



## The challenges of learning for school-aged children born prematurely

Despite the trickle of information on potential problems, the overwhelming message that comes through our everyday social interactions and the media is that premature babies start off small but then catch up and if they don't have an obvious disability, they will be normal. Recently we've had the Chicago neonatologist speaking for the NICU team who managed to save a 28 weeks baby born at less than 250g, announcing that it was expected her development would be normal.

The word "normal" itself is vexed because prematurely born children are surely normal for prematurely born children. The problem lies with the expectation – and this can be a real burden for parents and for the children themselves – that is unless there is a named and obvious disability, most children born extremely early will be as normal as their full-term peers.

In the last decade, scholarly research consistently shows that the most likely outcome for survivors born very preterm is not severe/multiple disability (although this will be the outcome for some, perhaps less than 15% of survivors, speaking generally.) The typical outcome is much more likely to be a learning disorder or

group of disorders, combined with behavioural and motor risk factors. These can be subtle, and despite the fact that they genuinely impact on the child's chances for academic success, they tend not to be recognized or given a name. They are sometimes described as "hidden disabilities"<sup>1</sup>.

One problem with hidden or subtle disabilities, particularly for school aged ex-prems, is that they are often attributed to personality rather than pathology. Families may find they get little support for their concerns and frustrations with the learning and social issues their children might be experiencing. The chance of getting government funding for school support to address subtle learning disabilities is zero to none.

To add insult to injury, there can be the suspicion, spoken or not, that parental concerns stem from an unhealthy pre-occupation with their child's prematurity, that is, a kind of parental hypochondria projected onto their children.

It's important to note that your child may not experience learning disabilities in primary school or later but it is common. It's also common for some children to sail through their early schooling with very encouraging academic marks only to find they struggle as the tasks become increasingly complex in high school. For

some it may only be a single area, such as maths, that doesn't make sense to the child while other areas of learning seem to be OK and on par with peers.

Here are some of the areas that have been identified as likely to affect our children's education, especially (but not confined to) those children born earlier than 27 weeks or weighing less than 1000g.

"Executive function (EF) refers to a collection of interrelated processes that are responsible for purposeful, goal-directed behaviour and is important in a child's cognitive functioning, behaviour, emotional control, and social interaction. Cognitive processes associated with EF are numerous, but the principle elements include anticipation, goal selection, planning and organization, initiation of activity, self-regulation, mental flexibility, deployment of attention, working memory and deployment of feedback"<sup>2</sup>.

This definition comes from a recent study done with a group of children born at less than 28 weeks, (excluding those children with significant neurosensory impairments), compared with a group of children the same age born at term. The study reports a global tendency for the children in the premature

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## From the Editor

Welcome to the first issue of Austprem Ink for 2005. In this issue, we look at some of the challenges facing school aged children born very preterm. We also have a report from two of our members who attended the NSW Consensus Workshops on Limits of Viability. I was invited to speak as a parent, on behalf of parents generally. I

thought this would be hard to do but the audience was so attentive and interested that it was an enjoyable experience. It was great to meet so many dedicated and passionate NICU professionals.

In the next issue of our newsletter, we'd like to focus on the impacts on siblings of having a having a medically fragile baby or older child

in the family. If you have some comments about your own experience or would like to write or contribute to a feature article, please contact me at [newsletter@austprem.org.au](mailto:newsletter@austprem.org.au)

Anne

## The challenges of learning for school-aged children born prematurely (cont.)

cohort to do less well in all areas of executive function than their full-term peers, although in some areas the difference was relatively minor.

The highest degree of difference, or impairment, appears to be in specific areas including holding information in mind (often called "working memory") and mental flexibility (adaptive function). Both these attributes can lead to a slower processing speed.

It's worth noting that children in the ELBW/very preterm cohort were found to be no more impulsive than the NBW children. This will come as good news to those parents of three year olds wondering if their children are going to outgrow their impulsiveness or if they should go ahead and dye their hair completely white and get it over with.

"Working memory is a process that involves holding task relevant information in the mind for brief intervals so that the information can be used to guide future actions. It is believed to be a critical component of organized goal-directed behaviour in adulthood and would certainly be involved in increasingly complex organizational tasks in school aged children."<sup>3</sup>

If you think your child might have difficulty with their working memory you can try providing gentle prompting or reminders as they organize tasks or work through abstract problems. This kind of

verbal mediation can be very helpful if you keep it low key and directed towards information "building blocks" rather than aiming at a quick solution.

