**Autumn 2010** 



#### AT A GLANCE

Austprem Inc. is a major national Internet based support group which now has well over 800 members!

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AND MORE ....



# Bringing your prem baby HOME!



# Joining Austprem

# Austprem is an Internet based support group.

To join Austprem Inc., you will need to go to <u>http://www.austprem.org.au/join.html</u> 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.

#### →<u>Austprem - Pregnancy Support Group</u>

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

# Bringing Your Prem Baby Home

One of the first things newly expecting parents start imagining is having their baby home with them and being a family together. They might start to set up the baby's room and sometimes prepare for the arrival of their new family member by reading books about bringing up children (especially if this is the first baby). When their baby arrives early, many of their plans are thrown into chaos, and, once the baby is stable, the question in everybody's mind is "When will my baby come home?"

Many prems come home around their due date, give or take a couple of weeks. Some, especially those born at later gestations might have shorter stays, and others, those who have been very sick, might stay well beyond their due date. It is important to start preparing for baby coming home even before you know the date

# Many prems come home around their due date, give or take a couple of weeks

as I know of many a family who are one day told "Baby can go home tomorrow" and there is little time to organise those last minute things.

Some hospitals recommend you do a first aid course, or that you are at least familiar with CPR, try to do any such courses as soon as you can. Sometimes babies go home with NG tubes or on oxygen, you will need to learn a number of things for the extra care this involves but you can do it, and it is certainly worthwhile to get your baby home.

Make sure you have a suitable child restraint in your car and that it has been correctly fitted.

Learn as much as you can about your baby while they are in hospital, get to know what soothes them and their likes and dislikes. Talk to them and read them stories so they know the sound of your voice. It isn't always easy bonding with a humidicrib in the way, but you will.

Before you leave hospital, make sure you have appointments made with your baby's paediatrician and any other specialists you need to see. If you haven't got appointments, make sure you know who to see and when. Follow up is very important. Make sure, too, that you know who to call at the hospital if you have any questions. Usually you can call the nursery where your baby was cared for and can get answers at any time of day or night!

Most of all, ENJOY YOUR BABY!

Kirsten

### Read more

Bringing Your Preemie Baby Home http://family.go.com/parenting/article-sk-19090-bringing-your-preemie-baby-home-t/

Taking Your Preemie Home http://kidshealth.org/parent/pregnancy\_newborn/medical\_care/preemie\_home.html#

Going Home http://www.prematurebaby.ie/goingHome.php

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# Katelyn's Story

This is a two part story one on bringing a baby closer to home from one Hospital to another closer to home. And then Home.

Katelyn was born at 27weeks weighing 1010grams She developed severed HMD and spent a couple of weeks in NICU but once she recovered from that she didn't look back.

When Katelyn was 5 weeks old, just before Christmas, were told that she would be moved from the city hospital to our home town hospital. I was delighted to hear she would be one step closer to home. We packed our things and we got all organised and went home and set up and then travelled back the hour and a bit to the city and by this time it was midnight - we went in to see her and the nurse came to talk to us and said that she was not going to be moving tomorrow because they had a case of whooping cough at our home hospital and they would not let her go to the



nursery there because they were worried she would catch it and die. Well, I was devastated - how could some inconsiderate person take whooping cough into that hospital at that time and it just wasn't fair.

I was given a small bit of advice from the social worker that sometimes it was not what you expect so not to be too excited anyway because hospitals do things differently. Basically in trying to calm me she said, "The grass is always greener on the other side until you get there and find out it is artificial turf."

I didn't really take a lot of notice of that as even if it was different it would be closer to home and better and I was upset.

A week later with the reassurance that all was well - 3 days before Christmas Katelyn was moved.

Well - things were different and were not what I was expecting. Katelyn had been given a lot of dignity and was left in clothing in the humidity crib and I had made several pretty dresses for her as she still did not fit 00000 or even prem baby clothes back in 1993 there was a lot less around for prems than there is now. When she got to the hospital we had followed the ambulance and a nurse got all clucky over her and took her out of the crib and carried her around with me at her heals - I was thinking, "Give her to me - I want to carry her - she is My baby." Then she put her into a crib and closed the door. I didn't even get a cuddle and then I was told - "Oh, she is exhausted from the trip now - come back latter."

