

## From the President

Dear Members,

Welcome to the Spring 2005 edition of our Newsletter!

Our 5<sup>th</sup> Annual Get Together was held in Melbourne during October and was a huge success. Read all about the weekend in this edition of our newsletter. Next year we will be heading back to Brisbane so look out for more information in our next newsletter.

We have completed the content for the Expectant Parents booklet and are in the process of finalising the design for it. We have begun work on booklets for surviving families and grieving families. If you are interested in contributing to either of these please contact us here at CHERUBS Australia.

Our website is currently receiving a mini face lift and should be up by early next year. The most important aspect of this will mean we should feature higher on the list when performing a Google search.

As this will be the last edition of our newsletter for 2005, CHERUBS Australia would like to take this opportunity to wish all of its CDH families and friends a Merry Christmas and all the best for a wonderful New Year.

Until our next edition J

Danielle Kessner – President, CHERUBS Australia

**DISCLAIMER:** The information in this newsletter is for education only. It is not meant to be used in the place of proper medical care and advice. CHERUBS Australia does not encourage or discourage any medical treatments or procedures. Our purpose is to educate families and medical care providers so that they may make the best decisions for the patients' interests. You cannot compare your child to other children born with CDH, they are all different. The opinions aired in this newsletter are not necessarily the views of all members, staff, or of CHERUBS Australia.

## Dedications

THIS NEWSLETTER IS IN MEMORY OF.....



## **WELCOME TO THE FAMILIES OF ALL OUR NEW MEMBERS.....**

Max Logozzo  
Fallon McClelland

## **NEW SIBLING ARRIVALS**

Dylan Ross Spadaro  
Emily Louise McErlean  
Aimee Kirsten West

## **THANK YOU FOR YOUR HELP.....**

Dr Nadia Badawi  
Jasmin Burns  
Saskia Ericson  
Anna Fogarty  
Vivien Fogarty  
Kirrily Hanlon  
Helen Harrison  
Melissa Heyme

Phillipa Jamieson  
Julian Kessner  
Joanne Kjaersgaard  
Damon Knott  
Wendy McKay  
Julie Murphy  
Natalie McErlean  
Anthony Quirk

Maryanne Reid  
Kristine Ross  
Judy Scherrenberg  
Dr Michael Stewart  
Karen Vella  
Chris Waite  
Tanya Waite  
Sue Wilkinson

## **Forever Angel**

Forever Angel, you'll be mine,  
Today, tomorrow, for all time.  
Upon my breast you lay so sweet,  
Dear child of mine, my pain is deep.  
Your eyes are closed, your breath is still,  
I could but think, this can't be real.  
So many plans, we had for you,  
are laid to rest, as you are too.  
A day won't pass, I won't forget,  
You'll forever be, my Angel yet.

Author Unknown

## ***LET ME OUT! By Joanne Kjaersgaard***

*"I don't understand why I can't go where I want, when I want? That's all I want to do. I'm not asking for a lot!" says the 15 year old cherub with defiant anger. In the milliseconds of quietness for gathering thoughts on the reply, I'm a bit stunned at how she sees her world and how short her memory is of her own, lets call them, 'stunts'.*

She might as well of said those words when she was born, and continued saying them from there on out. It seems that our cherub has been burning her own path in life from dot. All those things that good parents do, teach, guide and support, have been in our parent handbook, but seem to have been left out of her childhood handbook. I don't feel slighted, as she also seems to be missing the part of the handbook that explains about gravity and recognising danger. Or the part that said she should of died. Her book was obviously missing a few pages when it was published, or mine was.

Is she unique or different? Well, yes, we're all unique and different. Is she spirited because she had CDH? Possibly. But there came a time when I had to stop defining her as my 'sick' one and start defining her as her. CDH is not the whole of her; it is just a small part of the sum of her. When did CDH stop being how I defined her in my mind? Well, it took longer than her recovering from all the illness.

It helped that I had older kids. It helped because there was already a system in place for acceptable behaviour and non-acceptable behaviour. And one thing we all know about kids is that not only will they catch you being unjust, they'll plainly and loudly tell you all about it too! The other help was the girl herself. There is no way she would of let me wrap her in cotton wool, in fact, the few times I have tried to coddle her, I was given a quick lesson in reality.

In discussing these 'stunts' with friends, a common reply is "how old is she....oh, she's a TEENAGER, it's to be expected". Yep, that it is. I was never really joking when I said WE would have to be the survivors of HER teenage years!

I do think her having survived CDH has helped make her the person she is today. I have often watched her lips turn blue before she gets out of the water. I have seen her striding along, holding her side with a stitch in cross-country running, but I didn't see her slow or even brake that stride. I have seen her have the same cold we've all had, but rather than rest in misery in her bed, she's bolting around the backyard and jumping on the trampoline.