In addition, Luciana et al<sup>3</sup> recommend that preterm children be provided with problem solving strategies from an early age. If these

...recommend that preterm children be provided with problem solving strategies from an early age

are introduced early and reinforced at kindergarten and school it "may not only influence educational and behavioural outcomes ... but also may facilitate an altered course of neurodevelopment in the early injured brain as it proceeds through the critical window of middle childhood"<sup>5</sup>.

Another aspect to executive function that appears to be significantly more common in ex-prems than in their full term peers is mental flexibility, also called adaptive function. You may have noticed that your child persists with a conversation topic that has passed or that they become distressed about having to shift quickly from one activity to another. It will help them at school if the teacher understands this and can be

calm, patient and directive about activity switching.

In terms of psychology, extreme prematurity seems to result in some fairly consistent behaviours (compared with normal birthweight peers). The most strongly marked include high activity level, distrusting of own ability, gives up easily, reacts to failure unrealistically, and needs constant praise and encouragement<sup>1</sup>. Does this sound familiar to anyone?

Anderson and Doyle<sup>4</sup>, using research based on Victorian children in the past decade, attribute these behaviours to very specific aspects of the extremely preterm brain which is now recognized as being and remaining different to the neurology of children born and developing typically. The amazing thing is not that children born very preterm are different but that most of them do as well as they do at school and in society.

It's heartening to read Saroj Saigals's series of studies on a Canadian group of premature children now in their late teens. (These studies are available as free

The amazing thing is not that children born very preterm are different but that most of them do as well as they do at school and in society.

# The challenges of learning for school-aged children born prematurely (cont.)

full-text online through the *Pediatrics* website.)<sup>5</sup>. Many of the children in her cohort continue to experience the kinds of subtle or not so subtle learning disorders

...most have emerged as relatively competent young adults with good self-esteem

described in this article but most have emerged as relatively competent young adults with good self-esteem.

We are our children's advocates from the day they are born. Even though a good percentage of premature children will cope well at school, keeping up with their peers

with little or no apparent difficulty, it well worthwhile for parents to be wise about potential outcomes. For those parents for whom the issues of hidden learning disabilities come as no surprise, I hope this article has been helpful.

Anne Casey

## References

1. Whitfield, MF, Grunau, RV, Holsti, L.  
*Extremely premature (< or =800g) schoolchildren : multiple areas of hidden disability.*  
Arch Dis Child Fetal Neonatal Ed 1997; 77, pp 85-90
2. Peter J. Anderson, Lex W. Doyle and the Victorian Infant Collaborative Study Group.  
*Executive functioning in school-aged children who were born very preterm or with extremely low birthweight in the 1990s.*  
Pediatrics, Jul 2004; 114, pp 50 -57
3. Monica Luciana et al.  
*Neurobehavioural evidence for working memory deficits in school-aged children with histories of prematurity.*  
Dev. Med. & Child Neurology, 1999; 41: pp521-533
4. Peter J. Anderson, Lex W. Doyle and the Victorian Infant Collaborative Study Group  
*Neurobehavioural outcome of school-age children born extremely low birthweight or very preterm in the 1990s.*  
JAMA June 25, 2003; 289, 24 pp3264-3271
5. Saroj Saigal in *Pediatrics* <http://www.pediatrics.org/>

## Websites and Articles

Saigal, Saroj, *Limits of viability*, Pediatric Research, 49(451) 2001

<http://www.pedresearch.org/cgi/content/full/49/4/451>

<http://pediatrics.aappublications.org/>

(enter "Saigol, Saroj" in the author search box for a list of her articles on premature outcomes)

CLJ Huddy, A Johnson, PL Pope, *Educational and behavioural problems in babies of 32-35 weeks gestation*, Arch Dis Child Fetal Neonatal Ed 2001;85:F23-F28 (July)

<http://fn.bmjournals.com/cgi/content/full/85/1/F23>

premature-infant.com <http://www.premature-infant.com/Articles.html>

Parenting your premature baby and child : an emotional journey

<http://www.parentingyourprematurebaby.com>

Pediatrics (online journal)

<http://www.pediatrics.org>



## Very premature school aged children – some personal reflections

In this issue's main article, I wanted to present an overview of the current literature on outcomes for older children born very preterm. There is an almost overwhelming amount of research currently in progress and being published. One of the most significant studies is happening here in Melbourne in a joint undertaking by Royal Womens and Childrens Hospital Network to conduct MRIs of as many preterm babies as possible, at birth and at regular intervals as they grow, compared to a full-term group.