When I got back my grandmother had been to see her and I was so proud of her lovely Christmas dress I asked - "Did you like her pretty dress?" The reply was, "she wasn't wearing anything. They had given her a sponge."

Firstly, I had been bathing her in the tub in the other hospital and then putting her back into the humidicrib to warm up. It was the policy at this hospital not to bath them until they were in an open cot. I was so upset. Things were not the way I had thought at all and I suddenly wished she was back where things were familiar and I knew and understood the routines and the nurses knew me. I never really settled into a routine and a few weeks later she was big enough and well enough to come home.

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Home time came and they said I had to sleep in with her for one night. Wednesday night was arranged and so I got up all excited to spend a night in hospital with my baby and come home the next day. Wednesday morning the phone rang - "Sorry - we have no beds you will have to make it Friday night." Disappointing! Friday came and I was getting ready to go to the hospital yet again and the phone rang - "Sorry, it will have to be Monday because we don't have a bed and the Dr wont be able to discharge you on Saturday." Monday I left early and got to the Hospital with my bags packed and ready to stay the night for one night and bring Katelyn home the next day it had been almost a week since she was able to come home and I was so excited. I got to the Hospital only to find, "NO BED!"

That was it I cracked. I sat and cried and I said, "NO, I will sleep in the sun room or the nursery if I have to we are going home tomorrow and I am NOT leaving."

That day they gave 9 week old Katelyn her triple antigen and she was hot and flushed and like a zombie - she didn't feed well and was zonked out by it. She was now exactly 1800grams 4lbs. They found a bed! I stayed the night and the next day we went home.

As we walked out the door a nurse said to me, "You will be back anyway! She will get cold as home

is always colder than hospital and then she will get sick and you will be back because she is so little - they nearly always came back to us!" I shook with fear. OMG taking her home was suddenly so scary!

Things don't always work out the way you plan them

I put her into her crib and tucked her in she was in a crib beside our bed and I was so excited and scared and wor-

ried I had the thermometer and I took her temperature every half hour for the first 3 hours until I distinctly remember my husband saying very sternly to me. "For goodness sake will you leave the poor kid alone she is asleep and she is warm enough, you will be a nervous wreck if you keep this



up!" Katelyn never went back to hospital - not until age 5 to have her tonsils out. And she is now 16yrs old and very healthy!

Things don't always work out the way you plan them and people can say the most bizarre things but don't panic as it all happens the way it is meant to. If I could go back and do it again I would not worry or fuss quite so much and I would make sure that I enjoyed her beauty and her growth and her strength just a little more as they grow up so fast!

At the time those stresses of not moving when it was planned and not finding a bed and having to wait were traumatic but now I look back and think of all the things that might have been they were minor hurdles really.

Rhonda

#### Austprem Ink

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# Tanya's Tips

Benjamin was born at 25+6 weeks, weighing 914grams, on the 9th of November 2008. He spent just over 12 weeks at RPA and was then transferred closer to home, to Sutherland Hospital where he spent a further 3 and a half weeks. On the 27th of February 2009, after 110 days in hospital and weighing 2.23kg, we were finally able to take our precious boy home. We luckily had no major medical issues to contend with once he came home and he settled in really well, here a few things that helped me:

- Chances are if your baby has been in the NICU for a while, they are already in a 3 to 4 hourly routine. If you want to continue with a routine the hard work is already done, just change the times to suit you. I found 7am, 11am, 3pm etc worked well for me.

- If you have a few medications to give, draw up a chart and tick as you go. Sometimes things get a bit fuzzy at 3am, so it's a good reminder.



months, especially when out, so i carried a bottle of hand sanitizer in my handbag. I also kept a few bottles around the house, great for after changing a nappy.

- I found 'Baby Cubes' really useful for storing expressed milk in. They are available from Big W, Babies Galore etc and are relatively inexpensive. They are also great for freezing purees in when your baby starts solids.

- Most importantly just enjoy having your special little one at home!

