

From the President

Welcome to our Winter 2005 'Special Edition' Newsletter! This edition has been released shortly after the Autumn edition to get us back on track. Because of the reduced timeframe, we have a smaller newsletter. Our Spring edition will be back to normal and will be due out at the end of October.

We are looking forward to our 5th annual Get Together in Melbourne on the 22nd October this year. There is still time to contact us if you are interested in attending.

Thank you to all of the members who have returned their updated membership details. Your support is greatly appreciated.

Danielle Kessner
President

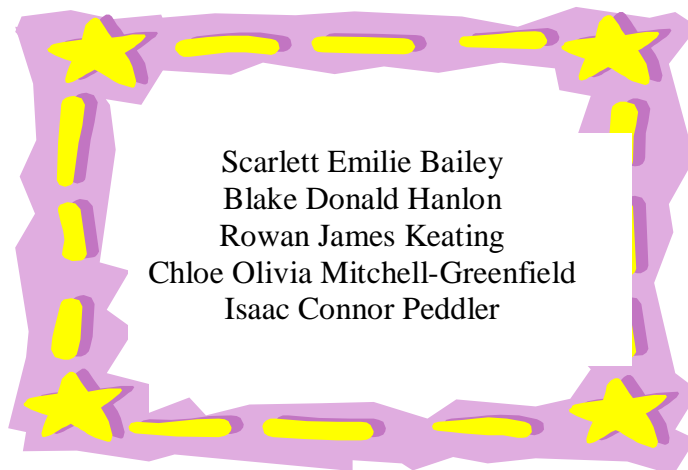
Sometimes love is for a moment. Sometimes love is for a lifetime. Sometimes a moment is a lifetime.

- Pamela S. Adams, The Compassionate Friends

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.....

Chloe Olivia Mitchell-Greenfield
Chloe Leigh Towne
William Anthony Tripodi

THANK YOU FOR YOUR HELP.....

Dr Nadia Badawi
Vivien Fogarty
Julian Kessner
Joanne Kjaersgaard

Dr John Levison
Wendy McKay
Natalie Pierssene
Maryanne Reid

The Editor apologises for any errors in the Autumn edition. Hopefully, all has been rectified in this Winter edition. Steps have been taken to minimise errors however, from time to time they will happen. Please do not hesitate to contact me if it does occur so that the problem can be fixed as soon as possible.

Welcome To Holland

by Emily Pearl Kingsley

I am often asked to describe the experience of raising a child with a disability to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a wonderful vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After several months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say, "What do you mean, Holland? I signed up for Italy. I'm supposed to be in Italy! All my life I've dreamed of going to Italy."

But there's been a change in flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and catch your breath, you look around and you begin to notice that Holland has windmills; Holland has tulips; Holland has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Damien Smith
18 – 28 September 1987

"To our perfect little man on what would have been your 18th birthday. I can't believe so many years have passed, it seems like only yesterday.

Planted on earth to bloom in heaven.

All my love Mum."

To my beautiful cherub Chloe Olivia. Wishing you a happy 2nd birthday, almost 2 years since you left us for a better place. We love and miss you everyday. Love your Mummy, Daddy, big sis Erika and your little brother Caleb. xxoo

OH, WHAT A DAY!

Here I sit, thinking about kids. Our wild child has just turned 15, and is trying to be 24! 15 years ago, all I could think about was 'is she going to make the next hour?' Now all I can think about is 'am I going to make the next hour?'

I want to tell you a story. A story that is sad, but has the funniest moments in it, and all thanks to the wild child.

On December the 30th, 1992, I gave birth to our fourth daughter. She had died in utero two days before. I was 37 ½ weeks pregnant when she died. After the birth, my family arrived to see her. There was a picnic to be had, thanks to the nurses, a baby to be held, and a lot of looking and crying to be done. That is, if you were not the wild child! If you were the wild child, then you had picnic to be eaten, the bed to jump off, the remotes to play with, a baby to hold, a hallway to run in, a toilet to put things in, and grandparents to be cuddled by (if they could catch you!).

Yes, she was 2 ½ and it felt like she had been living on high octane from birth. The one thing you can be sure about with her is to expect the unexpected, and she never lets you down.

It was the day of the funeral. 'The girls will be looked after', I was told by my mum, 'don't worry about them, there will be plenty of adults to do that for you.' We drove up to the car park and the girls were let out. Two of the girls stood quietly whilst one went on an adventure. I wish I could of given a crash course in 'Ariana 101', for they didn't know what had hit them.

Ariana had found the duck pond, so pretty and tranquil, and promptly took action, taking off her pink trainer pants and dropping them in. My neighbour was on route to Ariana as she saw the pink go plop. She dived in for the rescue, but decided to drop them back in when they came up with black mud on them! Not so bad, it was only the knickers and not the child, which wasn't beyond her around water.

