

### 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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# 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> <u>forums.html</u>

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.

#### →<u>Austprem - Pregnancy Support Group</u>

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

### Did you know?

Around 8% of babies in Australia each year are BORN EARLY (about 57 babies each day)<sup>1</sup>

The rate of spontaneous preterm birth for low-risk mothers having singleton births had actually increased between 1993 - 2004<sup>2</sup>

Over 6% of liveborn babies were of low birthweight (less than 2,500 grams)<sup>1</sup>

15.5% of all liveborn babies were admitted to a special care nursery or neonatal intensive care unit<sup>1</sup>

Almost 5000 preterm babies were admitted to level III neonatal intensive care units in Australia in 2005<sup>1</sup>

Just 0.9% (2,399) of babies were born between 20-27 weeks gestation, 0.8% (2,217) between 28-31 weeks, and 6.4% between 32-36 weeks (17,407)<sup>1</sup>

13.9% of babies born to Aboriginal and Torres Strait Islander mothers were preterm

The World Health Organisation (WHO) defined birthweight categories in 1992:

Low birthweight = <2500g (6.4% of babies in 2005)

Very low birthweight = <1500g (1.1% of babies in 2005)

Extremely low birthweight = <  $1000g (0.5\% \text{ of babies in } 2005)^{1}$ 

In 2005, 79.8% of babies born at <28 weeks survived to go home

<sup>1</sup> Laws PJ, Abeywardana S, Walker J, & Sullivan EA 2007. Australia's mothers and babies 2005. Perinatal statistics series no. 20. AIHW cat. no. PER 40. 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

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### Statistics and Outcomes

If you have ever studied statistics, you would know that the probability of any given event is 0 (zero). However, we all know that things happen! The world of prematurity is rife with statistics, and it can be difficult to understand what they all mean. There are tables of outcome data, information about the chances of this, or the likelihood of that, but no one seems to be telling you what this means for YOUR baby.

Statistics are always based on populations. They are compiled from data obtained by various means, and it is important to know where the data comes from before drawing any conclusions. Data from another country or another hospital's NICU may be less relevant to your NICU. Data from many years ago may be less relevant now. But no data will describe your baby. Your baby is an individual and statistics aren't about individuals. Basically, for your baby every statistic is either 100% (the event occurs) or 0% (it doesn't).

So although statistics can be helpful in showing trends, or what might be, or even giving you some idea of what to expect, they cannot tell if or how well your baby will survive the NICU experience and beyond.

That being said, many of us are desperate for information and outcome data about premature babies. We need to know our babies chances, likelihoods and odds. We rejoice when our baby "beats the odds", and are dejected when the chances go against the most positive outcome.

If you want more information about your baby, the best thing to do is ask those caring for him/her. Sometimes it can be hard to ask a question when you aren't sure what is happening in the first place. Suggested questions you may like to ask include:

1. What medical problems are affecting my baby now?

2. How can I get more information about my baby's problems?

3. How are those problems being treated?

4. What side effects could those treatments have?

5. Are there reasonable alternative treatments we could consider?

6. How can I get more involved in my baby's care?

7. What can I do to best nurture my baby?

8. How do I find emotional or spiritual support?

9. Can the newborn ICU's social worker help me with transportation, accommodation, financial aid, or other practical problems while my baby is in the newborn ICU?<sup>1</sup>



## Statistics and Outcomes

These questions should be redressed whenever there is a significant change in your baby's condition, or if your circumstances change, as the answers may have changed also.

Remember, though, there are no definite answers. The doctors would love to be able to tell you for sure that your baby would have no problems in the future, or the precise limitations that may face him or her, but they can't. Which brings us back to the statistics – they can give you an idea of what might be to come, the battles you may be facing, or what you might be up against, but you won't know until your child achieves (or doesn't) any given event, if that statistic applies to them or not.

## Gestation vs Outcome Table

This table is based on information from babies born at less than 29 weeks in 1996 in 50 NICUs across the U.S. (a total of 2025 babies); it only looks at those babies admitted to the NICU, so doesn't include those who could not be resuscitated at birth. And, of course, in 2008 this table is looking at "older" treatments for the various complications of prematurity, so the data from today may be a little different.