Yeah, I think her surviving CDH has made her strong of mind without her even knowing it, but it isn't the sum of her. She is many things, and for me to see those other things in her, I had to let go of the CDH definition of her. She had to become my child. Nothing else, just my child.

Just as well too, otherwise she may have been returned with the demand of a refund with the 'stunts' she has pulled. And what was my response to her demand of freedom? Easy. "I'm older, I go first. When I can have that, then you can have it, after your father and two bigger sisters that is!"

How clever and witty was I? I thought it was brilliant. She didn't, as she stomped off down the hallway with the words echoing in my ears "Why can't you just LET ME OUT?" Sigh, I think the spice in my life is going to give me a bit more heartburn and possibly an ulcer before she comes of age.....do you think someone will let me out or should I start practising more witty one liners?

## A DAD'S PERSPECTIVE

By Damon Knott

Where do I start? Sharon was carrying too much fluid and our obstetrician suggested a growth scan, nothing urgent but just to have a check. So at 32 weeks we and our then 4 year old daughter Chelsea-Rose, went for a 'normal' ultrasound check up.

I remember the sonographer saying she just had to check if something might have herniated. We had no idea what was going on and then the senior sonographer came in and said she was looking for something. This is still quite a blur, as I had no idea what they were talking about. They took us into



another office and said it looked like Congenital Diaphragmatic Hernia. What was that? She explained it but still I had no idea. From then on we had many appointments with neonatologists, surgeons, regular ultrasounds and obstetrician checkups with an MRI thrown in as well. We also had a look around NICU at King Edward Memorial Hospital (KEMH) and Princess Margaret Children's Hospital (PMH) as they had wanted to desensitise us to these areas.

We were told our son had a 50/50 chance of survival. For some reason, and I don't know why, I knew we were going to have a tough road ahead but I also knew that everything would be ok in the end. Maybe I am just a positive person but it was a strange feeling that every time I felt down about what we had been told, I knew the outcome was going to be ok.

Liam was born by c-section on April 30, 2003. I had never been so nervous in my life but I knew I had to stay positive for Sharon. They whisked him onto a special trolley and 4 doctors worked on him. I remember that when he was pulled out I heard a faint gurgle/cry. I thought that was a good sign because if he had underdeveloped lungs he would not have been able to do that. I thought it was better than what everyone had told us! There must have been at least 12 people in the theatre and more than half of them were for Liam! People everywhere were talking to us and telling us what was going on but I still have no idea what they said.

They eventually told us that they were taking him to Special Care Nursery 3 (SCN3) and I was to go with them. What about Sharon? I couldn't leave her by herself. What about Liam? I couldn't let him be by himself, even though I was powerless for him. I don't think I have ever felt so torn. I went with everyone in the lift with Liam and he was taken to SCN3. They started hooking him up to so many different things. They had prepared us for this but really nothing can prepare you to see your 10 minute old child hooked up to so many different machines and monitors. I kept apologizing for being in the way, as I didn't want to be a hindrance. 10 minutes after we got there I had to get out and tell Sharon what had happened. Really I didn't know but I knew I had to keep positive.

That day I went to and from SCN3 and Sharon's room and trying to keep her informed but anytime someone spoke to me it just did not sink in. I had no idea what was going on. I just kept telling myself everything would be ok. I also had to ring family and friends and to be honest, that was one thing I really did not like to do as it wasted so much of my time when I felt there were more important things I should be doing, like making sure I was there for both Liam and Sharon. What could you tell people when you really didn't know yourself, except that Liam was alive.

The next few days were extremely hard, as we really didn't get told much except they were hopefully going to transfer Liam to PMH. He went from normal ventilation to hi frequency, which was not good to hear, but then he started getting a little better and was put back onto conventional ventilation. This was great as all we wanted to do was get transferred to PMH so he could have his operation and he would start to get better. We could be home in a few weeks or so I thought.

It was now apparent as to how hard this was going to be for our daughter who didn't understand what was going on and why Mummy and Daddy were always at the hospital. She came in a few times but refused to go into SCN3 so she stood on a crate and looked through the glass. Now I thought how can I be there and protect my little princess as well. I suppose when I look back I wanted to be there for everyone, and I had to be positive and be 'the rock'. I feel that I didn't succeed 100% but Sharon always tells me that I did. I think I didn't let my feelings come out as I wanted to cry but I couldn't. I was being too positive for that.

We were transferred to NICU at PMH on day 5 and we were so excited. This was only the start of a very long and frustrating journey. We spent 3 months in NICU with numerous up and down days, 2 months on the infant's ward that was like going around in a big circle, 2 operations and 3 visits to the ICU. In all this time we had many laughs with the nursing staff and I think this was a very important factor of an extremely tough situation. We went through hell and back but we built some very special bonds with people.

