Premature birth, babies and beyond



AT A GLANCE

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

## <u>WHAT YOU'LL</u> <u>FIND IN THIS</u> <u>ISSUE</u>

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National Premature Birth Awareness Week

Austprem

Volume 5 Issue 4

24-30 November



Awareness. Research. Support.





Solving the puzzle of premature birth

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# Joining Austprem

Austprem is an Internet based support group.

To join Austprem Inc., you will need to go to <u>http://www.austprem.org.au/join.html</u> 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 <u>http://www.austprem.org.au/</u> 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: Carol Newnham

carol.newnham@austin.org.au Clinical & Health Psychology 1st Floor, South Wing, Centaur Building Heidelberg Repatriation Hospital 300 Waterdale Road Heidelberg West VIC 308

## 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, complex families who have experienced the 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, nonmembers are able to read forum, but only members can post articles to the group and join in any subsequent discussions.

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

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## National Premature Birth Awareness Week 24 - 30 November www.bornearly.org.au



"Preterm birth continues to be a major cause of neonatal deaths. Despite continuing research efforts, the number of women delivering preterm has not decreased over the last two decades. Part of the reason for this is that there are a number of causes for preterm birth. The only existing therapies work best if given early so it is important for women to be aware of potential problems and to seek help if they think something may be wrong"

### Dr Penny Sheehan

Staff Specialist Obstetrician Team leader maternity care program and preterm labour clinic Clinical Research Fellow, Pregnancy Research Centre Patron BORN EARLY Appeal

November 2007 will see the inaugural National Premature Birth Awareness Week!

NPBAW will run from 24 - 30 November each year. There are two main foci to the week. One is a celebration of those babies who have been born early, by giving those in hospital a gift. The other is to raise awareness of the signs and symptoms that may lead to premature birth – this is of relevance to EVERY pregnant woman and we hope that we can get the message out. If just one woman goes to her doctor sooner and so has time for steroids, or to be transferred to a hospital with a Level III NICU prior to the birth, we will consider our campaign a success.

The main signs and symptoms which might lead to premature birth can be summed up by:

Backache or pelvic pressure

Oedema swelling of hands or face

Regular contractions

Nausea, vomiting, diarrhoea and other flu-like symptoms

Eye or vision disturbances

Abdominal pain or cramps

Reduction in foetal movements

Leaking fluid from vagina

 $\gamma$ ou are worried, concerned or just don't 'feel right'

Visit the BORN EARLY website http://www.bornearly.org.au, in particular

<u>http://www.bornearly.org.au/npbaw</u> and look at some of the event ideas – you could organise something for your school or workplace. There is also a range of merchandise available for purchase through the Austprem BORN EARLY Online Shop.

Yesterday 57 babies were born prematurely.

Yesterday 57 families began the heartache of watching their baby struggle for life.

Yesterday **more** babies were born prematurely than 10 years ago.

The reason most of these babies are born early is still not known.

Without understanding the causes, there can be no cures.

# With your support, we can solve the puzzle of premature birth, one piece at a time.

for event ideas see http://www.bornearly.org.au/npbaw



Solving the puzzle of premature birth

www.bornearly.org.au

## Prematurity facts and figures

Each year in Australia around 8% of babies are born prematurely, that is about **57 babies being born early each day**.<sup>1</sup> A pregnancy generally lasts between 37 and 42 weeks; a preterm or premature baby is born before 37 weeks gestation. A recent population based study<sup>2</sup> looking at 10 years of preterm births found that the rate of spontaneous preterm birth for low-risk mothers having singleton births had actually increased between 1993 – 2004. Prematurity is an ongoing problem, and as the study states:

"What is most apparent is the fact that very little can be done to prevent the rising rates of preterm birth, while the causative factors remain uncertain"<sup>2</sup>

Prematurity not only affects the families directly involved but the costs related to intensive care for the babies are high, with sums for hospital stays for some of these babies easily reaching tens of thousands of dollars.<sup>3</sup> Decreasing the number of babies born early will have an impact on health expenditure by the hospitals, as well as other services such as early intervention, and will also save many families from having to experience the trauma of a premature birth.

<sup>1</sup> Laws PJ, Grayson N & Sullivan EA 2006. Australia's mothers and babies 2004. Perinatal statistics series no. 18. AIHW cat. no. PER 34. Sydney: AIHW National Perinatal Statistics Unit.

