



Feeding your premature baby



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Feeding your premature baby

We all know that people need to eat in order to live, and we all know that babies need to be fed appropriate amounts of the right types of foods on a regular basis for them to grow and develop as they should. But premature babies have a very different start to life,

and for some of them feeding can become a huge issue.

We hope this issue of Austprem Ink will give you some background on the causes of feeding issues in our premature baby, and that this may help people to understand why their baby is so difficult to

feed, and who to go to for help.

Rachel and Helene have shared their stories with us, and I hope you enjoy the photos of a number of our Austprem "babies", all enjoying eating at last!

Kirsten



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 prem babies grow.

You can see the resulting chart at

<http://www.austprem.org.au/journey/home/growth.html>

Further contributions most welcome!

Website Review

<http://raisingchildren.net.au>

Raising Children Network

Although this website isn't directly specifically at prems, it contains a wealth of information and resources, including expected development at various ages.

It is a very new site (launched on 17th May) so is still being worked on etc, but there is plenty of useful information there.

Feeding and Swallowing Problems in Preterm Infants

Prematurity

Infants born at term age are almost always able to maintain exclusive oral feeds from birth. However, it is very common for infants born pre-term to display initial difficulties with oral feeding (i.e. sucking and swallowing). Most pre-term infants will require some duration of tube feeding until they mature sufficiently and are medically stable enough to feed orally. Even once able to commence oral feeds, many infants born pre-term display difficulties with sucking strength, as well as co-ordination of sucking, swallowing, and breathing.

Oral feeding competence is influenced by a number of factors, such as post-natal age, level of maturity (corrected age), physiological stability, the presence of oral reflexes, strength and tone of oral musculature, as well as the infant's level of arousal before and during the feed.

Factors that have the potential to affect oral feeding in infants born pre-term include:

- Immature neurological development and weak muscle tone, affecting feeding and airway protection reflexes, as well as the strength of muscles of the mouth and throat
- Poor respiratory control, leading to poor suck-swallow-breath coordination
- Immature gut development, leading to poor tolerance of feeds, and gastroesophageal reflux

- Poor postural support for feeding
- Reduced endurance for feeding
- Autonomic instability (fluctuating heart rate and respiratory rate, apnoea)
- Immature state control (sleepy or irritable vs. awake and alert)
- Injury/ irritation within the mouth and throat from previous medical intervention (e.g. intubation, tube feeding)
- Ongoing medical intervention

...it is very common for infants born pre-term to display initial difficulties with oral feeding...

Important oral feeding milestones for preterm infants include:

- Commencement of oral feeds (first suck feed)
- Attainment of exclusive oral feeds (all suck feeds, cessation of tube feeds)
- Commencement of solids
- Transition to textured solids and biteable foods
- Adequate growth and nutrition

Why assess and treat oral feeding problems?

- If not managed appropriately, oral feeding problems have the potential to cause many complications for the premature infant.
- In the short term, oral feeding problems can cause airway complications, increased physiological stress, poor weight gain, delayed transition to exclusive oral feeds, and increased length of hospital stay.
- Long-term consequences can include poor development of oral motor skills required for eating and drinking, altered oral sensitivity, food refusal, poor growth, and poor developmental outcomes.
- Oral feeding problems can also affect mother-child bonding.
- Management of oral feeding problems in premature infants needs to commence with an individualized assessment of the infant's oral feeding performance, focusing on state control, stress, responses to tactile input, oral feeding position, oral motor control, physiologic control, and the co-ordination of sucking, swallowing, and breathing.
- Unless the specific issues that a child has are properly identified, it is difficult for specialists to address them.

Feeding and Swallowing Problems in Preterm Infants (Cont.)

Role of speech pathologists with premature infants

Speech pathologists have formal training in head and neck anatomy, neurology, biomechanics, and physiology. They specialise in the areas of communication and swallowing.

In relation to oral feeding, the speech pathologist's main role with infants is in the assessment and management of sucking and swallowing problems, as well as problems affecting the co-ordination of sucking, swallowing, and breathing.

Infants communicate via non-verbal methods. Therefore the speech pathologist's main role in relation to communication with this population is in educating parents and staff to effectively observe, interpret, and respond to infants' behavioural cues. This is a skill that is essential to allow Individualised Care (and is very important for oral feeding success).

The Individualised Care (or Developmentally Supportive) approach is based on Als' Synactive Theory. This theory assumes that infants actively communicate through their behaviour. Als suggested that carers need to recognise cues demonstrated by the infant and modify their own behaviour contingent on the infant's cues. In this way, the infant learns to regulate their own body functions, as well as to develop trust in the carer. It is believed that the Individualised Care approach leads to improved developmental outcomes. A recent Cochrane Systematic Review supports this claim.