The story of spending 5 months in hospital would be too long to go into here. Liam has now been home for 2 years. He still has a lot of vomits, a naso gastric feeding tube and a few other little problems, but he is also a typical happy, destructive 2 year old. He does need additional care but we would not have it any other way. The love he has for his Mummy, big sister and I is unbelievable after everything he has been through. He also loves life in general and I believe he

will be into extreme sports when he is older!

I would like to say to anyone reading this to be 100% positive about the situation you are about to be thrown into, ask questions of the doctors and nurses and if you don't get a proper answer – ask again and again if need be, until you understand.

In the 5 months Sharon missed out on going to the hospital only twice; she was there all day, every day. If that was me I don't know if I could have done it. I was back at work 2 weeks after Liam was born. That was really tough for me as I had no idea what was going on with my sick son until Sharon rang me around lunchtime. I believe this also made things easier for me as I had work to keep my mind off things. I visited Liam briefly most mornings and every evening and all weekend. We had to be home as early as we could for Chelsea-Rose and she came to the hospital every weekend. We look back now and it must have been so tough for her but she finally now realises that not every newborn baby has to spend such a long time in hospital.

To help you deal with the emotional side of things, think about the biggest roller coaster in the world and you will get the idea. You have some bad days and you have some good days. My message for other dads is that, yes it is hard when you have to tell you wife, children, family and friends that everything will be ok when really you don't know yourself. There is no point in getting angry about the situation – it will not help. Be calm and somehow pull yourself through it and always look for the light at the end of the tunnel and BE POSITIVE.

I hope this may give other parents some perspective on what to expect. I will say that I also found it very difficult to actually sit down and relive in words what we went through but I still wouldn't change a thing!

Damon – Liam's dad

*To our beautiful daughter Rebecca*

*Happy 3<sup>rd</sup> Birthday*

*Lots of love*

*Mum, Dad and Nicholas xx*



## HELP WITH QUESTIONNAIRE

Dear Parent,

The management of congenital diaphragmatic hernia remains a significant challenge with considerable mortality and morbidity despite modern intensive care techniques. To date, survival has been the main focus of research but increasingly the emphasis is shifting to the long term complications for these children. Historically these children have received follow-up in surgical clinics where the focus has been on the actual surgical repair. Other medical care has been fragmented. Some investigators have recommended the establishment of multidisciplinary clinics comprising paediatric surgeons, neonatologists or intensive care specialists, developmental specialists, nutritionists, respiratory physicians, occupational therapists and dieticians. Proponents of such clinics argue that this is essential to provide overall care for what is a very complex condition and thereby improve the long term outcome of the children and their families.

We are commencing a multidisciplinary follow-up clinic at the Children's Hospital at Westmead and to help us

cater for the needs of children who have undergone surgery for a congenital diaphragmatic hernia we would be grateful if you would complete the questionnaire.

Please email Pip with your completed survey on [pjam5193@med.usyd.edu.au](mailto:pjam5193@med.usyd.edu.au)

If you prefer to mail it to us then the best address is

Nadia Badawi  
Department of Neonatology  
Children's Hospital at Westmead  
Locked Bag 4001  
Westmead NSW 2145

Thank you for your help,

Nadia Badawi  
Phillipa Jamieson  
Consultant Neonatologist  
Medical Honours Student  
Clinical A/Professor  
University of Sydney  
University of Sydney

*Death leaves a heartache no  
one can heal, love leaves a  
memory no one can steal.*

## **CDH/Infant Lung Multidisciplinary Clinic up and running!**

1. Contact is via Dominic Fitzgerald's secretary [Debra] on 02 9845 3397.
2. The referral should be made to Associate Professor Dominic Fitzgerald, Dept of respiratory Medicine, The Children's Hospital at Westmead, Locked Bag 4001, Westmead, NSW 2145.  
A specialist to specialist referral is only good for 3 months, so it is probably best to have a referral from the patients GP as this usually lasts for 12 months [or indefinitely if so documented]. The clinic will generally be once monthly, on a Thursday morning [Feb to Dec].
3. Children from all over Australia are welcome. Obviously a little of teeing up, perhaps with a phone call to ensure that everybody is in the hospital on the particular day for long distance patients.
4. There will be a number of checks for each patient depending upon age. People involved will be neonatologists, paediatric cardiologists, paediatric surgeon and an interventional radiologist. We are hoping to have a physio and dietician but this is not in place as yet.
5. If other problems are found, the children will be referred on to other specialists [eg Orthopaedic surgeons for scoliosis].
6. This is a local initiative of the doctors involved meeting a perceived need. Unfortunately there is no funding from the hospital as yet for staff [eg physio or dietician]. Any transport costs would need to be met by the families or assistance of state funding agencies sought. For those in NSW who live more than 200km away there is a support scheme called IPTAS [isolated patient transfer assistance scheme I think] to help. Local paediatricians, physicians and GPs can fill this request in which is signed by the specialist in Sydney [for example].
7. Data exists from some overseas centres, for CDH and other chronic respiratory conditions such as cystic fibrosis, suggests that patients with uncommon chronic conditions are best helped by multi-disciplinary teams in large centres with the most individual and collective experience. The doctors involved have extensive experience in managing children with chronic respiratory and cardiac conditions.
8. "Children" up to age 18 years can be seen easily in the clinic.

