



## Siblings

Jessica and Vincent - 1995 (see pages 44-5)



Having a premature baby is a scary experience for many parents, and for those who already have other children to look after, it can be a distressing time having to provide for the needs of the other children whilst also spending the necessary time with a baby struggling to survive. Later it can be difficult

fitting in therapies and appointments around activities for older children. If bedrest is necessary during any pregnancy, caring for the children you already have can become a logistical nightmare. For those whose first baby is premature and has ongoing special needs, issues can arise with siblings born

later overtaking the older child in terms of skills, as well as juggling appointments and general daily life with a young family.

This issue includes many stories from families on how they coped and what they did to try to balance the needs of different family members.

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## From the Editor

In this issue of Austprem, we hear how the birth of a premature baby has impacted on other children in the family. There's no doubt that the birth of a fragile baby is traumatic for parents. Children experience this both in themselves and through their parents. Sometimes the whole family is affected by post-natal depression and sadness that can linger for years, especially when the early birth results in long term disability for the

premature child. Yet caring for a disabled child can bring great joy to a family. Siblings learn how to consider and care for those more vulnerable than themselves and to understand and accept difference. Those are great strengths to bring to society in general.

In the media recently there's been a lot of discussion about the ethics and cost of medical interventions for extremely preterm babies who have a

high risk of poor outcome. All of these phrases are subjective and controversial. Victoria's Minister for Health, Bronwyn Pike, has called for an open debate on the issue. Austprem hopes to participate actively in this debate as an advocacy agency for parents. We are developing a draft position statement for Austprem and welcome feedback from parents on this.

Anne

## Siblings - Kylie's Story

It is 8am. As my children prepare for another school day I watch them intently. Jakob, the eldest at 12, sits at the kitchen table promoting the benefits of oatmeal for breakfast. Ailish, 10, is concerned about her netball game later in the day and enthusiastically describes her game plan. Ella, 6, dances around the room believing she is a prima ballerina born to entertain us all. Harvey, the youngest at 4, watches on from the seat next to his big

brother and grins, thoroughly in awe of his older siblings. These are the moments I treasure, when everything is good, everyone is happy and we are together. Throughout the past four years, life hasn't always been like this.

Harvey was born 16 weeks premature. This experience had a profound effect on our way of life.

In January 2001, Harvey was born 16 weeks premature. This experience had a profound effect on our way of life. Harvey spent 150 days in a major metropolitan hospital almost 4 hours drive from our seaside home. This was a very trying time for his siblings – their little brother was fighting a daily battle for survival, a battle that they could not completely comprehend. A neonatal intensive care unit is not the ideal setting to meet your baby brother for the first time.

# Siblings - Kylie's Story (Cont.)

Health-wise Harvey had to overcome the long list of insults that most microprems endure. At the time we were certain he would ace NICU and be on his way back to our local hospital in Warrnambool in record time. This was not to be. For the duration of Harvey's hospitalisation he was a very ill child. Set back after set back extended our time in Melbourne. There were times I was desperate to find a way to improve the outlook for both Harvey and his siblings, but I had no control over the situation; we were helpless in plotting how our story would unfold.

How did the children adjust to the situation of separation and uncertainty?

No little girl should have to worry about...her little brother dying

Each child did it in their own time, and their own way. I can remember when Ailish tried to explain to me the physical pain she felt in her heart. This pain was a physical manifestation of the emotional distress she had to endure. No little girl should have to worry about ventilators, monitors, infections, resuscitation, blood transfusions, or her little brother dying.

My oldest son tried to be brave. He felt a sense of responsibility to save his baby brother from the pain and discomfort that was so much

a part of his short experience of life. Jakob would enter the nursery and check the monitors and medical equipment and review Harvey's notes in an attempt to understand his own predicament in addition to the plight his little brother faced. He found it extremely tough to be separated from Harvey and worried constantly about him. At times it was all too much for Jake and he would literally explode with emotion.

Ella had only been walking for a short time when Harvey was born. She was sweet and innocent but well aware that something monumental was happening to her precious family. She would cling to me tightly whenever she had the opportunity. Her eczema was very hard to keep under control throughout this period; I believe the stress Ella experienced during this time exacerbated her skin condition. Her eczema was an indicator of the emotional upset she was experiencing. When things were really tough her skin would be red, welled and itchy.

During the period of Harvey's hospitalisation we did all we could to keep our family together. My partner and I were acutely aware of the need to make time to talk, listen and be with Harvey's brother and sisters. We were aware that things were just as tough for them as they were for us. We tried to keep them informed and educated about

Harvey's condition. We visited Harvey with his siblings as much as we could so that they could bond with their baby brother.

