Austprem Ink

Volume 4 Issue 4

November 2006

First Christmas
- in hospital

Can you hear me?

Inside this issue:

From the Editor

Hi Everyone

It is November again and another year is almost over. It has been a busy year for my family, and I'm sure for everyone else too! Now we are looking to Christmas and beyond - what challenges will 2007 bring?

This issue of Austprem Ink has two main themes. "Can you hear me?" looks at hearing impairment, and Jodi has written very movingly about her experiences; future issues of Austprem Ink will look at some of the other consequences of prematurity.

In "First Christmas - in hospital", Wendy, Carolyn and Jenny share their stories of some different first Christmases and how they felt having their baby in hospital on this special day. There are some lovely ideas for others if you are also facing Christmas in the NICU or SCN.

When you think about Christmas gifts, you might want to consider our fundraising arrangement with "Toys and more". And the "You Name It" labels make great gifts, or you might need to order some for the new school year. Encourage your family and friends to support us this way too! More details on pages 9.

Watch out for a new look Austprem in the New Year. The Development Group is working hard on a revamp of the website and stationery - Austprem Ink will have a new look for the February issue too!

I hope that your holidays are happy and safe, and look forward to hearing about the milestones our prems have accomplished, and sharing the challenges of parenting a prem with you all in the coming year.

Kirsten

Website Reviews

http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=306&id=1878

Children with hearing loss - This site offers a description of the different types of hearing loss as well as suggestions on what to do and looking ahead to preschool and school. The Children with hearing loss - resources page has heaps of helpful organizations (mostly SA based), and also suggests book titles for both parents and children.

http://www.rch.org.au/vihsp/info.cfm?doc_id=7684

Contains the *Victorian Infant Hearing Screening Program* background information (this program is also run in NSW, QLD and ACT), FAQs can be found at http://www.rch.org.au/vihsp/parents.cfm?doc_id=7685

http://www.hearing.com.au
Australian Hearing provides government funded hearing services to Australian children aged up to 21 years who have a permanent or long term hearing loss.

http://www.aussiedeafkids.com

http://www.deafchildrenaustralia.org.au

Both offer information, links, and online support as well as covering early intervention, schooling and more.

Can you hear me?

Finding out that your child has any formal diagnosis can be very difficult, and that your child has a hearing impairment definitely falls into this category. Although there are interventions to help, it is still confronting and devastating, and, for some parents of prems, yet another sign that they somehow “failed” what others seem to do so easily - having a “normal” baby.

Most prems will have their hearing tested before they leave hospital. This gives families some advance warning that there may be a problem. Sometimes further testing shows that hearing is “normal”, other times that further testing shows that the baby does indeed have a hearing impairment. There are also times when the initial hearing test result is okay, but concerns are raised later and further testing then reveals that there is a hearing impairment.

Parents whose child is diagnosed with hearing impairment face a steep learning curve...

There are different types of hearing impairment, and each has its own specific risk factors and treatments. A conductive loss may be due to fluid in the ear, which can go away of its own accord, or may need some help with the insertion of grommets. Hearing aids, which amplify the sounds a person does hear may be of assistance for many children, others will benefit from a Cochlear implant.

Various studies show the risk factors for hearing impairment to include high levels of ototoxic drugs, mechanical ventilation for more than 24 hours, low Apgar score, severe asphyxia, hyperbilirubinemia, congenital perinatal infection, prematurity and low birth weight as well as genetic factors which play a huge role and congenital anomalies and syndromes which some studies suggest to be the highest risk factor of all. Of course there are other studies that suggest that some of these factors aren’t as important as others, or may not be important at all, but most children who experience some or all of these risk factors should have their hearing checked.[1-3]

The suggestion is also made that audiologic assessments should be performed on a regular basis in sick preterm infants as hearing loss can have delayed onset.[3]

Parents whose child is diagnosed with hearing impairment face a steep learning curve, and the need to make important decisions. Some choose for their child to learn to speak using sign language (Auslan in Australia), others prefer that their child attempts to learn to speak verbally; some do both; some will go for hearing aids, lip reading or Cochlear implants, or a combination of these and other appropriate treatments. Finding someone to talk to about the diagnosis and prognosis is very helpful, as is talking to other families who are in a similar situation. Hearing the different points of view from families who are a bit further along the path than you can help you to understand the implications of your decisions, but nobody can decide for you, and you need to make the right decision for your family.