There is now no doubt at all that prem brains are different and stay different, that is, they don't become like the full term brains over time. There seems to be a race on to provide studies in all areas of neurology and psychology to illustrate what that difference might mean for all stages of life. It's interesting and enlightening to read but can be depressing for parents.

I've noticed in my own son, 10 year Vincent, that he does at times experience the kinds of memory/executive function problems that I've reported in the main article. However, it's definitely not something that troubles him every day. Perhaps stress and tiredness also come into the equation. We still don't know what our children's early environment means for them in the long term. There may be other triggers for stress than those we know about in our own lives.

I'd like to offer some suggestions for therapies and activities that I've found helpful for Vincent over the years. You may like to adapt some of these for your premature child or children depending on

your own preferences and how they respond.

**Massage.** A full body massage is ideal (for parents not just for children!) but if your child is too restless, all forms of backrub can help a child feel calmer and more organized. This can be as simple as resting your hand on a child's back or shoulders when they are struggling with a situation at school or home.

There is now no doubt at all that prem brains are different and stay different

**Craniosacral therapy and homeopathy.** Many parents have found alternative therapies brought about a great improvement in their child's behaviour and capacity to learn and cope at school. Dianne Maroney, RN, gave a presentation on this topic at the Preemie-L conference in August last year, and a good number of the audience stood up to give their own version of alternative therapies, including diets, that have helped their children. It's worth a try!

**Good sleep habits - regular bedtime and avoiding late nights.** This is true for most children but seems to be especially important for the very preterm.

**Bilateral activities like cycling and swimming** seems to have a regulatory effect on the brain. There is a link between crawling and the capacity for mathematics

later in life. The relationship is between the crawling stage as an essential part of development, not how early or how well a child crawls.

Memory games such as animal pairs as well as card games such as poker which rely on the child remembering what cards have been used and what people have shown in previous moves. As a sidenote, I've just finished playing Rainbow Fish memory game with Vincent, and I'm sorry to say he beat me three times in a row. That doesn't say much for the middle aged brain.



**Cooking** is an excellent activity for executive function. You can have your child prepare everything, including assembling the ingredients and utensils and tidying away afterwards while you stand back, offering only verbal prompting if needed, and assistance with anything hot, of course. Doing something fun that requires you to plan ahead and foresee all the steps is great practice for the organizational challenges of school related tasks.

Austprem Inc. would welcome any ideas or suggestions from parents for activities or therapies that have helped their own children. Any insights or comments about learning difficulties are also welcome. It's not so much that experts tell us what we don't know. They can give names to things we observe in our children but we have the contexts, we know our children and that is what helps us and them through the challenges.

Anne Casey





## Vincent's Healthy Smoothie Recipe



Vincent Hardy, age 10

First take the jug from the blender and make sure the bottom piece and sealing ring are on properly. If they're not on properly, it will go everywhere!

Check the bench is clean.

Take out the ingredients and line them up, with the spoons for each one.

For this smoothie, you will need—

Weiss mango sorbet

Milk

Strawberries or banana, you can use both if you like. Frozen berries are nice.

A few drops of vanilla essence adds a special touch. You should put the drops in a teaspoon. Otherwise you might accidentally add too much.

Put the spoons in the sink after you've used them and put everything away before you do the blending.

It's very important to put the lid on carefully, otherwise it will go EVERYWHERE!!!

Blend for a minute or two. Pulse also works well.

You can make all kinds of smoothies, with icecream, syrup, malted milk. They are healthy and fun.

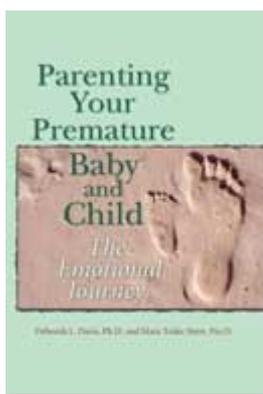
Vincent Hardy

"Cooking is an excellent activity for executive function"

## Book Review

Deborah L. Davis and Mara Tessler Stein

*Parenting Your Premature Baby and Child: The Emotional Journey* (Fulcrum, 2004).