Tanya

# Coming Home to Food

Despite what you think during your long stay in the nurseries, your child will not start school from the hospital. You will actually go home with your baby in your arms.

#### And it is scary.

Suddenly you do not have a nurse you can turn to and ask a question. Suddenly it is you and your child. There are no doctors to look for, who will tell you what is wrong when you baby cries. There are no monitors that beep, nor a watchful, yet critical eye looking over your shoulder as you bathe your baby. No one is there to test that the water is too hot, or too cold. No one is there to remind you that you have to change nappies, powder bottoms, burp after every feed.

And whilst you know all that, have been doing all that, by yourself, there has always been a safety net.

And now you are going home. And someone is taking that safety net away from you.

So how do you cope? And what if you have more than one baby coming home?



That was my case; I had two tiny boys coming home. I was lucky in that they didn't leave on the same day. It certainly gave me a few days to get the hang of things before the chaos reigned. But in some ways I didn't like it either. The second day home was one of the worst. I didn't make it in to the hospital to be with Lewis, all day. And I felt so guilty about that. Still do to some extent.

So how did I get myself ready?

We had a couple of days notice, but we had been planning it for a while anyway. Car seats were fitted, nursery was ready, baby clothes washed and in the drawers, and we had a nappy bag ready with the pram. Of course the camera had film in it, with extra film (these days you would clear the memory stick and charge the battery).

Most importantly, the pantry was stocked with easy to prepare and cook meals.

Food is a most important but easy to forget item. So far you would have been living off take-away meals; we did. A quick visit to Maccas, or the hospital canteen on the way to the nursery, eating on the way. But now you want to bring your child home and avoid those well populated places. So now you want to cook, just like your mother did. With a bit of planning, it isn't hard to have good meals that don't take all day to prepare.

Our pantry was filled with one-pan meals - jars of sauces to which you add meat, packets of pre-flavoured rice or pasta. Frozen dinners filled the freezer - they really are quite nutritional and tasty. Cans of vegetables lined the pantry shelves, frozen veggies joined the frozen meals. Packed meat from the supermarket were bought in the correct weights - if the sauce required 500g of chicken, then we bough a pack of 500g of chicken. If we had two jars, each requiring 500g, we bought two packs, each weighing 500g.

The meals we had were quick to prepare, required only one hand to eat (hard to cut up a steak when a baby needs to be rocked). And, so we discovered, they tasted rather good when we reheated them three hours later, because a baby or two decided that our meal time was a good time to poop, wee and vomit.

We did make sure there was always fruit; a banana is a great energy source, an apple or a pear is easy to eat on the go (no peeling, no cutting up necessary). Mandarins are quick to extract from the skin, much easier than oranges and less juice everywhere. Grapes are a small package of pure energy - I would take the time to take them off the stalks the moment I got home from shopping.

There was a loaf of bread, sometimes in the freezer - toasted sandwiches with the left overs is acceptable once in a while. And milk in the fridge, a chocolate milkshake is always easy to gulp down if time is really a hassle.

If you really want a home cooked meal you can always do a roast in an oven bag - cut up veggies and pop them and the roast in the bag, cook for required time and serve. The only thing remaining task is to make gravy (a tin of gravy mix made that easy). Cleaning up is easy too.

There are also slow cookers and great recipes that include the meat and vegetables, so once again it is prepare, cook and forget and little to clean up. And some microwave recipes are the same, a complete meal in one hit.

It might mean a change in thinking, buying new recipe books or some new kitchen appliances. It might mean having to write out shopping lists, or walking the shopping aisles looking for the one missing item. But you can make eating well a easy task of your day, giving you more time to spend with your baby.