Services offered by speech pathologists relating to premature infants

- Infant-focused services:
- Assessment of oral feeding skills
- Recommendations and planning

- Therapy

Therapy Services may be offered either:

On a consultation basis, where the speech pathologist assesses the infant and develops a therapy plan for parents to implement, or

Where ongoing therapy is provided by the speech pathologist.

Parent-focused services:

- Training in how to effectively read and respond to infant cues
- Training in oral feeding therapy techniques
- Providing information regarding long-term developmental outcomes for premature infants in relation to both oral feeding and communication
- Linking parents in with appropriate health service providers for ongoing care - particularly high risk groups, such as infants with cleft



Feeding and Swallowing Problems in Preterm Infants (Cont.)


palates or other craniofacial disorders, infants who are tracheostomised, or infants with chronic respiratory disorders.

Staff-focused services:

- Staff inservices at special care nurseries

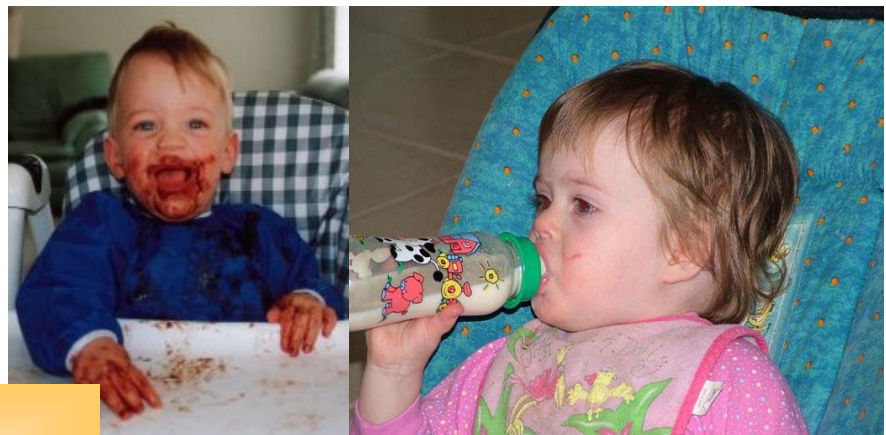
Input to multi-disciplinary team projects – Development of policies and procedures (e.g. policies regarding introduction of oral feeds).

Pamela Dodrill
the pero clinic
Queensland



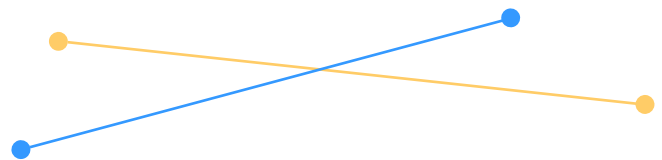
feeding • swallowing • head & neck clinic • education • research

the pero clinic treats people with feeding or swallowing problems, offers professional development about swallowing disorders (dysphagia), and is a centre for research on swallowing assessment and rehabilitation
<http://www.theperoclinic.com.au>



Please note:

Not all speech pathologists provide services for infants and children with feeding problems. You will need to clarify this when you call to arrange an appointment.



Stephanie's Suggestion

Katinka never really got the hang of the bottle teat thingy - she really enjoyed the breastfeeding - and still does - but I have had an enormous problem if ever I have wanted to leave her with her dad - because even with the pigeon peristaltic nipple - (recommended by paed) she still would not take it - and then I found this amazing

"booby" bottle (named by 7 & 5 year olds) that actually looks and feels like a breast - and Katinka will feed from it... check it out on the net...<http://www.adiri.com> - it has a link to the website in Australia that I bought mine from. They are expensive and can leak if not put back in their holder correctly, but if you use them

properly they work really well. When the bottle has milk in it - against Katinka's face - it seems like there is a breast there...

I get amazing looks when I get it out... but it works for Katinka - and that's all that matters...

Stephanie

Katinka was born at 33 weeks

Rachel's Story Helene's Story

Michaela was born at 30 weeks and suffers from severe reflux.

When Michaela was first discharged from hospital she came home on Zantac three times a day, like many prem babies. Within two months of being home she was put on losec as her symptoms worsened. Two months later she was rushed to Melbourne's Royal Childrens Hospital vomiting blood. It was a really scary time for our family, and horrible to see Michaela in so much pain. Michaela was seen by the head of gastroenterology, Mr. Tony Catto-Smith, who performed her gastroscopy and confirmed that the acid had caused a small perforation which led to internal bleeding. Michaela stayed in hospital for a week and was discharged on Zoton. She is almost off the reflux medication at 21 months and can eat much coarser foods after lots of practice and patience.