This is the most comprehensive book to be published on the subject of the emotional impacts of prematurity. The book is written especially for parents and family but NICU and follow up staff, as well as social workers, psychologists and family health workers will also find it both interesting and very helpful.

There are many quotes from parents throughout the book. These voices give depth and resonance to the situations and are answered in the compassion and practical advice given in every chapter. The authors are both psychologists, specialising in reproductive and perinatal loss. Debbie Davis has written a number of books in the past and these are all highly recommended.

At over 900 pages long, *Parenting Your Premature Baby and Child* is not the kind of book you can read straight through but it is definitely the kind of book you will come back to over and over again. The book has a very good table of contents and an index to help you find the information you are looking for.

When I think back to the hundreds of hours I spent sitting beside my own son's incubator, wondering what lay ahead for us all, I can only wish that I'd had this book to help pass the time and to help me feel less shocked and alone.

This wonderful book is not yet readily available in most Australian bookshops although it can be ordered, either from bookshops or from amazon.com. Fortunately Austprem has a number of copies which are available for only \$44.95 (including delivery to your door!) which is less than the standard retail price. If you'd like a copy, for yourself, for someone you know or to donate to your NICU, please contact [austprem@austprem.org.au](mailto:austprem@austprem.org.au), or watch the Austprem Forum and website for ordering details.

## 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 (about 66!). 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* (see page 5 for details of this book) 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!

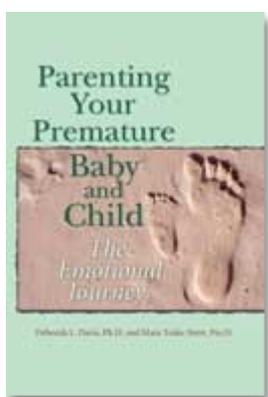
Simply nominate Austprem, Sunbury, VIC as the fundraising recipient at Step 5 when you order.

<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 can 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](http://www.austprem.org.au/promotion/you_name_it_fundraising.html)



# Perinatal Care at the Borderlines of Viability Workshop NSW

Early in January Austprem was invited to send two of our members along to a workshop on “Perinatal care at the borderlines of viability” to be held in Sydney. The Workshop was organized by the NSW Perinatal Services Network with the support of NSW Health.

Rachael Bourne and Jannette Cass-Dunbar both attended, and Anne Casey presented a paper. Rachael and Jannette agreed to write about their experiences at the Workshop so that we could all find out a little about it all. It sounds like they had a very interesting, although at times emotional, time, and I thank them for attending on behalf of Austprem.

## Jannette

Rachael Bourne, Anne Casey and I attended the above workshop on behalf of Austprem, along with 3 other consumer representatives from the Multiple Births Association. There were around 100 clinicians in attendance from both tertiary and non-tertiary hospitals. These included obstetricians, midwives, neonatologists, NICU nurses, clinical nurse consultants, social workers, psychologists, and developmental paediatricians, as well as researchers and other interested parties such as a representative from NETS (the NSW newborn emergency transport service).

The stated aim of the workshop was “to bring together clinicians and consumers with an interest in perinatal care to share knowledge and

- To produce a consensus statement for NSW and ACT addressing the issue of limits of viability in very low gestation and small babies.

To agree on accurate, meaningful and consistent information across NSW and ACT to clinicians, parents or prospective parents of very low gestation and small babies.

It was stated during the introduction that the aim was not to “draw a line in the sand” as there needs to be some discretion on a case by case basis, but that we should be endeavouring to find the grey zone where it would be unethical to initiate treatment at the lower level, and unethical not to initiate treatment at the upper level. The question of withdrawal of treatment was also covered, but the main focus was on communication with parents, and their participation in decision-making.

During the first session we were spoken to by an ethicist, a neonatologist who gave survival and 3 year follow-up outcome data for NSW

and ACT for the period 1998-2000, and by Anne who spoke on “What do parents want to know and how much do they want to participate in decisions”. During the 2nd session there was an interactive discussion on current issues and dilemmas. From this 12 key issues were identified that were discussed in further detail by small workgroups in the 4<sup>th</sup> session. The questions used as discussion starters were:

- “Is our current communication with parents good enough to inform their decision making?”
- “Do we consider long term emotional impact of extremely pre-term birth?”
- “Do we place different values on different babies?”
- “Can society afford intensive care for very tiny babies?”