<sup>2</sup> Tracy S, Tracy M, Dean J, Laws P, Sullivan E. Spontaneous preterm birth of liveborn infants in women at low risk in Australia over 10 years: a population-based study. BJOG 2007;114:731–735

<sup>3</sup> Doyle LW. Evaluation of neonatal intensive care for extremely low birth weight infants in Victoria over two decades: II. efficiency. Pediatrics. March 2004 v113 i3 p510(5).

## National Premature Birth Awareness Week

The inaugural **National Premature Birth Awareness Week** will be held from 24 – 30 November 2007. Saturday 24<sup>th</sup> November will see cooler bags distributed to all Level III nurseries in Australia The bags will be packed with samples, vouchers and useful information for parents of premature babies.

As a part of increasing knowledge about premature birth, Austprem Inc. will be offering information to ALL pregnant women in the hope of decreasing the rising numbers of premature births in Australia with Austprem Inc.'s new brochure

## "Pregnant? It's probably nothing but it might be something.

The brochure will be launched during National Premature Birth Awareness Week. and contains a summary of the indications that may lead to premature birth and encourages women to check with their doctor, hospital or health care provider if they are at all concerned.

## Austprem BORN EARLY Appeal

The *Austprem BORN EARLY Appeal* hopes to raise sufficient money over time to fund research into the causative factors of premature birth, in the hope of reducing the number of babies born early. It is difficult to combat the increasing number of early arrivals when so little is known as to the causes.

As part of the *Austprem BORN EARLY Appeal*, merchandise, including ribbons, will be on sale to help raise funds. Donations are of course welcome and those over \$2 are tax deductible.

Those wishing to make a donation or purchase merchandise can visit http://www.bornearly.org.au/shop and place your order online.

#### Austprem Ink

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## **Sean's Poem**

## Sean Simpson

Kai was initially in hospital for 56 days and was sent back to hospital 3 times afterwards. He has now been home for about 3 weeks without incident and touch wood he stays that way. I am finally able to reflect on what has happened over the past four and a half months. I thought I would put pen to paper and write a poem.

Time stands still, the day has arrived A baby born early, has he survived? Emotions are torn, what should I do? Lost in a world that's so new to you.

The baby is rushed into NICU care Mum on a table, it doesn't seem fair A mother and baby, two floors apart Separated by distance, connected by heart

You stand on the outside as the scene flashes by The team go to work, don't let him die Tubes and machines keep him alive You pray for a miracle, let him survive.

The doctors they tell you, prepare for the worst Your world tears apart your dreams are immersed He is far too small, he has a battle ahead You search for some hope in the eyes of the Ped.

The day turns to night and the team goes away A doctor and nurse are the only to stay The clock goes so slowly yet the hours still pass Your try to reach out to that face behind the glass

Your life is the monitor you watch every beat You watch every breath; you don't leave your seat You don't leave his side he is your blood and your life You would give your left arm and so would your wife.









A father's pain is hard yet it only seems token Compared to a Mum who lays battered and broken Her dream has been robbed and so has her joy Her only life's wish is to hold her new boy.

As night starts to deepen you start to reflect You start to question what to expect You try to reason you try to make sense You feel joy yet your pain is intense

The longest night in history draws to a close The day that stood still, the day where time froze The smallest human you have ever seen So tough, so hard, courage unseen.



Hours become days and days become weeks Weeks become months, with falls and peaks The road is long the journey is hard The climb is tough your mind is scarred.

But your family and friends are there, you're not alone Your soldier on regardless as NICU becomes your home

Those brilliant doctors and staff are there on your ride With those Angels of MERCY there at your side

How can one so little be so tough and brave And defy all the odds that once looked so grave A heart the size of the MCG in a body built so small He took on every challenge and answered every call



Sometimes when he is sleeping, I sit there at his side And appreciate every second and watch him with such pride

Our boy came home, his battle was hard, the lucky we were among

Some Angels stay there forever, forever they are young.