Harvey did not magically get better when he was discharged from hospital

Harvey did not magically get better when he was discharged from hospital after his birth. He has ongoing health problems in addition to a physical disability and a hearing impairment. Despite all the problems we have endured as a family in the past 4 years the children have grown and adjusted to our fate. They have adapted to living with a sibling who often is confronted with life threatening bouts of illness. They are happy, well adjusted kids who are all outstanding in their own right. I am proud of their resilience, their compassion and their love of life.

My four children have shared a unique experience together as siblings; one that has taught them many positive lessons. Despite the heart-ache the children have a special bond with each other that I hope they will carry with them into their adult lives.

Kylie



# Siblings - Anne's Story

We left our two year daughter at home sleeping, in the care of a neighbour, when I went into labour unexpectedly at 26 weeks. Little Jessica woke up

Little Jessica woke up the next morning to a vastly different world.

the next morning to a vastly different world. Early in the NICU period, I decided to continue keeping Jessica in crèche 4 days a week because I didn't have the emotional strength to be look after her while I spent hours each day at Vincent's bedside. It was a bewildering time for Jessica, and I know our reassurances were often distracted and feeble.

Once Vincent came home, I took Jessica out of creche and we began our lives together as a different kind of family. We found a lovely teenage babysitter to come to our house each day after school to help me with housework and caring for Jessica. They played boardgames, cards, baked biscuits and cakes which we all enjoyed, made playdough and turned it into

fantastic creations – all the things I wanted to do but didn't have the energy for. This was a huge help for us that first year when Vincent needed three hourly feeds and I spent half my conscious life attached to a breast pump.

We were very fortunate to have Professor Lex Doyle as Vincent's neonatologist. At our very first visit, post term, we came to the clinic as a family and he said to us, "The best thing for Vincent will be his sister. She'll keep him on his toes." And she has done, always. He doesn't get away with nearly as much as he'd like to with Jessica around.

"The best thing for Vincent will be his sister."

She's incredibly patient with him most of the time but if she's not in the mood, she tells him so.

Sometimes it has almost felt like Vincent has three parents. Other times he and Jessica are ordinary siblings, competing for the same things, striking elaborate deals with each other, teasing. There's a

real creative dynamic between them and a strong bond.

There's a real creative dynamic between them and a strong bond.

Vincent still has special needs but they aren't as dominant as they were when he was younger. Along the way, Jessica has grown into a wise and compassionate young girl, strong, steady and sensitive to the needs of others.

When you have children and one of them takes much more time and care than the others, it can look and feel like a raw deal for the siblings. Yet it's much more than this. Family members can give each other the strength to keep trying, even through the hard times (re hospitalisations, setbacks and new diagnoses). Caring for another being, putting their needs above your own when necessary, is one of the essential ingredients of happiness. It's one of the things that prem siblings learn, often every early in their lives. It's one of the reasons they are so special.

Anne

Dividing your time between children at home and children in hospital can be very difficult and distressing. Accept any baby sitting offers that come your way so you get to spend some time with your new baby, without worrying about your toddler disturbing others in the NICU. Investigate day care or occasional care. If you need to take your child with you to the hospital, try to organize frequent, short visits. Or take snacks and have breaks whenever your child needs to. When you are home with your other children, try to spend some time playing with them without distractions. And remember that although it seems like forever, it will end, and most children will quickly forget the time you spent apart.

# Siblings - Jessica's Story

My name is Jessica. I was two and a half when my brother Vincent was born three months early. He's always needed extra care because he has cerebral palsy. When I was little I used to feel like I didn't get enough attention because it all went to him. I can remember once when I'd drawn a special picture and was trying to show it to my mum and dad. But they were busy trying to get a bib on Vincent – both of them – and they wouldn't look at the drawing.

I don't feel like this any more. I am thirteen and Vincent is 10 and it's like he doesn't even have a disability any more. Except sometimes I feel like he takes advantage of his



disability, like making mum fetch him things that he could get himself. That can be annoying! Despite that, I get along with him really well now and it's much better than being an only child.

Jessica

*Jessica and Vincent - 2005*



# Siblings - Nadine's Story

When my prem, Caleb, was born at 30 weeks, my older son, Jayden was just 20 months old. I was in hospital myself for just over a week and Caleb was in NICU and SCN for 7 weeks. I was lucky in the fact that I had a great support network with my family and my husband's family, they all rallied around to help with Jayden, which was great for me as Jayden hated visiting NICU. He would throw tantrums and generally make a nuisance of himself. I could never take Jayden to the hospital on my own so would either call on a relative to come

with me to watch Jayden, or have them baby sit him at their home. I would not have gotten through it if it wasn't for their help.