Associate Professor Dominic Fitzgerald MBBS PhD FRACP  
 Paediatric Respiratory and Sleep Physician  
 Dept of Respiratory Medicine  
 The Children's Hospital at Westmead, Sydney.

**30 October 1994**

To Our Beautiful Cherub Sarah  
 Happy 11<sup>th</sup> Birthday Darling  
 Love Mummy, Kai and Justin  
 XXXXXXXXXXXXXXXX  
 OOOOOOOOOOOO



**MELBOURNE 2005 GET TOGETHER**

CHERUBS Australia had its 5<sup>th</sup> Annual Get Together on Saturday 22<sup>nd</sup> October 2005. It was held in the 10<sup>th</sup> floor conference rooms of the Royal Children’s Hospital (RCH), Melbourne – the same venue as our very 1<sup>st</sup> Get Together.

On the Friday night before the Get Together, a few members met for dinner at a La Porchetta’s restaurant. Even though there was only a few of us it was an interesting evening. Bailey, Harrison and Thomas played with the salt and pepper, spreading it all over the table. Thomas decided to test the theory that pepper makes you sneeze – by putting it up his nose! To his surprise (and distress!) he discovered that it burnt.

We arrived at 9am on Saturday for the Get Together. We were fortunate enough to have four FANTASTIC babysitters (and two older children as assistants!) look after the children all day. There were planned activities as well as a visit to the Starlight Room and play time in the fully enclosed outdoor playground. Having the babysitters allowed the parents to focus fully on our guest speakers and get the most out of the day.

Dr Michael Stewart is a neonatologist who works at the RCH and also with NETS (emergency transport) at the Royal Women’s Hospital. He delivered a wonderful presentation on the recent changes the RCH is using to treat CDH babies. It was a joy to hear that in the past couple of years, survival rates have increased dramatically.

We were also lucky enough to have two adult CDH survivors as guest speakers. Anna and Melissa shared their experiences with the parents and were able to give them an insight into how it felt to be a child born with CDH.

On Saturday night a number of us met for dinner at The Moreland Hotel which has a sensational indoor playground to help keep the kids occupied. It was a relaxing way to end the day and get to know each other a little better.

Our final ‘formal’ meeting was a family day at Scienceworks. Everyone had heaps of fun before saying their final good byes – until next year in Brisbane of course! ;-)

“It was great to catch up with the members we already knew and to meet new members. We had a great time and were very impressed with the organised babysitting. See you all again next year in Brisbane!” (Lynda and Wayne, NSW)

“It was a great experience to have my daughter Anna (20) talk about growing up with CDH. As a mother I enjoyed having Anna’s sisters there to join in the discussion. Anna’s dad and aunty also joined the discussion.” (Viv, VIC)

“I really enjoyed the Melbourne get together and it was great to finally meet other people with CDH. Thank you to all the parents for making me feel comfortable when sharing my story I hope in some small way it helped. I look forward to catching up next year in Brisbane.” (Melissa, NSW)

“It was great to catch up with old friends and meet new ones. I can’t thank the babysitters enough for volunteering their time – it made a huge difference for the parents. I thoroughly enjoyed all the guest speakers and was so excited to hear from Dr Stewart about the increased survival rates of CDH babies being treated at the RCH. I can’t wait for Brisbane!” (Danielle, VIC)

“The Saturday Get Together at the RCH was a great day; catching up with old friends and finally putting faces to everyone from their emails. Meeting Melissa and Anna and listening to their experiences as they grew up gave us an insight into what may lie ahead. Sunday at Scienceworks was a relaxing way to see everyone again and say farewell until next year. Thanks to everyone from Victoria who made this years Get Together such a success.” (Maryanne and Carl, WA)

## SPECIAL THANKS

CHERUBS Australia would like to extend their thanks to the following people for their help with the Melbourne 2005 Get Together:

The Babysitters – Julie, Tanya, Anthony and Chris

The Organisers – Danielle, Sas, Karen and Viv

The Guest Speakers – Dr Michael Stewart, Melissa and Anna (adult CDH survivors)

All of the local members for donating items for morning and afternoon tea.

GSNV for the use of the conference rooms

All attendees – especially those that travelled from interstate to join us.