In the 3<sup>rd</sup> session a lawyer discussed the current medico-legal situation, and then we used the digital voting system for the first time to ascertain opinions on the grey zones using hypothetical situations. An example of a hypothetical question was “rank in order of importance the following when determining whether to initiate treatment for an extremely pre-term baby – birth weight, condition at birth, absence of congenital abnormalities, health care resources and parental wishes. It was very difficult answering some of these questions, as there was insufficient information given in the hypothetical, or it was too emotionally close to our own experiences! There was a lot of emphasis on the difference between delivering at a tertiary hospital (one with a NICU), or needing to transfer the baby after birth, and how that affects the situation.



Shea, 2 years

The final two sessions involved the workgroups giving their feedback on the 12 key issues, from which 40 statements of consensus were developed, and voted on. The voting was not “yes / no” but was on the basis of “strongly agree, agree, disagree, strongly disagree or can’t decide”. In most cases we only had 10 seconds to register our vote, which became very mentally draining by the end, as well as the whole workshop being very emotionally draining as it brought back so many memories from our NICU experiences, and made us aware of how many clinicians are not in fact in favour of lowering the current NSW and ACT guidelines of around 24 weeks gestation and 600-700g set in 1998, due to the long term outcomes for both the babies and the family as a whole.

The consensus results were shown on the screen during voting but too quickly to jot down, so I will pass on the updated consensus statement when it is released after review. One of the major agreement areas was the need for better public education through provision of antenatal information to all pregnant women on the signs of preterm labour and outcomes of preterm birth, and the need for a more balanced portrayal of premies by the media, who like to promote the “miracle babies” without giving the alternative stories.

Alongside this exercise, the booklets “Outcomes for Premature Babies in NSW and ACT – information for parents and prospective parents” from NSW Pregnancy and Newborn Services Network, and “Care around Preterm Birth – A guide for Parents” from National Health and Medical

# Perinatal Care at the Borderlines of Viability Workshop NSW

Research Council, are currently being updated. If you have either of these booklets and have time to review them, the publishers would appreciate hearing if you feel anything should be updated.

Overall, even given the mental and emotional strain, I was extremely grateful to have been given the opportunity to participate in the workshop. It certainly gave me insights into the current attitudes amongst clinicians, and I hope we were able to give them insights into the feelings of the “consumers” of perinatal care.

Jannette Cass-Dunbar

Mum to Shea and his angel twin Tainn born at 24+6 weeks weighing 740 and 620g, so very close to the current guidelines for non-initiation of treatment!



Shea and Tainn

For those interested, a link to  
◀ “Care around Preterm Birth : a guide for parents”  
can be found at  
<http://www.austprem.org.au/journey/pregnancy/pregnancy.html>

## Rachael

Despite the fact that the birth of our premature child occurred over two years ago, the “NSW & ACT Workshop on Perinatal Care at the Borderlines of Viability” was a confronting and emotional step back to that time. When the information presented was factual and concise, there was some distance between what was being discussed and your own situation. It was all numbers and words. When we started voting on hypotheticals it became a much more emotional. I found it very difficult to remain rational and

distanced from the opinions being expressed in the voting. It was a draining day and a half but very informative and worthwhile.

As members of Austprem, we were lucky to have Anne and Janette representing us, helping to dispel the assumptions and generalisations made by some in the medical profession about the parents and families of prems. At this workshop there was a view expressed that all parents of prems were from a particular background in relation to levels of education and socio-economic status. Anne’s presentation and the participation of all the parents

in the discussion groups would hopefully have changed that view. We are a very diverse group and need to be treated as such. Everybody has a different emotional threshold and what as parents and families we are prepared or able to accept in terms of disability, the burden of ongoing care and the ongoing emotional/psychological problems experienced by many needs to be more fully examined. At present many of the decisions impacting on the above are being made for us.

The babies and situations being used in the hypotheticals were the reality faced by many of the members of this group. The available responses to some of the hypotheticals were not adequate to be able to give a clear indication of the difficulty faced by parents when in a particular situation. As parents we do not have the emotional distance in these situations as afforded the medical profession, being on the other side of the fence. It was particularly distressing when asked to vote on a hypothetical so similar to the birth story of your child, all they needed to do was insert names, and have the vote go against you as to whether your child would have been resuscitated by many of the clinicians present.

