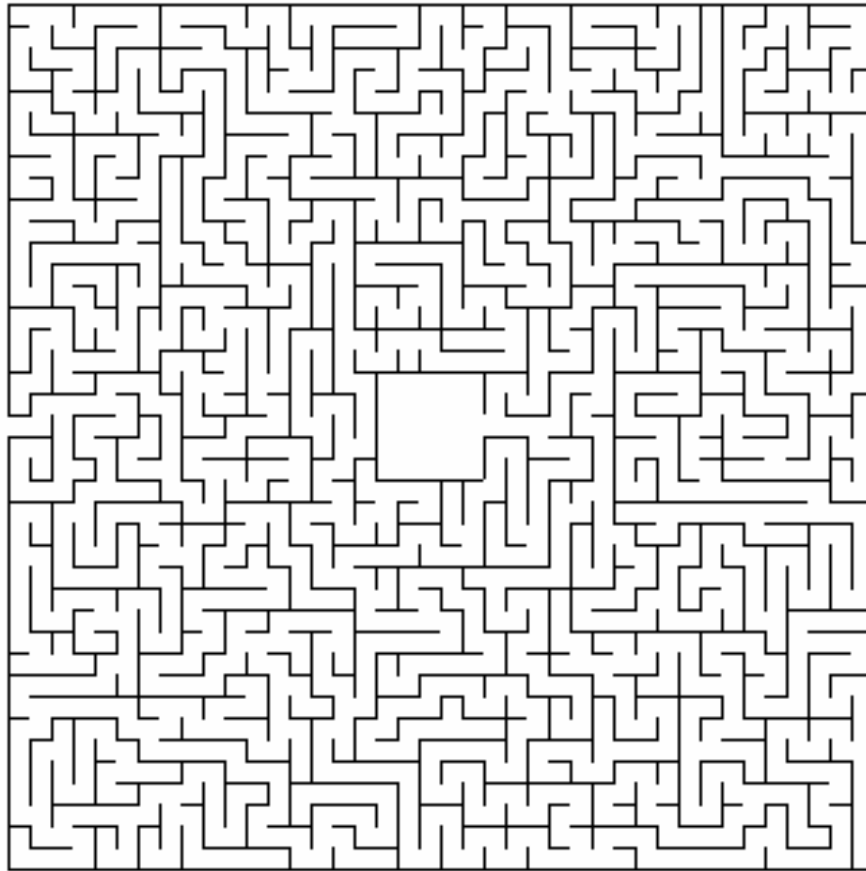
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## Austprem Ink Puzzle Corner

Find your way through the maze!



### What is Austprem Inc.?

Austprem is registered as a non-profit organisation with the Australian Taxation Office. We are also an approved charity. Our aim is to provide support to as many of those parents of premature babies as we can. Your support can help us to achieve this goal. Membership of Austprem is open to anyone who has a prematurely born baby or child. Further information about Austprem can be found at [www.austprem.org.au](http://www.austprem.org.au), or by emailing [austprem@austprem.org.au](mailto:austprem@austprem.org.au)

Austprem also offers online support forums including *Austprem*, *Austprem - Pregnancy Support Group* and *Prematurity in the Press*.



### Donations - Your support is greatly appreciated!

Austprem Inc. is a non-profit organisation with no on-going funding.

If you would like to make a donation to Austprem Inc., please send your cheque or money order to:

Austprem Inc. P.O. Box 2157 Sunbury VIC 3429

Please include your name and address so that a receipt can be posted to you.  
Donations \$2 and over are tax deductible.



## Your Austprem Committee

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Austprem Ink

Premature birth, babies and beyond

**A**ustprem Inc. asks that you please check with your doctor or health care provider as to what interventions are appropriate for YOUR baby!



## Copies of Austprem Ink

may be downloaded from:

<http://www.austprem.org.au/newsletters.shtml>



## Benefits to all involved

**RITCHIES**  
ESTABLISHED 1979

## Ritchies Community Benefit Card

Buy your groceries, and support Austprem too!  
Simply nominate Austprem Inc. as your CB Card recipient and 1% of your purchase total will be donated to Austprem.

The Ritchies Community Benefits Program operates in both Victoria and NSW.

Victoria: Austprem Inc. CB number is 93772

NSW: Austprem Inc. CB number is 93807

More information:

<http://www.austprem.org.au/promotion/ritchies.shtml>

## Disclaimer

Please note that Austprem Inc. does not recommend that any interventions are made to any baby or child without the knowledge and assent of the child's doctor or other health care provider.

Austprem Inc. cannot be held liable for the actions of any person based on information that Austprem Inc. has provided.

## Suggestions and Comments?

[newsletter@austprem.org.au](mailto:newsletter@austprem.org.au)

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