Bon appetite

Catrin., mum to Angel Cassie, teenagers Lewis and Kyle



# Kerry's Coming Home Tips

- Make sure you have your camera and take lots of photos of the farewells to the hospital setting as well as the first days home as they are very precious times you will enjoy reminiscing about
- Keep the day as free as possible, without time pressures or distractions or anywhere else to be, so you can focus on relaxing with and getting to know your baby at home
- I tried to replicate some of the routines Emily had become comfortable with in special care, such as soft lighting all night, a baby hammock for day sleeps, and following the same feeding-time schedule
- Be well-rested and prepared to be cuddling, comforting and feeding baby a lot overnight
- Don't be hard on yourself and have realistic expectations as premature babies are (very often) more difficult to bring home and care for than full-term babies
- Contact your Maternal/Child Health Nurse ASAP and request they visit you at home due to your baby's prematurity, and request information about what supports are available in the local area such as Playgroups for parents of prems, Mother/Baby units for help with sleep/settling, etc
- Utilise the internet for Woolworths/Coles home-delivered shopping, and log on to Austprem for emotional support and information



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# Zeik's Story



Coming home seemed to go on forever for us. Like us all I suppose.

I first came home when my waters broke at 23 weeks. I was at the hospital after the waters broke, there a mistake, they thought i was actually 22 weeks so they looked at me with pity and kindness, but sent me home to wait. There was nothing they could do.

But nothing happened, no labour and when I went back to the hospital they recalculated the dates, decided I was bang on 24 weeks and then whipped me into hospital. 4 weeks later - no labour, no baby and a small medical mystery - I came home again.

Then there were weeks of day-stay, ultrasounds, blood tests, cardiograms etc. etc. where I just came

and went and not much seemed to happen. Till it all happened in a rush - my placenta detached one day unexpectedly while I was at home alone. It was staggeringly painful. I found my neighbour and she drove me into hospital. 1/2 an hour later, I was in the theatre having an emergency c-section.

Finally here was here! our baby boy! our very sick, small, baby. He went straight to level three intensive care - and stayed there for the next 3 months. I came home without him.

So the days, weeks, months went by, a blur of this medical procedure and that - and a ridiculous amount of breast pumping!

At last, at a point where I was so used to the hospital I couldn't really imagine life without it (you know you've been there too long when they give you the staff discount at the cafe!) - we came home.

Madeleine



The most memorable tip has been 'If you're worried, call an ambulance - that way you'll get to the front of the queue at the Emergency department'. Thankfully I haven't had to use that advice.

### In the News

#### New Research Shows "Kangaroo Mother Care" Reduces Newborn Deaths More than 50 Percent, Proven to be More Effective than Incubators for Stable Preterm Babies

"Kangaroo Mother Care is one of the most effective ways to save preterm babies, according to a new meta-analysis released today on the effectiveness of this simple, low-cost intervention in which mothers serve as human incubators for their newborns."

http://www.savethechildren.org/newsroom/2010/pr-new-study-shows-kangaroo.html

#### Large dose of vitamin D in pregnancy cuts premature births

"Women should take up to 10 times the current recommended dose of vitamin D during pregnancy, experts have said after it was found to cut premature birth by half."

http://www.thaindian.com/newsportal/health1/large-dose-of-vitamin-d-in-pregnancy-cuts-prematurebirths 100357047.html http://www.thaindian.com/newsportal/health/vitamin-d-supplements-canprevent-preterm-laborbirths 100356748.html

#### **Premature Births Remain a Medical Mystery**

"After rising for 16 years, the rate of premature births in the United States dropped for the second year in a row, according to a report released this month. Despite the good news, still more than half a million babies are born early in the country, putting them at risk for conditions such as respiratory disorders, blindness, and learning disabilities

http://news.vahoo.com/s/livescience/20100425/sc livescience/prematurebirthsremainamedicalmystery

#### Over one million pre-term babies die worldwide each year: WHO

"More than one million infants die every year after being born too early, recently released World Health Organization data suggests - a number that one advocacy group says is likely "very conservative"."

http://www.vancouversun.com/health/Over+million+term+babies+worldwide+each+year/2067462/story.html

# 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 <u>http://www.austprem.org.au/promotion/books.shtml</u>



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http://www.toysandmore.com.au

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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.

For further information and subscription details please contact: **Carol Newnham** carol.newnham@austin.org.au

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# National Premature Birth Awareness Week

# 24-30 November 2010



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

Austprem





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.

# NNALIONS - 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 donate online using Paymate

A receipt will be emailed to you.

Donations \$2 and over are tax deductible.



# 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**

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.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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