While the aim of the workshop was “to bring clinicians and consumers”



Cibella, 4 days

# Perinatal Care at the Borderlines of Viability Workshop NSW

together, more parents/advocates being present would have given a more accurate picture to the clinicians of how parents and families cope with birth at the “borderlines of viability”, premature birth in general and life after NICU. At least half the discussion groups did not contain a parent/advocate ( 6.9% of attendees were parent/advocates) which was telling in the guidelines those groups put forward for voting. The discussion groups were a chance to give more in depth information to a smaller group of clinicians as the parent of a child born on the “borderline of viability”. This was an opportunity to communicate to the medical profession that parents/ siblings/ extended families of premature babies need to be treated in a holistic sense, as the experience does not end with discharge from NICU/SCN. For a lot of parents and families this will be one of the most traumatic experiences of their lives and the effects are longer term than probably appreciated by the medical profession. It is a big ask for our health system but the whole family needs to be cared for, not only the developmental/neurological progress of the child. And not just the families of babies born on the “borderlines of viability”, this is a traumatic experience, a NICU is a confronting environment, for everyone exposed to it, gestation isn't the only indicator.

It was also stated at the outset that the aim was not to ‘draw a line in the sand’ in terms of gestational viability, although in my discussion group there was a clinician who stated that's what he was there for! He said he needed something to work to. I hope it was made difficult for him by having me there, with pictures of my ex 23 weeker and her siblings. As this was held in Sydney, a number of the large Sydney NICUs were well represented and were vocal in their opinions of viable gestations. This was very confronting. It appeared that there is an opinion in NSW that the gestational age should be higher than it is currently. It can only be assumed this was partly based on the statistical information given on Thursday afternoon relating to outcomes/levels of disability for babies born in what was being called the grey zone (23-26 weeks), but also based on the current medico-legal situation in Australia. This

expressed opinion though doesn't seem to directly translate into lack of action. Anecdotal information from midwives at these hospitals was that it is “all hands on deck”, even births of what is considered extremely low gestations (23-24 weeks).

Anne gave an excellent presentation from a parents' perspective. I hope those involved in the care of our children were able to take some insight into our feelings about our babies and growing children and will be mindful of that in their treatment of parents, babies and families in the future. In the guidelines session a neonatologist was particularly rude when asked by a parent to explain terminology, which had not been used before. Terminology needs to be consistent throughout the state and Australia wide, and also be clearly explained at all times. Anne also made this important point in her presentation.

To give an idea of the weight of the topics for discussion and formulation of guidelines, my group looked at the gestational age at which it is ethical to initiate treatment. The second part of the question was to decide at what gestational age is it ethical for a medical practitioner to overrule the wishes of informed parents and initiate treatment. In the first part of the question the way in which the viability of a baby was decided upon appeared to be dictated purely by birthweight and gestation. In a naïve, non-medical fashion I suggested something like the Apgar score for assessment be developed rather than it solely being based on gestation and birthweight. All babies, as we know are not the same, and gestation and birthweight is not always the only accurate indicator of that. The second part of the question did cause a lot of discussion but leads to the assumption that some medical practitioners feel they can disregard the decisions made by parents. This attitude ultimately affects the future life of a child in our society.

I look forward to reading the consensus statement. When voting many of the formulated guidelines contradicted one another. To address these discrepancies will be a difficult task. Much of what was discussed and formulated I can agree with and unfortunately as time goes on I can see the opinion of the medical



*Cibella, Jan 2005,  
with Memphis and Huon*

profession and their apparent reluctance to push the boundaries. But my own opinion lies in the area of “this is my child, I want to be informed and I want to make the decisions when I can”. I know I don't speak for everyone and I could go on about the emotions and conflicting issues some of the discussions gave rise to. I felt a real sense of frustration, as there weren't more parents/advocates present, so therefore the medical profession skews the guidelines. An accurate indication of what parents can, do and are prepared to accept in terms of outcome needs to be more clearly communicated and reflected in guidelines such as these for use by the medical profession.

