

Central Coast Premms

Quarterly Newsletter

Volume 1, Issue 2

May 2008

Welcome

Welcome again to the Central Coast Premmie and Sick Newborn Support (CCPSNS) quarterly newsletter. We are enjoying a busy Term 2 with excellent guest speakers at our monthly meetings. We have now established a core group of members and last week held our first "organizational" meeting in preparation for the upcoming National Premmie Day. There is always more room for those interested in getting involved, so please contact Fiona or myself if you wish to help.

This quarter we have included a new section called "Your Story", which is an opportunity for you premmie mums to tell others of your experience. My (Sally's) Thomas is almost one year old, and as with every anniversary it's a time for reflection and mulling over memories so I've taken advantage of this opportunity to share my story this quarter. I will be looking for others who are willing to share theirs in the coming months so please email them to me at wegs@exemail.com.au.

Our next exciting development will be meeting with social workers and the SCN staff of Gosford Hospital to discuss how best to support mums who are still in hospital with their bubs. We are really looking forward to supporting the mums and these fantastic staff in what they do.

Looking forward to seeing you at one of our monthly meetings.

Fiona and Sally

Inside this issue:

Welcome	1
National Premmie Day	1
Diary Dates	2
Your Story	2 & 3
Who are We?	4
Some Things to Remember	4
Contact Details & Sponsors	4



Central Coast Premmie & Sick Newborn Support
Invites you to join us for morning tea in recognition of

National Premmie Day and RSV Awareness

Dr Adam Buckmaster presents:
What is RSV?

Why are premmie bubs at risk?
What can we do about it?

25th July 2008 ~ 10am - 12noon

Tuggerah Lakes Golf Club, Shelly Beach Road, Shelly Beach NSW 2261

RSVP 4353 4688 before 11th July.
Light refreshments available. Childcare available on request.
Central Coast Community ~ taking baby steps together

**Always
remember
that the
future
comes one
day at a
time.**

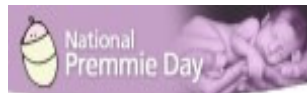
**Dean
Acheson**

Diary Dates

Our monthly support meetings are held on the last Wednesday of every month at The Entrance Baptist Church Hall, 8 Yakalla Street, Bateau Bay, from 10.30am till 12 noon. Light refreshments are provided, and allergies are catered for—please contact us if you have special dietary requirements.

25th June 2008—First Aid/CPR update. A volunteer from St Johns Ambulance service will present an update on first aid/CPR with a special focus on choking (a common concern for young babies and children), and enable us to practise our skills. There is no fee for this service, however, donations are welcome.

25th July 2008—NATIONAL PREMMIE DAY! See Page 1 for details.



30th July 2008—During our monthly meeting we will hear feedback from National Premmie Day and enjoy a relaxed social time over a yummy morning tea.....

Your Story

This issue's story comes from Sally and Thomas Wegener. Thomas was born in May 2007 at John Hunter Hospital. Sally is married to Stephen, and they have another son Charlie who is 4 years old and was born full-term.

I always had a “funny” feeling about this pregnancy. I’d had Braxton Hicks early on, but I started having painful contractions from 28 weeks which were attributed to my “irritable uterus”. I was to travel to Wagga when I was 32 weeks pregnant, and I was petrified of having my baby by the side of the road – a prediction that scarily would have come true had I gone.



Thomas going home aged 4 weeks (minus 3.5 weeks corrected!)

Stephen and I decided to spend a night in the Hunter Valley to celebrate our 10th anniversary. I woke at 5am to discover I was bleeding and my waters had broken. Stephen and I leapt out of bed, and after a couple of quick phone calls we hopped in the car and headed for John Hunter Hospital. Over the next 2 days the bleeding continued and the contractions came and went. Stephen decided to make one last trip to Newcastle before taking over babysitting duties from my mum. I’d been having contractions since 5pm and hadn’t taken much notice of them, but thought I should call the nurse just in case. She monitored me for a while, then told me with a concerned face that I’d be going up to the delivery suite. When I arrived, I told the registrar who was examining me that I was visualizing a tightly closed cervix – until he announced I was 4cm dilated. Bummer. I wanted to be upright, so the midwives manoeuvred me around the wires until I was able to kneel – one thing achieved from my birth plan! At 10.15pm, at 32 weeks gestation, weighing 1920g (4lb 4oz), my beautiful baby boy was born. He was breathing independently, so I was allowed to cuddle him before he was taken to the NICU with Stephen in tow. Thomas was having trouble maintaining his temperature, so he was now in a crib. He looked so tiny, even though compared to most of the other babies in the NICU he was a giant! Thomas stayed in the crib for the next 2 days, except for a couple of “kangaroo” cuddles. He was reportedly doing so well that the doctors decided to transfer him to Gosford Hospital.

Our arrival at Gosford Hospital SCN was a bit of a shock. I'd become accustomed to the high-tech machines, noise and buzz of JHH NICU, and the quiet, dimmed SCN at rest-time was quite a contrast. In some strange way all the "bells and whistles" of JHH had been comforting, and it wasn't until a few days later that I came to appreciate the value of the atmosphere in Gosford's SCN. I learnt in transit that Thomas was experiencing "apnoea of prematurity", which was initially very frightening for me. Our first night at Gosford his apnoea became quite bad and he required constant stimulation to breathe. I remember the nurse asking me if I wanted to hold him. I thought she meant that he was dying and was offering for me to have one last cuddle. Even though it was only a moment in time, I'll never forget that feeling. The nurse soon explained exactly what was happening, and I was filled with relief. She and the registrar also picked up that he was jaundiced, and he was placed under the lights just after receiving his first dose of caffeine for his apnoea.