The first feeding problems we encountered due to reflux, was actually getting milk into her. Michaela would choke, stop breathing and turn blue several times during a bottle feed. Things improved little by little as she slowly grew bigger and sat more upright. She was always fed sitting upright on our laps, facing outwards really for the explosion! There was always cloth nappies close by to catch and clean up!

The feeding problems associated with reflux continued when solids were introduced. This was mainly due to either the texture being too lumpy or the acidity of certain foods. When Michaela was first eating solids she was fed through a mesh bag, to reduce the lumps.

These feeding problems have now been resolved and Michaela is almost over this problem, she certainly doesn't have a problem with texture any more, just the acid reflux! She has come so far and we are so close to closing this chapter of our lives.

Rachel

The twins started breastfeeding after they were about 2 months old - still in hospital. They had dummies from when they were in intensive care (to stimulate the sucking reflex). We went well to start with and then we had some ups and downs (over a few weeks) - worked one day and not the next (very frustrating). I obtained a twin feeding pillow which made a HUGE difference - it was virtually impossible to maintain a good position without one. From the beginning I was also very reliant on hubbie to assist with burping the girls during feeds (as they needed burping at different times).

I found it extremely difficult to keep one child feeding while burping the other one - whenever I tried the feeding baby would inevitably become detached.

Before discharge (after 102 days) everything was going smoothly. We had got into a great pattern and fortunately, for me, hubbie and I had long service leave (and other leave) for nearly a year - so I was very very very lucky to have him to help all the time (he's marvellous).

We started with one breastfeed a day and then progressively went up to more and more until they fully breast fed when they came home.

I started expressing after the girls were born. It was something that I clung to that gave me control over something. On reflection I'm not really sure how I kept up the regime for so long (every 4



hours) - Stubborn I guess, and the medical staff did tell me it would be of great benefit to them. The girls were fed breast milk from when they were 4 days old and I was able to breast feed them until they were 8 months old (by then they needed more milk than I could provide).

From the start I had to use a nipple cup because the girls mouths were to small and we didn't have any success without them. In the end I used the cups up until the end as it was what we were all used to. They were used to the feel and shape of it and didn't respond well to any changes. I did try to move to the bottle when they were 6 months old but they weren't interested - what a carry on that was! But we had to make the move at the 8 month mark they just needed more food.

On reflection I think we were lucky that it all worked - and perhaps very stubborn. I'm glad that I expressed for all that time and that I got to breast feed them for as long as I did (it was hard to stay motivated when you didn't know if it would ever work). I feel REALLY proud that I did it—that I got to do 'something' for them. Perhaps it also helped to build a bond between us - they were getting a part of me. Sounds all rather warm and fuzzy doesn't it? Believe me I was never a maternal or baby type before the girls - makes me laugh to hear myself say that I was so proud of myself for breast feeding ... HA! The things you learn.

Helene

Michaela aged 14 1/2 months
eating using her mesh bag

Research Opportunities

Research is usually conducted to help people to understand the implications of various interventions, and, in particular, whether they should be made available to the wider population. Involving your child in a research study is a decision that only the parents can make, and each study should be looked at carefully before you make this decision. Many of the research studies are of benefit to your child, and offer them opportunities for treatments and interventions that they may otherwise miss out on. Usually there are no costs involved. It is wonderful that there are many people looking into the causes and consequences of prematurity, and what can be done to minimise the impact their early arrival has on our babies.

Do you have a child born prematurely?

Are you interested in your child participating in a research study using a new immunisation that may protect against bronchiolitis?

Bronchiolitis is a common respiratory infection affecting up to 25% of all children in their first year of life. Approximately 2% of children will require hospitalisation for this. Children who are either born prematurely or have Chronic Lung Disease of Prematurity, are at a higher risk of needing hospitalisation.

If your child was born at 35 weeks or less:

- Is less than 6 months old
- or
- Is less than 2 years old with chronic lung disease



Please call for more information, The Royal Children's Hospital, Department of Respiratory Medicine



Professor Colin Robertson or Ms Jo Kappers 9345 6802



WA - Mothers of Preterm Babies needed for study



We are seeking **West Australian mothers** who have had preterm infants to participate in a study into the unique psychosocial experiences of preterm mothers, and how parent-to-parent support groups impact on their experiences of preterm motherhood.

If you are interested in participating in this study or would like further information then please do not hesitate to contact Susan Tobiassen or Sue McElhinney on 0403 048 048 or 0429 686 809 or email support_study@hotmail.com. For further information about the study please see <http://www.austprem.org.au/resources/projects.html>



PremieHUGS

Would you like more information about parenting your prematurely born baby?

