Premature birth, babies and beyond

2



### AT A GLANCE

Volume 7 Issue 1

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

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

Austprem Forums and Message Boards	2
Occupational therapy	3
OT—more than just fine motor skills	4
Shea's story	6
National Premature Birth Awareness Week	7
In the News	8
Cooler bags now available	9
The BubBE book	10
Austprem Ink Puzzle Corner	11

AND MORE ....

Occupational



- what is it and why does my baby need it?



### Page 2

# 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.



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### Austprem Forums / Message Boards

### Austprem - Forum

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

### → Austprem - Pregnancy Support Group

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

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

### Prematurity in the Press

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

# Occupational Therapy

Occupational therapy sounds like something overworked office workers should be doing, and seems, at a quick glance, to have little to do with babies. However occupational therapists can be vital in helping our babies develop and learn new skills. Occupational therapy enables people to participate in everyday activities; this is achieved either by enhancing their abilities or modifying the environment. Of particular relevance to our prems, occupational therapy can

assist with self-care skills and play skills.

Until you see your child struggle with a seemingly simple skill, you don't realise the number of steps involved in achieving that skill and the number of smaller skills that need to be conquered first. It never occurred to Occupational therapy offers support and advice for children who are having difficulties in their everyday living skills.

me that my 3 year old should be able to dress and undress himself; a conversation with another mother was my first inkling that perhaps Michael was more delayed than I thought. He was actually already receiving therapy but we had been working on other skills and hadn't touched on dressing. When we did approach this area, it was an eye-opener for me. We started by trying to teach Michael to put his own pants on. We broke the process down into little steps and verbally said them as we went along. As well as having to learn all the steps, he also needed the balance to lift one leg - this was a while coming and he sat down for this part of the process for a long time.

Occupational therapy can help with issues such as handedness - many children don't show a preference and just use whichever hand is most convenient at the time, others have trouble crossing their midline, so will use their left hand for things on their left side, and their right hand for things on the right.

Many of our prems have sensory integration issues, varying from craving touch to avoiding it, loving strong tastes and smells to preferring blandness, needing peace and quiet to turning the volume up loud. Occupational therapists can offer insight and assistance with all of these things.

Occupational therapists aren't miracle workers but together with parents and carers they can help to make life more comfortable and enjoyable for our prems!

Kirsten Burkitt

### Read more:

<u>http://www.ausot.com.au/inner.asp?pageid=4</u> <u>http://www.ausot.com.au/inner.asp?relid=7&pageid=129</u> <u>http://www.disability.vic.gov.au/dsonline/dsarticles.nsf/pages/Occupational\_therapy?</u> <u>OpenDocument</u>

#### Austprem Ink

### Page 4

# Occupational Therapy -More than just fine motor skills!

My son Thomas Linton Devine was born at 28 weeks in February 2005. He weighed just 734g and spent 105 days in hospital. We were advised to seek the assistance of an occupational therapist shortly after



Thomas's one year corrected follow up as part of the Silver Star Clinic at RPA (Sydney). I had noticed in the follow up that Thomas was not particularly good with small objects and I put this down to the fact that we had not given him small things to play with for fear he might swallow them. We contacted our local early childhood centre occupational therapist (OT) through the physiotherapist Thomas had been seeing. We were placed on a waiting list and eventually Mick took Thomas to see the OT as I was back at work and he had more flexible time. Initially, the OT wanted to work on Thomas's fine motor skills for an intensive period of 4 weeks and then she would review him later. She also commented on how he lacked the ability to concentrate. I thought this was most unusual but then as I attended sessions with Thomas my eyes opened up to a whole new world. Not only did she teach Thomas how to use his hands to complete tasks, but she worked on his pencil grip skills, coordination, hand-eye movement and his ability to complete tasks. All things I know children need for school but I was quite naïve to the fact that he should have been developing them much earlier than I realised.



We stopped seeing the OT and things were going well, or at least I assumed they were. We were quite shocked at his 3 year corrected follow up to find out his motor skills were the area of concern. Given Thomas's hearing loss and language deficit, I was more than sure that would be the area of greatest concern. We reconnected with the OT much to my relief. I had felt extremely bad for losing contact with her. However, she was just as brilliant as she was the first time and we begun a process of working on skills and meeting up with her each school holidays. She sets realistic and user-friendly goals for Thomas

### Page 5

## I have a far better understanding of the skills Thomas needs

and us to work on. The goals are relayed to his teachers at daycare and preschool and the other early intervention therapists he works with, including his audio-verbal therapist at the Shepherd Centre and his speech pathologist (private). I have even found myself using a lot of what I have seen in the OT ses-

sions at school in my Kindergarten classroom. I have a far better understanding of the skills Thomas needs and should have that are appropriate to his age. We are still working on identifying Thomas's hand preference. We use a tally sheet to help identify which hand he uses the most. If anything, working with the OT has empowered us. Something which I feel is critical; in our daily life with the most important person, Thomas!