	GESTATION IN WEEKS			
Estimates for survivors:	23	24	25-26	27-28
total number of babies admitted to NICU in 1996	209	291	455	761
(% of babies who survive )	(18)	(52)	(81)	(91)
% of survivors with breathing problems needing assisted ventilation	100	98	98	90%
Average no. of days fully ventilated	59	40	30	15
% of survivors needing extra oxygen for >1 month.	100	100	80	47
Average no. of days in hospital before going home/baby: MDS data only	130	97	91	69
significant abnormal brain scans %	23	20	19	10
Jaundice needing phototherapy %	100	73	85	83
Heart condition (PDA) needing treatment %	31.6	52	53	36

MDS, Medical Data Systems

<sup>1</sup> Derleth, Doug. An introduction to extremely preterm babies <u>http://members.aol.com/DDerleth/extreme.html</u> as retrieved on 12 Feb 2008 06:11:51 GMT. <sup>2</sup> Koh THHG, Harrison H, Morley C. Gestation versus Outcome Table for parents of extremely premature infants Journal

of Perinatology (1999) 19 (6) 452-3

# National Premature Birth Awareness Week

# UPDATE

24 - 30 November 2007 saw the inaugural National Premature Birth Awareness Week. Cooler bags were distributed to every family with a baby in NICU or SCN at a Level III hospital and were welcomed and much appreciated.

**Earlybirds** and **Aromababy** were the main sponsors for the bags and their support was invaluable. Huge thanks also to **David Docherty of D&D Mailing** in Noble Park, Victoria. **D&D Mailing** packed and distributed bags to our helpers all over Australia. The helpers then took the bags into the hospitals and gave them to the families. Thank you to all those helpers around Australia for their support - we couldn't have done it without you.

The brochure "Pregnant? It may be nothing but it might be something" focusing on the signs and symptoms leading to premature birth was launched during the week. It's final format was put together by **Grant from Grant Gittus Graphics**, he did a wonderful job and we would like to publicly thank him also.

Thank you too to everyone who bought Awareness Week Ribbons and Blankie Squares or held Morning Teas. I know that at my work I heard from a number of people who had had prems, been prems or knew prems and they were generous in their support.

I would like to encourage everyone to start thinking about **National Premature Birth Awareness Week 2008** and what YOU can do to help. Every little bit counts!

Merchandise, including Awareness Week Ribbons, Cooler Bags and Blankie Squares may be purchased at any time from the Austprem BORN EARLY Online Shop at <a href="http://www.bornearly.org.au/shop">http://www.bornearly.org.au/shop</a> - you don't have to wait until the next Awareness Week!

### Special thanks to all our sponsors:

Earlybirds D&D Mailing Grant Gittus Graphics Aromababy Kiwi Green Exquisite Children Bambini International Marakye Think Twins Moment-by-Moment



24-30 November www.bornearly.org.au

National Premature Birth Awareness Week



# The BORN EARLY Blankie

A new Blankie square costs just \$20; once an initial purchase has been made, donations of any amount may be added in that child's name.

See the BORN EARLY Blankie online at http://www.bornearly.org.au/blankie.



## In the News

#### Folic acid simple way to fight premature births

Women who take folic acid supplements for at least a year before becoming pregnant can greatly reduce their risk of delivering a baby prematurely, American researchers say.

Folic acid, a B vitamin, is already known to prevent major birth defects involving a baby's brain or spine.

This study shows it may provide another benefit - cutting down on premature births in which babies have less time to develop in the womb and are more likely to experience serious medical problems.

The study tracked about 35,000 pregnant women between 1999 and 2002 who disclosed their folic acid intake.

It found that women who took folic acid supplements for at least a year before pregnancy cut their chances for very early pre-term births - 20 to 28 weeks into the pregnancy - by 70 per cent.

### - REUTERS

Read more: <u>http://www.nzherald.co.nz/topic/story.cfm?c\_id=204&objectid=10489925</u>

#### MRI predicts development delay

New techniques mean tailored treatments for premature babies, writes **Denise Cullen** 

But a novel study in Melbourne is using high-tech magnetic resonance imaging (MRI) to uncover vital clues as to how premature babies will develop, by identifying specific abnormalities in their brains.