Do you have questions about your baby's development?

Would you like to meet other parents of prems?

Premature babies are little individuals and their needs can vary from those of other babies.

Our specialist team provides information and support to enhance your baby's early development through a free research-based community program.

Can we help you? We would love to hear from you! Groups starting April and throughout 2006.

Contact

phone 9496 4496
email bronwyn.leigh@austin.org.au
nisha.brown@mcri.edu.au



PARENT-INFANT
RESEARCH INSTITUTE

Royal Children's Hospital Redevelopment - Vic

Late next year building starts on the new Royal Children's Hospital in Melbourne. They are seeking family input from EVERYONE into the new design and layout.

"...It is also important we get ideas from people who might come to the hospital for all sorts of reasons, so don't think if you have only been to the hospital once, or you haven't had to stay your opinion doesn't matter." If you are interested in helping out, please complete the survey at:

<http://www.rch.org.au/workingwithfamilies/>

This website address is where further updates and requests for assistance will be placed, so bookmark it and visit regularly to keep in touch with the redevelopment project.

Supporting Austprem!

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.

Donations

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 support is greatly appreciated.

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.html>



Austprem Bendigo Fundraiser



Austprem Bendigo is thrilled to have available for sale the 2006 release of the Children's Rose.

Order now for delivery of this beautifully fragrant rose in late June/July

More information:

<http://www.austprem.org.au/promotions/roseindex.php>

Supporting Austprem!

Austprem receives no ongoing funding from any source, and so relies on donations and fundraising to provide revenue so we can continue to offer support and services to families of prems.

For a while now we have been promoting the "You Name It Labels" fundraiser, and we thank you for the many orders which have been placed. Keep them coming!

I am pleased to announce that Austprem has put in place a further fundraiser with Toys and More! Toys and More are an online toy store offering some great deals and fantastic service. Austprem Inc. will receive credits to the value of 20% of any order you make! Just order the toys you would like, and at Step 5 simply type in Austprem, Sunbury, VIC as the fundraising recipient. Anyone can nominate Austprem as a fundraising recipient. The credits we receive will be used to purchase supplies for the Playgroups as they grow, or to purchase items to offer as prizes for future competitions.

Funds raised through Austprem's sales of *Parenting Your Premature Baby and Child: The Emotional Journey* will also help to support Austprem's programmes.

Austprem thanks you for your ongoing support.

Toys and More

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>

▲ Use Toys and More for Christmas and Birthday gifts. Your friends and family may like to support Austprem this way too!



Great Gift Idea!

Pass the code onto your family and friends - anyone may use it!



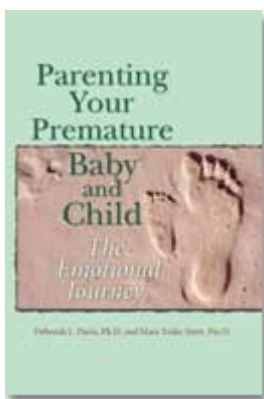
You Name It Labels Fundraiser

- 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 **aiv0603** (all lower case, no spaces).

More details from

http://www.austprem.org.au/promotion/you_name_it_fundraising.html

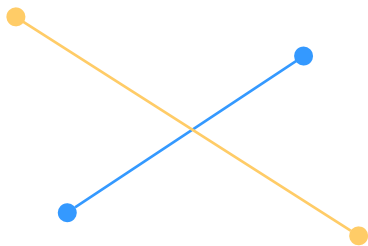


▲ We still have some copies available if you are interested! Just \$44.95! (Including delivery to your door). For a review of this title, check out the Feb 2005 Austprem Ink. To order your copy, please email austprem@austprem.org.au or visit <http://www.austprem.org.au/promotion/support.html>

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 will be 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 will be a semi-public group, non-members will be able to read forum, but only members can post articles to the group and join in any subsequent discussions.

For information on joining see <http://www.austprem.org.au/pip.html>



Pregnancy Support Group

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

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

Chats

Chats are a great way to get to know other members better. They are usually held on Thursday (not in January) and Sunday nights from about 9pm (Eastern Time) and on Friday mornings. 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.

“You can turn up in your pj’s and you don’t need a babysitter”

Chats are very informal - you can turn up in your pj’s (who’s going to know?) and you don’t need a babysitter. But you can still receive great support and understanding from other parents, or just have a social chat - a bonus if you have been isolated at home all day.

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.

You can find information about joining Austprem – Pregnancy Support Group at the web address above.