Many of the risk factors for hearing impairment are also risk factors for other conditions, so it is important that your premature baby is also followed up for any other delays or concerns you may have, but try not to worry too much.

Always remember, no matter what the diagnosis, you still have the same beautiful child you always had.

Always remember, no matter what the diagnosis, you still have the same beautiful child you always had.

Kirsten

References

1. Korres S. et al. Newborn hearing screening: effectiveness, importance of high-risk factors, and characteristics of infants in the neonatal intensive care unit and well-baby nursery. *Otology & Neurotology.* 26(6):1186-90, 2005 Nov.

2. Wroblewska-Seniuk K. et al. The results of newborn hearing screening by means of transient evoked otoacoustic emissions. *International Journal of Pediatric Otorhinolaryngology.* 69(10):1351-7, 2005 Oct.

3. Borradori C. et al. Risk factors of sensorineural hearing loss in preterm infants. *Biology of the Neonate*. 71(1):1-10, 1997.

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!

Your Story - Thomas Linton Devine

I still remember the day quite vividly. It was the Tuesday after the June long weekend in 2005. Thomas was a little over 20 weeks actual age or 17 corrected and he was due to have an ABR at the Westmead Children's Hospital in Sydney as he had failed the two SWISH tests in the nursery. I was sick. I had made myself so sick and so worked up that I couldn't go with him. Mick took Thomas all by himself and I stayed at home on the lounge. Mum was staying with us at the time. The test was to start at 9:00am and I knew that it would go for a couple of hours. Thomas settled well for the test and drunk his bottle and fell asleep like he was supposed to. The audiologist quizzed Mick about Thomas's progress. Mick told her how Thomas would jump to the sound of plates banging and the vacuum cleaner screeching. She said that it may be fluid as some babies tend to have fluid in their ears. Mick rang me to tell me this. But something still felt strange.

A couple of hours passed and by now I was even more worried. I waited and waited for Mick to call. When he did I was relieved to hear his voice as he struggled to talk over the noise of the passing cars. Something was not right. He paused. He could hear me but he wasn't saying anything. I asked him how he went. Nothing. There was not a sound. Mick was crying. He told me that Thomas was deaf. He was deaf and he could not hear a thing. I said it would be all right. I had to, I had to be positive.

June 2005

4 months

Mick drove home and seemed to take forever. When he brought Thomas inside I picked him up and cuddled him. He was still my boy. I talked to Mick but he was in complete shock. He said the audiologist and the social worker wanted to talk to me. I went into pilot mode and rang them to discuss the results of the test. Thomas had bilateral severe-profound hearing loss. There was some hope that he would be able to hear with hearing aids. But all this vocabulary and technical language just floored me.

What followed this day I will never forget. The endless appointments at Australian Hearing for ear moulds, two more ABRs at Westmead, ENT follow-ups, cortical testing at Chatswood and a week's readmission to hospital for gastro-oesophagul reflux disease (where it was revealed that Thomas has kidney stones).

At the time this all happened I wondered how we would ever get through it. But we did and we still try to 'get through it'! For me, it was the people around Thomas who helped. The social worker (as persistent as she was), the audiologist at Westmead who knew it was tough for us, the ENT at Westmead who stood six feet tall as an ex 29 weeker, a counsellor I was seeing for PND, my mum, my family, my husband and Thomas himself.

Your Story - Thomas Linton Devine

After much procrastination I decided to visit the Shepherd Centre at Casula to explore early intervention options and it was there that I met possibly the most supportive woman ever. I cried the day I met her because I opened up and revealed that I had been slack and had not been putting Tom's hearing aids in as much as I should have. But Jenny encouraged me to, without making me feel guilty, and I resolved to put Thomas's hearing aids in 'all waking hours'.

Thomas's hearing loss was reclassified as modified hearing loss early in February 2006. He has had two 'puppet tests' since then which support the modified hearing loss. He attends the Shepherd Centre weekly and works intensively with Jenny, his therapist, for one hour. He is learning to talk through listening to the speech sounds. He can say mum, dad, up, hello, moo, ta, boo, uh-oh, mmm. He can also clap when you ask him to clap hands, dance when you tell him he should be dancing, say, 'Ta' for everything, point to the Wests Tigers poster if you ask him where the Tigers are, look for daddy when you ask, 'Where's Daddy?' and much more.