Doctor Peter Anderson, a psychologist and senior research fellow at the University of Melbourne and Murdoch Childrens Research Institute (MCRI), says the long-term study will follow 230 children recruited as premature babies from 2001-2003, throughout childhood and hopefully into adulthood.

In doing so, it will focus on the consequences of brain abnormalities revealed in the neonatal period on subsequent brain development and neurobehavioural outcome in this high-risk population.

"Cranial ultrasound is the standard technique for assessing brain injury in premature infants, and while this technique is good at picking up significant abnormalities, it is not as sensitive when it comes to picking up more common and subtle brain abnormalities," Anderson says.

"We have also demonstrated that brain MRI scans are more predictive of early developmental delay than cranial ultrasound."

Read more: http://www.theaustralian.news.com.au/story/0,25197,23139948-23289,00.html

#### Volume 6 Issue 1

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earlybirds

Proudly sponsored by Earlybirds

and Aromababy

# Cooler Bags

# now available.

# Great for transporting your precious breast milk to hospital

Purchase a cooler bag directly from Austprem! Our bags feature an adjustable long carry strap, handy front pocket for keys, phone, loose change etc and fit around 6 bottles. Also fantastic for picnics and as a lunch bag.

Available filled with an assortment of goodies and vouchers for your new baby, including an Earlybirds hat and an Aromababy sample; or unfilled.

> \$15 Filled \$10 Unfilled Price includes postage

Available exclusively from the Austprem BORN EARLY Online Shop <u>http://www.bornearly.org.au/shop</u>





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 says,

#### Austprem Ink









1 Hani (10) 1 Daley (8) 1 Chloe (6) 1 Cooper (5) 1 Alexandra (5) 1 Isabelle (1) 2 Jarrod (9) 2 Amber (4) 2 Brianna (4) 2 Hunter (2) 3 Mikaela (11) 3 Jaiden (6) 3 Hannah (6) 3 Willow (2) 4 Benjamin (4) 5 Mitchell (8) 5 Chloe (4) 6 Jaxon (5) 6 Aaliyah (2)

6 Daisy (3) 7 Dakotah (4) 7 Isabella (3) 8 Kirra (2) 8 Kostya (1) 9 Gabriella (5) 9 Sophie (3) 9 Talan (3) 9 Amanda (3) 9 Joshua (3) 9 Lachlan (2) 9 Rory (1) 9 Henry (1) 10 Corey (13) 10 Emelia (4) 10 Aidan (4) 11 Beau (11) 11 Dana (8)

6 Abigail (2)

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12 Shannon (9) 13 Isabella (6) 13 Zane (3) 14 Antonio (9) 14 Cameron (1) 14 Charlie (1) 15 Ariana (5) 16 Bryce (9) 16 Thomas (7) 16 Jonathan (7) 16 Max (3) 16 Jayden (1) 17 Jake (9) 17 Ronan (2) 18 Lachlan (5) 18 Sienna (3) 19 Jackson (5) 19 Molly (4)

11 Braedon (6)

19 Eleanor (3) 20 Laine (7) 20 Talia (1) 21 Sarah (3) 21 Ryan (3) 22 Adam (3) 23 Jack (4) 23 Sarah (1) 25 Kimberley (12) 26 Megan (8) 26 Haiden (7) 26 Brendan (1) 27 Callista (9) 27 Perry (6) 27 Emily (5) 27 Jasmine (5) 27 Chloe (5) 28 Jackson (2) 29 Kyle (8)

29 Isabel (3) 30 Parker (5) 30 Isabella (5) 30 Alessandro (4) 30 Mackenzie (2) 30 Lachlan (1) 31 Zachary (13) 31 Bindi-Lee (4) 31 Frederick (1) 31 Ethan (1) 31 Benaiah (1)

14 Marlee (8) 14 Keegan (3) 15 Maddison (6) 15 Maddison (3) 15 Pyper (2) 15 Thomas (1) 16 Lochlan (3) 17 Kammryn (10) 17 Megan (6) 17 Olivia (3) 17 Peter (3) 17 Nixon (2) 17 Emma (1) 18 Aimee (3) 18 Tarkvn (3) 19 Pretoria (12) 19 Deegan (5) 19 Emily (3)