In the following days Thomas stayed under the lights. Then I read more about kangaroo care and decided that I wanted to do it as much as possible. The staff were very supportive, and helped us to have two lovely long cuddles each day. Within 2 days Thomas was tolerating feeds, putting on weight, and his apnoeas had decreased. I like to think that his "mummy love" was the best medicine of all. Before long, Thomas moved into a bassinet. We kept trying him on the breast, and after a few visits from the lactation consultant and speech pathologist, he finally attached. He fed more and more each day, and finally at the age of 3 weeks and 5 days, it was home time!

Once home, Thomas started putting on weight rapidly. He seemed in excellent health, and was a very settled baby except for being a "chucker". As the months passed he seemed to be catching up, although physically he was behind his peers. We'd noticed that his head was big, but so was Charlie's so for a long time we put it down to that. But when Thomas was 6 months old I had some photos developed, and freaked out when I saw the contrast from 4 months to 6 months. Within 3 days we were at the paediatrician. The following day I was sitting in Gosford Hospital again, watching as the first radiographer took some images, left the room and returned with another radiographer, then left the room and returned with the radiologist. I'm a health professional myself and had heard about hydrocephalus at uni, but to hear the radiologist utter that word was a different story altogether. Soon I was sitting in front of another paediatrician while he spoke to the senior neurosurgeon at Westmead Children's Hospital, instructing me to take Thomas to Westmead emergency department the next morning. The following day was a LONG one, but Thomas finally had his CT scan, and an MRI the next day, which confirmed he did have hydrocephalus – fluid on the brain. Finally the day of surgery – which just happened to be Christmas Eve - arrived, and I said goodbye to my little boy in the operating theatre. After a few long and anxious hours, we were taken into recovery and cradled our brave little man. He spent a quiet Christmas Day in hospital, but our little trooper bounced back quickly and within 4 days we were home. Although Thomas still seems behind in his development, the physiotherapist and paediatrician assure me he is within the normal range for his corrected age, and we are hopeful he will continue to grow and develop well.

There have been many ups and downs since Thomas' birth, but through everything we have had the support of friends, family, our church, and our faith in God. We are thankful that we have been spared the heartache of some parents whose babies have not survived, or have far more devastating disabilities. At the same time we have allowed ourselves to feel the pain and grief that has come our way. The journey is far from over, and there are many times that I find myself dissolving into tears. Memories flit into my life unexpected, often bittersweet, and evoked by the tiniest everyday events. Like tonight when I stroked Thomas' hair and noticed the five wispy strands of "baby hair" which never fell out and are still longer than the all the rest. Or when I see the tiny white dots on his hands which are the scars of numerous blood tests and IV lines – scars which made finding a suitable vein so difficult in December that the doctor ended up using a vein in his ankle. But sitting here tonight I watch my baby sleeping and I smile. And when we celebrate his first birthday in 2 days time, I will be cheering the loudest of all!



Thomas aged 1 year
(10.5 months corrected)

***“Memories
flit into my
life
unexpected,
often
bittersweet,
and evoked
by the
tiniest
everyday
events”***

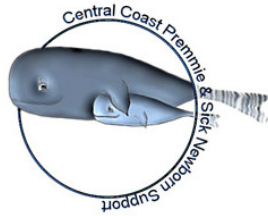
1300 PREM BABY
(1300 773 622)

www.centralcoast
prems.com

How to Contact Us Local Contacts

Fiona Dixon
0408 689 330

Sally Wegener
0411 522 651



Central Coast Premmie and Sick Newborn Support (CCPSNS)

Who Are We?

The Central Coast Premmie & Sick Newborn Support Group was the vision of Fiona Dixon after her own daughter Airlie Fae was born at 27 weeks gestation in January 2006 due to Pre Eclampsia and HELLP Syndrome.

With a federal grant provided by the Benevolent Society and Strengthening Neighbourhoods the group was able to go ahead. Now with the help of other Central Coast parents the group meets once a month to provide parent to parent support. We arrange for guest speakers to provide parents with access to information tailored to premature and sick newborns.

We envisage that our future role will expand to include hospital visitation, phone support, fundraising, and liaison with hospitals and other health care providers.

The Central Coast Premmie & Sick Newborn Support Group is a founding member of the National Premmie Foundation (www.prembaby.org.au)

Some Things to Remember

In order to ensure the smooth running of our monthly meetings, some basic “guidelines” have been developed, and include:

- We are a parent group and as such are not experts. People are welcome to share their experiences and express their opinions, but each case is individual. Please check with your health care provider for any health advice you may need.
- Some babies who attend the meetings may be very young or fragile. Please allow these babies “space”, be aware of basic hygiene (eg. Washing hands), avoid attending the meeting if you or your child/ren are sick.
- Each parent is responsible for their own children during the meeting.
- Some members of our group have severe food allergies, and for this reason morning tea is provided for the group. If you do bring any food, please ensure it is free from nuts, sesame and fish/seafood. Children should be supervised so that food is contained to the designated eating area. If you or your child/ren have food allergies, please let us know so we can work to provide a safe and relaxing time for you.
- We want to create a safe place for people to share their experiences. Please maintain confidentiality for all members—what is shared in the group remains in the group.