Both Mick and I believe we had Thomas for a reason. Someone up there thought we could cope and so we were chosen. But we don't know what to think about Thomas's hearing. We believe he hears more than any tests show and I guess only time will tell. To us he is still our little brave man and he has shown us that life goes on…and it does get easier.

Jodi

October 2006

20 months

Thomas was born in February 2005 at 28 weeks gestation and weighed only 734g

First Christmas - in hospital

Christmas in hospital is never fun, and families whose babies spend their very special first Christmas in the NICU or SCN often feel a bit down about the prospect. The experience is often a long way from the "First Christmas" they imagined for their baby, and generally comes a year earlier than they expected too.

But Christmas with your baby in hospital can be very special too. Some of our Austprem members share their experiences.

On Christmas Eve with tears streaming down my face, I bought a candle with Sophie's name on it. I needed to give her something for her first Christmas in NICU (she wasn't due until Good Friday!). I still look at the candle in her room today and I am reminded of the joy we experience when we held our daughter for the first time on Christmas morning.

The week before Christmas I made her a little stocking to add to the end of her humidicrib. Sophie was critically sick fighting multiple infections. I guess I was subconsciously willing her to survive the next week.

It was so hard to celebrate Christmas with our baby in NICU. Even around friends and family at such a special time I felt so isolated and terribly sad.

Wendy, mum to Sophie, born at 24 weeks

Beth was born on the 28th of November at 24 weeks gestation, so she was about 1 month old when we had our first Christmas as a family. We made her a Christmas tree ball with her name on it and put it at the top of the tree, It made us feel like a part of her could be home with us at Christmas, even though she was in hospital. I made her a small patchwork blanket and hot washed it to give to her for Christmas. She slept under it in the incubator. We were delighted to find her dressed up in a Christmas shirt, and she gave us a gift too. It was a card with her footprints on it (thanks to the wonderful nurses). Although it was awful to see our baby spent her first Christmas in the NICU, it was these little memories that made it special.

Carolyn, mum to Beth, born at 24 weeks

First Christmas - in hospital

Molly's first Christmas

Molly was 13 days old for Christmas 2005. Born due to pre-eclampsia at 27 weeks, Molly weighed in at 810g on 12th December 2005. By Christmas Day she was still under her birth weight but stable on CPAP. On Christmas eve we hung a personalised bauble above her isolette (hoping the glitter wouldn't contaminate the NICU!) Christmas morning I was up early and at the hospital by 9am. What a delight to find a Christmas stocking on her isolette! It was full of little treats, including many items donated by prior NICU families. The card was gorgeous: "Merry Christmas Mum and Dad, love from Molly". The unit was full of cheer, smiles and cardboard stars hanging from the ceiling (normal decorations gather too much dust for an ICU) I gave chocolates to the staff, but it seems they already had a HUGE supply! I went home for lunch, which was quiet as my family were all celebrating elsewhere. When we returned to the hospital that afternoon I received the best gift ever: I got to hold Molly for the first time! Still hooked up to her CPAP, the nurse placed Molly on my chest whilst I relaxed in the recliner. A scary, yet blissful experience. After lots of cuddles we went home to open our presents, including opening Molly's gifts. It certainly was a different Christmas. This year I hope to return the favour and donate some items to be included for NICU babies' Christmas stockings.

My advice to parents going through the NICU experience this year is to check out what the NICU staff might like....they seemed to be overloaded in chocolates! Perhaps a cake (or some beers!) may be in order. My other piece of advice is not to place too many expectations on yourself for Christmas. I didn't have gifts bought and did not buy gifts until much later! We just took the Christmas season and NICU experience one day at a time. Turns out it was a wonderful memory after all.

Jenny, mum to
Molly, born at
27 weeks, 810g

Beth on Christmas Day

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 you 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

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.

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

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

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.

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 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

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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:

December

1 Bella (6)
1 Jessinda (4)
1 Flynn (1)
1 Halle (1)
1 Sebastien (1)
2 Max (16)
2 Mathew (2)
3 Christopher (10)
5 Maddy (3)
5 Sophie (2)
6 Rhiannon (9)
6 Rebekah (7)
6 Brock (3)
7 Ella (1)
7 Jett (1)
7 Jeremy (1)
9 Xavier (9)
9 William (8)
9 Annabelle (5)
9 Sam (2)
9 Lea (2)
10 Coen (7)
10 Zoe (3)
11 Connor (8)
11 Zali (2)
12 Isaac (3)
12 Molly (1)
12 Finn (1)
12 Eli (1)
12 Zak (1)
13 Joshua (3)
14 Angus (3)
15 Mathew (3)
16 Jess (18)
17 Hannah (8)
17 Emma (2)
18 Tanika (10)
18 Tyson (10)
18 Corey (10)
19 Chloe (2)
20 Daniel (14)
20 Renee (14)
20 Gideon (4)
20 Lottie (2)
21 Elaina (5)
21 Jon (1)
21 Connor (1)
22 Natasha (10)
22 Layla (7)
22 Brandon (2)
24 Sarah (14)
24 Ashleigh (14)
24 Emma (2)
24 Brandon (2)
24 William (2)
25 Olivia (6)
26 Brianna (2)
28 Jack (5)
28 Calan (1)
29 Liam (9)
29 Jack (5)
29 Morgan (4)
29 Matthew (2)
30 Izabella (2)

January

2 Leonie (8)
2 Gemma (1)
3 Brooke (7)
3 Charlotte (4)
3 Erin (1)
3 James (1)
5 Tony (5)
5 Bianca (5)
5 Toby (2)
5 Jack (1)
6 Archisha (2)
6 Paige (2)
6 Airlie (1)
7 Dylan (4)
8 Caleb (9)
8 Zeth (5)
10 Enrico (2)
10 Chloe (1)
11 Alesya (4)
11 Mackenzie (4)
11 Devlyn (3)
11 Amber (2)
11 Byron (2)
12 Connor (7)
12 Charlotte (3)
12 Julian (2)
13 Kade (4)
13 Mitchell (2)
14 Wisaal Yasmina (5)
14 Bobby (3)
14 William (3)
15 Kaitlyn (13)
15 Timothy (6)
15 Tiernan (3)
15 Jessica (4)
16 Caellum (5)
17 Beauden (2)
17 Alexander (1)
21 Harry (2)
21 Madeleine (2)
23 Seth (4)
23 Emerald (1)
24 Campbell (3)
24 Sebastian (3)
24 Tayah (2)
25 Angela (12)
25 Sharon (6)
25 Benjamin (2)
25 Elise (2)
26 Chloe (4)
26 Nathan (3)
27 Cooper (2)
27 Rhyley (1)
27 Bailey (1)
29 Tye (10)
29 Ben (4)
29 Savanah (3)
29 Aidan (3)
30 Kyle (6)
30 Jared (3)
30 Jacob (1)
30 Samuel (1)
31 Robert (3)
31 Jaryd (2)

February

1 Ellandi (8)
1 Jack (6)
1 Kaihdyn (4)
1 Charli (1)
2 Blair (8)
2 Thomas (2)
2 Thomas (2)
3 Dylan (6)
3 Elizabeth (6)
3 Lee (4)
3 Tyler (3)
3 Tom (2)
3 Isabella (2)
4 Jessica (15)
4 Marcus (3)
4 Lachlan (2)
5 Sophia (3)
6 Lily-Jai (2)
6 Jackson (1)
7 Courtney (17)
7 Jethro (2)
7 Xavier (1)
8 Alexander (2)
9 Yolanda (13)
11 Bailey (9)
11 Zac (9)
11 Hannah (3)
12 Alexander (5)
12 Marcus (4)
12 Lachlan (4)
13 Chloe (9)
14 Zoe (5)
14 Heather (4)
14 Jayde (3)
14 Lauren (3)
14 Ryan (3)
14 Abigail (2)
14 Isaac (1)
16 Joshua (6)
16 Samara (2)
16 Kate (2)
16 Kyle (2)
17 Victoria (5)
18 Zackery (3)
18 Tallis (2)
19 Xander (3)
20 Therese (6)
20 Jacob (6)
21 Joseph (12)
21 Connor (7)
21 Iman (2)
22 Eponine (8)
23 Jasmine (6)
23 Lily (6)
23 Nathan (4)
24 Caitlin (9)
24 Kaleb (1)
25 Jakson (3)
26 Thomas (8)
27 Constantine-Antonio (1)
28 Angus (1)
29 Declan (3)

Our Angels

Kobi born 12/12/2005
Nicholas born 13/12/2000
Jenna born 14/12/2003

Liljana born 28/01/2004

Molly born 2/02/2005
Kyle born 3/02/2003
James born 7/02/1997
Edan born 16/02/1999
Matthew born 16/02/2001
Liam born 22/02/2004
Aidan born 22/02/2004

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

ABN 67 731 996 316

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.