# What I've learnt from my daughters in their first year of life....

- 1. If you want something, make it known otherwise no-one will know.
- 2. If you want to do something, keep working at it, no matter how often you fall on your burn, you will eventually be able to do it.
- 3. Everything is worth studying in detail at least once even the tags on soft-toys.
- 4. It's ok to be happy most of the time.
- 5. Smile at everyone, they usually smile back.
- 6. It's ok to find amusement in simple things like hiding behind your own hands to play peek-a-boo.
- 7. Soft-toys are worthy of extended cuddles.
- 8. It's important to have a special friend to take to bed with you.
- 9. When you want a hug, go get it.
- 10. If you are told no, keep trying sometimes you may get away with it.
- 11. Some boundaries in life are not able to be pushed, but most of them are.
- 12. Take care of yourself eat when you need it, sleep when you need it and follow your instincts.
- 13. Explore everything go places you haven't been before.
- 14. Even non-edible items might be fun to chew on.
- 15. Just because you've done something before, doesn't mean you can't find new joy in doing it again.
- 16. When you achieve something, be proud of yourself you deserve to be and it doesn't matter what anyone else thinks.
- 17. When you see yourself in the mirror, it's ok to smile and like the person looking back at you.
- 18. Believe in yourself and that you can do anything you set your mind to.
- 19. Talk, sing, giggle, laugh and dance whenever you feel like it.
- 20. Be in the moment, enjoy what's happening right now and don't worry about later for this moment will pass soon enough.
- If you see someone doing something that looks like fun and you want to join in, just do it.
   You never know how much fun you might have.
- 22. You can get away with A LOT, just by being cute!





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austprem@austprem.org.au



Order your toys online, get great products, delivery to your door and support Austprem too!

Simply nominate Austprem, Sunbury, VIC as the fundraising recipient at Step 5 when you order.

http://www.toysandmore.com.au

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#### Austprem Ink



## PCOMDE

7 Jett (2)

7 Jeremy (2)

9 Xavier (10)

9 William (9)

9 Sam (3)

9 Lea (3)

9 Annabelle (6)

10 Brandon (9)

8 Katya (1)

Austprem says.

1 Bella (7) 1 Jessinda (5) 1 Flynn (2) 1 Halle (2) 1 Sebastien (2) 2 Mathew (3) 3 Christopher (11) 3 Rhodry (7) 3 Kyle (4) 5 Maddy (4) 5 Sophie (3) 6 Rhiannon (10) 6 Rebekah (8) 6 Brock (4) 7 Ella (2) 2

11 Ziggy (1) 2 Leonie (9) 2 Gemma (2) 3 Brooke (8) 3 Charlotte (5) 3 Erin (2) 3 James (2) 4 Charlie (1) 5 Tony (6) 5 Bianca (6) 5 Toby (3) 5 Jack (2) 5 Liam (1) 6 Archisha (3) 6 Paige (3) 6 Airlie (2)

10 Coen (8) 10 Oliver (6) 10 Zoe (4) 11 Connor (9) 11 Zali (3) 12 Lachlan (5) 6 Robert (1) 7 Dylan (5) 7 Oliver (2) 8 Emily-Jade (10) 8 Caleb (10) 8 Zeth (6) 8 Kaleb (3) 8 Corey (1) 10 Enrico (3) 10 Chloe (2) 11 Alesya (5) 11 Mackenzie (5)

11 Devlyn (4) 11 Amber (3) 11 Byron (3) 11 Benjamin (2)

## Boruañ

1 Ellandi (9) 1 Jack (7) 1 Kaihdyn (5) 1 Alice (2) 1 Charli (2) 2 Blair (9) 2 Thomas (3) 2 Thomas (3) 3 Dylan (7) 3 Elizabeth (7) 3 Lee (5) 3 Tyler (4) 3 Tom (3) 3 Isabella (3) 3 Boston (2) 4 Tallina (11) 4 Marcus (4)

4 Lachlan (3) 4 Victoria (3) 4 Tylah (2) 5 Aliesha (8) 5 Sophia (4) 6 Lily-Jai (3) 6 Jackson (2) 7 Maximus (4) 7 Jethro (3) 7 Xavier (2) 7 Robert (1) 8 Alexander (3) 8 Sarah (1) 8 Ava (1) 9 Lane (5) 11 Bailey (10)

11 Zac (10)



12 Isaac (4) 12 Molly (2) 12 Finn (2) 12 Eli (2) 12 Zak (2) 13 Joshua (4) 14 Angus (4) 14 Philippa (1) 15 Mathew (4) 17 Hannah (10) 17 Emma (3) 18 Tanika (11) 18 Tyson (11) 18 Corey (11) 19 Chloe (3)

11 Liam (1) 12 Connor (8) 12 Charlotte (4) 12 Julian (3) 13 Kade (5) 13 Mitchell (3) 14 Wisaal Yasmina (6) 14 Bobby (4) 14 William (4) 14 Alyssandra (1) 15 Timothy (7) 15 Jessica (5) 15 Tiernan (4) 16 Caellum (6) 17 Beauden (3) 17 Alexander (2)