Jodi Devine



Shea and his building block tower (read Shea's story over the page)

### Page 6

# Shea's Story

Shea was born at 24+6 weighing 740g and is a surviving twin. He lost the fingertips off his right hand while in NICU. He also has mild CP and a mild intellectual disability after a grade IV IVH which resulted in hydrocephalus requiring a shunt. He has some sensory issues which tend to change day by day – either seeking or avoiding depending on his mood. He has trouble completing complex tasks and following complex directions.

We have used Occupational Therapy for such things as hand skills, sensory issues, routines, self-help like dressing and toileting and also for feeding issues.

Some of the sensory stuff was a bit too "airy fairy" – squashing him between pillows before meals and cleaning teeth to "waken" his mouth before meals didn't really work for us, but other bits have definitely helped – kicking balls or balancing games before meals, only serving cold meals or serving ice cream before mains were really helpful suggestions. Offering preferred foods and non-preferred foods on the same plate and thinking about what type of plates and cutlery are preferred. We learnt to watch for the smell, look and feel of food as well as the taste. And we found that using heavier and thicker cutlery and drinking glasses is easier for Shea to handle than light plastic things as there is more sensory feedback.

To strengthen hands we have done hours and hours of playdough, blocks, pegging, using tongs (tea bag squeezers or ice cube tongs), and worked our way up to training using chopsticks! Hand strength and grip is still an issue that will require constant working on, but these activities can be incorporated into everyday games and routines very easily.

To encourage writing we have purchased every toy we could find that had a writing implement or stylus – from doodle pads to aqua doodle bears to bath crayons to leap frog / FP writing toys and a Leapster. We are currently investigating introducing a keyboard for long journal style writing at school, while maintaining hand writing training for shorter writing needs as his hands can't keep up with his thought processes.

OT's are a great resource for help with self-help skills. For dressing we learnt to work on the last step first – ie if you are working on putting on trousers you help them put their feet in, but let them pull them up (from knees then from ankles), then let them do second foot, then both feet with you holding top, then on their own. This routine works well for many of the self-help tasks.

OT's can also help with boardmaker or other visual aides for routines too – from a morning / bedtime routine, to the steps required for self-toileting. Breaking down the steps into manageable chunks really makes a difference, sometimes remembering the order of the steps can be difficult so using visual cues can be a real benefit.

We have found occupational therapy invaluable in helping Shea to achieve many things.

Jannette

# National Premature Birth Awareness Week

### 24 - 30 November 2009



NPBAW 2008 saw the launch of Brady the BORN EARLY Bear. Brady is soft and cuddly and comes with his own BORN EARLY ribbon. You can purchase Brady from the Austprem BORN EARLY Online shop for just \$20

# Get your own Brady now!

http://www.bornearly.org.au/shop



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



#### Page 8

### In the News

### Taking Folic Acid for a Year Before Pregnancy May Reduce Risk of Preterm Birth

"Women who take folic acid supplements for at least one year before they become pregnant may cut their risk of having a premature baby by half, according to research published this week in the online journal, PLOS Medicine."

http://www.marchofdimes.com/aboutus/22684 59572.asp

### Adelaide University develops pregnancy complication test

"The problem with complications is that we are unable to predict which women are at risk until symptoms develop, and then therapies can be too little, too late."

Associate Professor Claire Roberts

A genetic test that can predict which women are at risk of suffering pregnancy complications is being developed in South Australia.

http://www.livenews.com.au/science-and-tech/adelaide-universitydevelops-pregnancy-complication-test/2009/5/11/206059

### ACOG 2009: Late-Preterm Infants Found to Have 3 Times Higher Mortality Rate Than Term Infants

"The overall rate of late-preterm births is rising, and so are rates of morbidity and mortality, especially among infants born by cesarean delivery without labor. "

http://www.medscape.com/viewarticle/702590

### Job conditions tied to pregnancy outcomes

"Pregnant women who work physically demanding jobs, long work weeks or irregular hours may be at increased risk of delivering prematurely or having an underweight baby, a new study suggests. "

http://uk.reuters.com/article/healthNewsMolt/idUKTRE54C59L20090513

# Great Resource!

Parenting Your Premature Baby and Child

The price remains at \$44.95 (including delivery to your door)! To order your copy, please email <u>austprem@austprem.org.au</u> or visit http:/ www.austprem.org.au/promotion/books.shtml





### Page 9



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http://www.toysandmore.com.au

#### Page 10



A book created to provide parents of a premature child with a 'baby book' unique to the Neonatal Intensive Care Unit (NICU) experience.

For more information and how to order, see <u>http://www.bubbornearly.com.au/</u>



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

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# Austprem Ink Puzzle Corner

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FΟ	J	Е	Т	Y	Е	Ζ	Ν	I	W	Η	0	Ν	S	PLAYDOUGH
RG	3 S	Y	А	R	U	Ν	I	А	S	L	R	F	Е	PROCESS
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Austprem is registered as a non-profit organisation with the Australian Taxation Office. We are also an approved charity. Our aim is to provide support to as many of those parents of premature babies as we can. Your support can help us to achieve this goal. Membership of Austprem is open to anyone who has a prematurely born baby or child. Further information about Austprem can be found at www.austprem.org.au, or by emailing austprem@austprem.org.au

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

Mailons - 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.

### Page 11

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### Your Austprem Committee

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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**

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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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