I was overwhelmed with feelings of guilt. Guilt that I was neglecting Jayden and guilt that I couldn't spend as much time at the hospital with Caleb like the other mothers I saw there with their babies. Even when I could be home with Jayden, I still didn't feel like I gave him enough time as I always seemed to be busy expressing or catching up on other things I hadn't done.

The staff in NICU were great and very understanding of this matter, constantly reassuring me that I was doing the best that I could under the circumstances. Talking with the social worker was also a great help for me when dealing with my emotions during that time.

I thought when Caleb came home that there would be jealousy on Jayden's behalf but he adored his little brother and lavished him with kisses and cuddles whenever he could.

Nadine

## Bedrest Tips - Occupying Young Children

Bedrest at home brings many challenges, including how to occupy your other child/children

- As much as possible, try to have your children cared for by others, if friends or family offer to help out, take them up on it. For care outside the home try family day care or a crèche. At home, you might be able to find a babysitter who can play with your child while you provide some supervision.
- If your child is old enough, teach them how to use the video and/or dvd player so they can put their own shows on.
- Have a box of story books, colouring books and pencils/crayons/textas near where you are resting.
- Jigsaw puzzles can be fun to do together.
- Get your child to rub your tummy and talk to the baby.
- Have someone pre-prepare snacks and drinks that your child can get for themselves. They could also get them out for you!
- Think of fun games to play, such as "basketball" using rolled up socks and a clothes basket - not too taxing for you, and your child will have a ball!



## Siblings - Kirsten's Story

Having an older child with special needs means that everyone in the family is affected. Depending on the disability and the level of functioning, family life can be disrupted to a greater or lesser extent.

... family life can be disrupted to a greater or lesser extent.

Michael was born at 31 weeks, 1278g. He is now almost 9 years old and has had regular therapy of one sort or another for almost all his life.

Rebekah was born just after Michael turned 3. She has attended therapy for most of her life too, not as a patient but because she had to come with us to Michael's appointments.

There were times when if I hadn't laughed I would have cried - like when Michael was having an OT assessment at age 5. Rebekah, not quite 3 could do almost all the activities with ease, while Michael was struggling to complete most of them.

Rebekah wonders why Michael has all these appointments - "When will I go to see Dr X?" "Do I have a doctor like that?" "Why don't I go to see Y?". She struggles to understand why Michael doesn't have to do some things, and she does. At the age of 5, life is very unfair.

We try not to treat the children differently, but we do have different expectations. We know that Rebekah is capable of some things that Michael will always have trouble with, but the juggle to

encourage her while not discouraging Michael can be hard. I have doubts that Michael will ever ride a bike, Rebekah is missing out here, because we haven't spent the time with her to help her learn. I know we should.

Michael doesn't like to go out. Weekends and school holidays are very difficult - Rebekah wants to go out and have fun, Michael resists and sometimes I just can't face the struggle to get out the door.

In some ways it is easier that they are different genders, and as Rebekah gets older we will be able to explain to her why things happen as they do and why Michael is different. I hope she understands, and I hope she doesn't hold all the missed opportunities on her part against us.

Kirsten

# Siblings - Rebekah's Story

I was on bedrest my whole pregnancy with Kahira, I ended up putting Kaihdyn in daycare 5 days a week from 9 - 5pm, but it was hard to have him away from me.

When Kaihdyn (28 weeker) was born my 2 older children, Liam and Olivia, had to go and live with my aunty. We were so far from home and it was Liam's first year at school and we did not want to upset their routine. It was very hard

as the first 2 months Kaihdyn was in Newcastle and Canberra, they are both over 600kms away from home, so I only saw the kids once in 2 months. I used to cry myself to sleep, wanting to be there for Liam and Olivia, and also for Kaihdyn.

Once we got transferred to Wodonga Hospital which was only 300kms from home I was going home on the Thursday morning by bus and coming

back to the hospital on Saturdays, then staying till the following Thursday. Paul had to go back to work so he did the opposite, he came over on the Thursday and went back the Sunday so we kept missing each other. We spent one night a week together.

Rebekah

## Websites

### **Supporting siblings of premature babies in the nurseries**

<http://www.preemie-l.org/siblings.htm>

This is a wonderful resource with ideas and information for looking after young children while also spending time with your baby in the hospital.