11 Hannah (4) 12 Alexander (6) 12 Marcus (5) 12 Lachlan (5) 12 Samantha (2) 13 Chloe (10) 13 Memphis (3) 14 Zoe (6) 14 Heather (5) 14 Jayde (4) 14 Lauren (4) 14 Ryan (4) 14 Abigail (3) 14 Isaac (2) 15 Sarah (5) 16 Joshua (7) 16 Samara (3)



20 Rory (6) 20 Gideon (5) 20 Lottie (3) 21 Elaina (6) 21 Jon (2) 21 Connor (2) 21 Ben (1) 21 Matthew (1) 22 Natasha (11) 22 Layla (8) 22 Brandon (3) 22 Shane (1) 23 Benjamin (2) 24 Emma (3)

19 Tara (1) 19 Taj (1) 21 Harry (3) 21 Madeleine (3) 23 Caitlyn (5) 23 Seth (5) 23 Emerald (2) 24 Campbell (4) 24 Sebastian (4) 24 Tayah (3) 25 Sharon (7) 25 Bailey (6) 25 Benjamin (3) 25 Elise (3) 26 Chloe (5) 26 Nathan (4)

16 Kate (3) 16 Kyle (3) 17 Victoria (6) 18 Zackery (4) 18 Tallis (3) 19 Xander (4) 19 Thomas (1) 20 Therese (7) 20 Jacob (7) 21 Nick (11) 21 Connor (8) 21 Liam (4) 21 Iman (3) 22 Chloe (9) 22 Eponine (9) 22 Xander (4) 23 Jasmine (7)



24 Brandon (3) 24 William (3) 24 Amelia (1) 25 Olivia (7) 26 Brianna (3) 28 Jack (6) 28 Calan (2) 29 Liam (10) 29 Jack (6) 29 Morgan (5) 29 Matthew (3) 30 Izabella (3) 31 Stephanie (1)

26 Joshua (2) 27 Cooper (3) 27 Rhyley (2) 27 Bailey (2) 29 Tye (11) 29 Ben (5) 29 Savanah (4) 29 Aidan (4) 30 Kyle (7) 30 Jared (4) 30 Jacob (2) 30 Samuel (2) 31 Robert 4) 31 Jaryd (3)

23 Lily (7) 23 Rachael (6) 23 David (6) 23 Nathan (5) 24 Caitlin (10) 24 Kaleb (2) 25 Jakson (4) 26 Thomas (9) 27 Kurtis (12) 27 Constantine-Antonio (2)27 Jasper (1) 28 Angus (2) 28 Hannah (2) 29 Declan (4)

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## 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

Purchase address labels, stick on and iron on name labels for clothing, bottles, snack boxes etc, and heaps of other stuff, and support Austprem too!

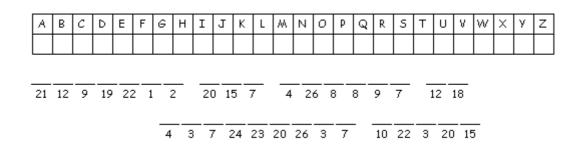


Order at http://www.younameitlabels.com using our code <u>aiv0603</u> (all lower case, no spaces).

More details from: http://www.austprem.org.au/promotion/ you name it.shtml

# Austprem Ink Puzzle Corner

This quarter's puzzle is a Cryptogram, making a very timely phrase! Send your answer to newsletter@austprem.org.au to be in the running for a prize!





Austprem Inc. wishes everyone who reads this a safe and happy Christmas and New Year.

I am sure 2008 will be another busy year, we will be working towards the Second National Premature Birth Awareness Week and hope to organise some more get-togethers for our members. If you have any suggestions about what you would like to see happen, please send an email to austprem@austprem.org.au - we look forward to hearing from you!



# Onations - 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 you name and address so that a receipt can be posted to you. Donations \$2 and over are tax deductible.



## Your Austprem Committee

President Leanne Uwland Vice President Catrin Pitt Secretary Kirsten Burkitt Treasurer Leanne Uwland Chat Host Coordinator Nadine Jones QLD State Rep. Catrin Pitt NSW/ACT State Rep. Liz Mattiuzzo VIC State Rep. Jessica White Austprem Ink Editor Kirsten Burkitt Other Committee Members Lorina Clements Narelle Kerry Gillian Menzies

http://www.austprem.org.au

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 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

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