19 Savannah (1) 19 Bridget (1) 20 Bayley (7) 20 Lachlan (7) 20 Liam (5) 20 Ella-Maree (2) 21 Alexander (2) 22 Rick (8) 22 Emma (4) 22 Toby (4) 22 Kent (3) 22 Jacob (2) 23 Kane (8) 23 Noah (4) 23 Miracle (2) 24 Isobel (4) 25 Logan (5) 25 Rafferty (1)

26 Brianna (4) 26 Joanne (6) 26 Lara (3) 27 Jessica (8) 27 Declan (4) 27 Siobhan (4) 27 Lily (2) 28 Caleb (8) 28 Tyson (3) 28 Cooper (3) 29 Maddison (13) 29 Tyson (4) 29 Ella (2) 29 Connor (2) 29 Emily (2)

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## 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 <u>http://www.austprem.org.au/journey/</u> <u>superheroes/birthdays.shtml</u> please email <u>kirsten@austprem.org.au</u>





Beautiful clothing for premature and small babies

www.earlybirds.com.au 1800 666 550



1 Aimee (8) 1 Lance (2) 2 Jake (5) 2 Samuel (3) 2 Lucas (1) 2 Thomas (1) 3 Joshua (7) 3 Joshua (4) 3 Mariah (3) 4 Harley (7) 4 Catherine (2) 4 Charlotte (2) 5 Sophie (12) 5 Charlie (6) 5 Oscar (6) 5 Courtney (3) 5 Thomas (2) 6 Sarah (9) 7 Aurora (5) 7 Charlotte (2)

7 Ameliah (2) 8 Georgie (10) 8 Zara (5) 8 Lydia (5) 9 Courtney (8) 9 Zane (6) 9 Grace (3) 9 Jasmine (3) 10 Hannah (11) 10 Kristal (10) 10 Jacqueline (6) 10 Cooper (5) 10 Jack (3) 11 Ben (8) 11 Marshall (4) 11 Tara (2) 11 Matilda (2) 12 Tre (6) 12 Jackson (4) 12 Cohen (3)

13 Jack (8) 13 Jasper (4) 14 Joshua (11) 14 Thomas (6) 14 Jazmyn (2) 15 Abigail (4) 16 Connor (3) 17 Faith (4) 17 Sasha-Honey (4) 17 Samantha-Lee (4)18 Ruby (4) 18 Jordan (2) 18 Joshua (2) 19 Samantha (12) 19 Matthew (12) 19 Nathan (4) 20 Sian (11) 20 Bella (7) 20 Lachlan (5)

20 Kathryn (5) 20 Emily (4) 20 Haroop (3) 20 Talia (3) 21 Ethan (6) 21 Joe (6) 22 Janarra (12) 23 Jordan (6) 23 Jack (5) 23 Angel (5) 23 Lutin (3) 24 Aaron (10) 24 Rebecca (3) 25 Brayden (4) 25 Joshua (3) 26 James (10) 26 Charlie (3) 26 Brooke (3) 26 Isaac (3) 26 Jasmine (2)

27 Tayah (1) 28 Max (4) 28 Zachary (1) 28 Anna (1) 29 Jeremiah (6) 29 Madison (4) 29 Tammin (4) 29 Naomi (1) 30 Sarah (8) 30 Jake (8) 30 Max (4) 30 Atticus (4) 30 Gretel (4) 31 Jack (12) 31 Alexander (7) 31 Tahlia (7) 31 Daisy (3) 31 Benjamin (2) 31 Mia (1)

### **Angel Babies**

Our Angel Georgia born 1st March 2005



Our Angel Nikolas born 5th May 2005



Our Angel Noah born 17th May 2004



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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



ABRUPTION AUSTPREM BABY EARLY FORUM FRIENDSHIP FULLTERM INFORMATION LABOUR NEONATAL NURSERY PREECLAMPSIA

17

1 FAM

PREGNANCY PREMATURE PRETERM SUPERHEROES SUPPORT

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

at www.austprem.org.au, or by emailing austprem@austprem.org.au

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

# Mations - 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 **Committee Members** Lorina Clements Narelle Kerry Gillian Menzies http://www.austprem.org.au

Austprem Ink

Premature birth, babies and beyond

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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