### **For Parents of Premies / Other Topics / Siblings**

<http://www.pediatrics.wisc.edu/patientcare/preemies/othertopics.html#Siblings>

This website contains much useful information, and the section on Siblings is also excellent. It covers topics such as "What do I tell my other children?", "What are some common reactions of young children to having a baby in the NICU?", "Should my other children visit my new baby?", "What are common concerns of children while visiting?", "My baby is dying, what do I tell my children?".

### **Supporting Your Other Children**

[http://www.marchofdimes.com/prematurity/11202\\_11209.asp](http://www.marchofdimes.com/prematurity/11202_11209.asp)

Information here includes activities other children can do for their new baby as well as tips on explaining the NICU environment to prepare children for what they might see.

## Book Review

### ***The pregnancy bedrest book : a survival guide for expectant mothers and their families***

Amy Tracy

Berkley Press, New York, 2001

This is a helpful book for women who find themselves confined to bed with threatened PTL. There is a chapter called "siblings in waiting" which has some great ideas for helping your children through this time, including addressing fears that their mother might die. This is one of the neglected issues affecting siblings following a traumatic birth and one too easy to overlook when dealing with young children.



# 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

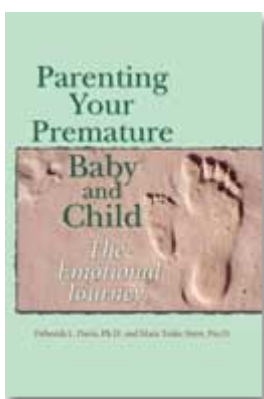
- purchase address labels, stick on and iron on name labels for clothing, bottles, snack boxes etc, and heaps of other stuff, and support Austprem too!

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

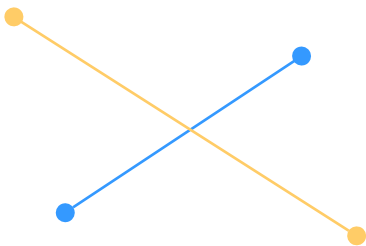


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## Prematurity in the Press

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 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.

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

<b>President</b>	Leanne Uwland
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<b>SA/NT State Rep</b>	Lisa Reid
<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.

### AGM

The Austprem Inc. AGM will be held on Sunday 28th August 2005 at 6:30pm (WA), 8:00pm (SA/NT), 8:30pm (QLD/NSW/VIC/TAS) in the Austprem chat room. Hope to see you there!!!

# Happy Birthday wishes to:

## June

4 Olivia (6)  
5 Amy (2)  
7 Cameron (1)  
11 Jayke (1)  
13 James (10)  
14 Chelsea (1)  
15 Jacob (6)  
19 Jessica (3)  
21 Cullen (3)  
21 Nina (2)  
21 Xavier (2)  
21 Marcus (1)  
22 George (5)  
25 Tayah (1)  
26 Thaddeus (12)

8 Chae (10)  
8 Anthony   
9 Molly (8)  
9 Monet (1)  
9 Jesse   
18 Angelo (5)  
20 David (5)  
20 Nicholas (5)  
21 Micayla (7)  
22 Alexander (10)  
22 Charlotte (1)  
22 Ethan (5)  
24 Belinda (3)  
24 Mitchell (3)  
25 Sheldon (6)  
25 Kylara (4)

25 Mitchell (1)  
27 Stephanie (5)  
29 Memphis (8)  
29 Lachlan (6)  
30 Dylan (7)  
30 Bella (3)  
30 Jack (3)  
31 Aleesha (1)

7 Kate (8)  
13 Elizabeth (13)  
16 Nicholas (5)  
16 Mitchell (1)  
16 Harrison (1)  
18 Monique (3)  
18 Joshua (3)  
18 Stephanie (3)

## August

2 Chloe (3)  
2 Kahira-Jade (1)  
5 Lochie (6)  
5 Maxwell (1)  
5 Rhett (1)  
5 Marcos (1)  
6 Jayden (7)  
6 Mollie-Maree (4)  
6 Georgia (3)  
6 Jeremy (3)

19 Imogen (5)  
21 Coby (3)  
21 Aiden (2)  
21 Caleb (2)  
22 Lachlan (9)  
25 Benjamin (4)  
26 Daniel (8)  
27 Tayla (5)  
28 Nicholas (8)  
29 Saffron (5)  
29 Hayley (2)  
30 Taniesha (11)

## July

1 Luca (1)  
1 Jackson (1)  
3 Taylor (6)  
3 Brooke (2)  
6 Esther (2)  
6 Tiana (1)

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.

## 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.

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

Visit the Austprem website :  
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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.

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