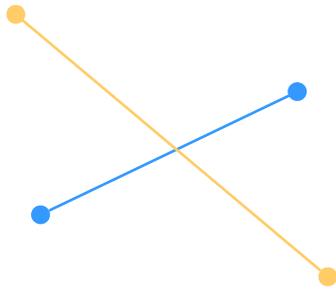
Rachael Bourne

Mum to Memphis, Huon and Cibella (born at 23 + 3 weeks weighing 600g, just made it by weight but not gestation)

## 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 Thursdays (not in January) and Sunday nights from about 9pm (Eastern Time). Late chats, from 9pm WA time are held on the 2nd and 4th Sundays of each month. A reminder is 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.

## Your Austprem Committee

<b>President</b>	Leanne Uwland
<b>Vice President</b>	Catrin Pitt
<b>Secretary</b>	Kirsten Burkitt
<b>Treasurer</b>	Leanne Uwland
<b>Media/Promotions Officer</b>	Jodie Ward-Davies
<b>Newsletter Editor</b>	Anne Casey
<b>Chat Host Co-Ordinator</b>	Narelle Austin
<b>NSW State Rep</b>	Nadine Jones
<b>QLD State Rep</b>	Narelle Austin
<b>SANT State Rep (acting)</b>	Anita Stergiou
<b>WA State Rep</b>	Anita Stergiou

## 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](mailto:austprem@austprem.org.au)**

and it will be forwarded to the appropriate person.

## Pregnancy Support Group

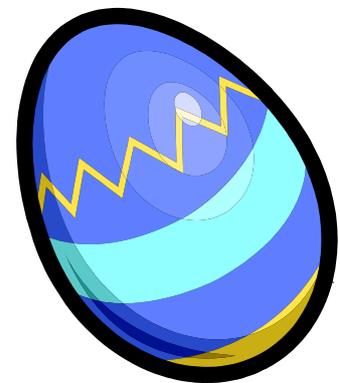
<http://www.austprem.org.au/psg.html>

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.



# Happy Birthday wishes to:

## March

1 Hani (7)  
1 Alexandra (2)  
1 Cooper (2)  
2 Jarrod (6)  
2 Amber (1)  
2 Brianna (1)  
3 Mikaela (8)  
3 Jaiden (3)  
3 Hannah (3)  
5 Mitchell (5)  
5 Chloe (1)  
6 Jaxon (2)  
9 Sophie (1)  
11 Dana (5)  
13 Isabella (3)  
14 Antonio (6)  
15 Ariana (2)  
16 Bryce (6)  
20 Laine (4)  
23 Jack (1)  
26 Megan (5)  
27 Perry (3)

29 Kyle (5)  
29 Baydn (4)  
30 Parker (2)  
30 Isabella (2)  
31 Zachary (10)  
31 Bindi-Lee (1)

## April

7 Breanna (4)  
7 Koji (2)  
8 Jonty (5)  
10 Michaela (1)  
12 Eva (1)  
13 Tayla (9)  
13 Jessie (9)  
14 Marlee (5)

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](mailto:kirsten@austprem.org.au)

Your support helps Austprem Inc. to grow and improve.

## Donations

Austprem Inc. is a non-profit organization 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.

15 Maddison (3)  
17 Bradley (12)  
17 Kammryn (7)  
19 Millie (14)  
20 Bayley (4)  
20 Lachlan (4)  
23 Noah (1)  
24 Isobel (1)  
25 Logan (2)  
27 Jessica (5)  
27 Declan (1)  
27 Siobhan (1)  
28 Caleb (5)  
29 Maddison (10)

## May

1 Aimee (5)  
3 Joshua (4)  
5 Karissa (11)

5 Sophie (9)  
5 Charlie (3)  
5 Oscar (3)  
6 Sarah (6)  
9 Courtney (5)  
10 Cooper (2)  
11 Ben (5)  
11 Marshall (1)  
12 Jackson (1)  
13 Jack (5)  
17 Faith (1)  
17 Noah (1)  
17 Sasha-Honey (1)  
18 Ruby (1)  
19 Samantha (10)  
19 Matthew (10)  
20 Bella (4)  
20 Emily (1)  
21 Ethan (3)

## 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.



ABN 67 731 996 316

Austprem Inc.

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

Visit our website  
[www.austprem.org.au](http://www.austprem.org.au)

Contact Us:

[austprem@austprem.org.au](mailto:austprem@austprem.org.au)

Newsletter

Suggestions and Comments?  
[newsletter@austprem.org.au](mailto:newsletter@austprem.org.au)

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