Your Austprem Committee

President	Leanne Uwland
Vice President	Catrin Pitt
Secretary	Kirsten Burkitt
Treasurer	Leanne Uwland
Media/Promotions Officer	Amanda Lonergan
Chat Host Co-Ordinator	Lisa Reid
QLD State Rep	Catrin Pitt
SANT State Rep	Lisa Reid
Bendigo Regional Rep	Amanda Lonergan

Contacting the Committee

If you need to contact any of the Committee, please email them by clicking on their name in the Members list of the mc2 group, or send an email to

austprem@austprem.org.au

and it will be forwarded to the appropriate person.

Your support helps Austprem Inc. to grow and improve.

Happy Birthday wishes to:

June

2 Jeremy (9)
4 Olivia (7)
5 Amy (3)
6 Kiana (1)
7 Cameron (2)
10 Mathew (8)
10 Dakota (1)
11 Jayke (2)
11 Bradley (2)
11 Grace (1)
12 Jade (1)
13 James (11)
14 Chelsea (2)

15 Jacob (7)
15 Liam (1)
16 Jessica (4)
16 Joshua (1)
17 Samantha (4)
17 Aimee-Rose (3)
18 Rhys (8)
21 Cullen (4)
21 Nina (3)
21 Xavier (3)
21 Marcus (2)
22 George (6)
22 Finn (1)

23 Cody (2)
23 Baxter (2)
25 Gabbi (2)
25 Tayah (2)
26 Thaddeus (13)
26 Chiara (1)
28 Brett (3)
29 Gabrielle (11)
29 Lucas (1)
29 Darcy (1)

Our Angels

Anthony
born 8th July 1994
Jesse
born 9th July 2004



July

1 Luca (2)
1 Jackson (2)
2 Auriella (4)
2 Abby (1)
2 Ryan (1)
3 Taylor (7)
3 Brooke (3)
3 Noah (2)
6 Esther (3)
6 Tiana (2)
7 Tamara (13)
8 Chae (12)
9 Molly (9)
9 Monet (2)

15 Matthew (1)
18 Angelo (6)
19 Indiana (1)
20 Cody (11)
20 David (6)
20 Nicholas (6)
21 Micayla (8)
21 Jaycob (4)
22 Alexander (11)
22 Ethan (6)
22 Charlotte (2)
22 Fergus (1)
22 Logan (1)

24 Madeleine (4)
24 Belinda (4)
24 Mitchell (4)
24 Michaela (2)
24 Liam (2)
25 Sarah-Louise (10)
25 Sheldon (7)
25 Kylara (5)
25 Mitchell (2)
25 Laura (2)
25 Lachlan (1)
26 Vince (6)
26 Jayden (4)

27 Stephanie (6)
27 Harper (1)
29 Memphis (9)
29 Lachlan (7)
29 Samantha (1)
30 Dylan (8)
30 Bella (4)
30 Jack (4)
30 Kye (1)
31 Aleesha (2)



August

2 Robert (6)
2 Chloe (4)
2 Kahira (2)
3 Kyla (1)
4 Dacian (2)
4 Samuel (2)
4 Mia (1)
5 Maxwell (2)
5 Rhett (2)
5 Marcos (2)
5 Bastien (1)
6 Jayden (8)
6 Mollie-Maree (5)

6 Georgia (4)
6 Jeremy (4)
7 Kate (9)
8 Brodie (4)
8 Jorrdan (4)
9 Benjamin (11)
9 Elizabeth (4)
11 Dylan (10)
13 Elizabeth (14)
14 Tate (3)
14 Destiney (2)
15 Brianna (9)
15 Nicholas (1)

16 Nicholas (6)
16 Mitchell (2)
16 Harrison (2)
18 Monique (4)
18 Joshua (4)
18 Stephanie (4)
18 Hamish (1)
19 Imogen (6)
20 Patrick (4)
21 Coby (4)
21 Aiden (3)
21 Caleb (3)
21 Kyla (1)

22 Lachlan (10)
23 Brice (11)
24 Charlee (9)
25 Benjamin (5)
25 Ryan (1)
25 Harry (1)
26 Sean (15)
26 Daniel (9)
27 Tayla (6)
28 Nicholas (9)
29 Saffron (6)
29 Hayley (3)
30 Taneisha (12)

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

Copies of Austprem Ink

may be downloaded from:

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

Austprem Inc.

Providing friendship,
information and support for
families of premature babies
and children.

Visit the Austprem website :

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

Contact Us:

austprem@austprem.org.au

Newsletter

Suggestions and Comments?

newsletter@austprem.org.au

Please support
those that
support us!



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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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.

Please check with your doctor or health care provider as to what interventions are appropriate for YOUR baby.