We now had a knickerless child in a very pretty dress being gently guided back to the crowd. In we go. As we approached the small coffin, I see that people have covered the area with flowers and cards, and so could the girls. 'Can we see?' said one of the girls. 'Sure' I say and start lifting them up onto the marble table. The first two girls move around looking at the gifts and flowers, as does the third, but unlike the first two, the third one doesn't 'stop and smell the roses'. Oh no, she decides to do a lap on her hands and knees around the marble table, checking out the flowers. The knickerless state is not obvious, not that Lars and I knew anyway, we hadn't seen her since she left the car!

To Ariana's great surprise, she found 4 buttons on the side of the marble table around the back. Imagine this....four people standing just off to the right of the grieving family - my parents, the funeral director and my brother. They could all see what was going to happen and froze. My dad went white, my mum thought to herself 'the coffin is going to disappear in front of them 20 min early and she's going to loose 2 of them in one go'. The funeral director nearly hit the roof, and my brother was catapulted into action by the funeral directors flinch and jumped forward to grab Ariana just as her finger was on the button. Phew. And would you believe it, Lars and I didn't know any of this was happening. Mind shattering numbness can do that to you.

It's not over yet. Ariana now finds herself in the grip of her uncle and starts to wiggle. He puts her down and surreptitiously watches her. She finds the step in front of the rise and climbs onto it. As she stands up, she realises there's a bunch of people looking at her (not really, they were looking to the front, she just happened to be in their line of vision). She tries on the 'I'm shy' act and grabs the bottom of her dress and pulls it up to her face! Now everyone in the place knows she is knickerless except her mum and dad! Imagine this.....you are sitting in the pews at a baby's funeral, the sadness is overwhelming. You look up and see...! People didn't know what to do. Muffled sniggers and giggles were heard, but not by Lars and I, we were still in our world.

Ariana now realises she has a captive audience. No one has stopped her on the steps (not possible without disturbing the unaware parents), so she gathers herself, steps down and starts doing forward rolls! Fantastic. How do you catch a wild child at her sister's funeral without making a scene? The easy answer is, you don't. Now we have a white bum flashing by followed closely by black patent shoes. Oh dear.

She was captured before her parents saw her (by rolling into someone in the front row), and she was then firmly gripped by her grandmother until the coffin went. We headed outside to be surrounded by our friends and family. That would be all but the wild child. She spotted the beautifully manicured lawns that framed the driveway. These lawns were prettily separated by a white chain on low rises. 'Look at that', thinks the wild child, 'someone made me hurdles!' And that is how the pretty white chain came to be off the rises and on the ground, and how her pretty dress became grass stained.

Believe it or not, I didn't know any of this until months later. People told me things that happened, or what they saw happen, as time went by. I'm so glad I didn't know on the day, and so much for 'we'll look after the kids'! What a hoot. Would you believe this if you were reading it in a magazine? Probably not. How could one little child get into so much at a funeral? Easy, her nickname is 'the wild child' for good reason. You should hear the one about the time she ran away from school before she was 8! What a day.....

So there it is, the two sides of life. The death of our baby is still mind shattering, and the life of Ariana is still amazing. Did I appreciate Ariana more because she had lived through her CDH? No, not really. She never allowed me to wrap her in cotton wool (she would have set fire to it if I had), because Ariana innately knows that life is to be lived, and that is what she does at 110%, still today!!!! We love her to bits, and she drives us crazy, she never sits still long enough, and every single day is to be loved.

Happy 4th Birthday **Adam**
On August 22

We love you very, very much

Mum, Dad, Kaitlin and Byron
xxxxxx

Happy 3rd Birthday **Jackson!**
April 6

Lots of hugs and kisses

Mummy, Daddy, Connor & Chelsea
xxxxxxxx

Dear **William** (cherub) and Thomas,
 Wishing you both a very special 2nd birthday.
 With lots of love, kisses and cuddles
 from Mummy, Daddy and Lucas

CHERUBS Australia would like to invite fathers to contribute their thoughts and feelings on their own experiences for our 'Dad's Perspective' section. Please email any articles directly to k_wmckay@samford.net.au

CHERUBS Australia Annual Get Together Melbourne 2005

This year, our annual CHERUBS Australia Get Together will take place on Saturday 22nd October at the Royal Children's Hospital in Melbourne. They will be held in conference rooms on the 10th floor.

Everyone affected by CDH is welcome to attend. We have not only had parents and children attend in the past, but also a sister and sister-in-law. So if you have a close family member or friend who would like to attend with you, let us know! Our Get Together is attended by both grieving and surviving families (along with surviving cherubs and surviving siblings). Parents expecting a CDH baby are also invited.

On the day:

- We will spend time getting to know each other.
- We will split into two groups for part of the day to share our CDH experiences. This allows everyone to openly express their feelings without fear of upsetting other members who may have had a different outcome.
- We will have a short ceremony to honour all of our cherubs.
- We will have a guest speaker deliver a presentation for us. This is Doctor Michael Stewart, a neonatologist who works at the RCH.
- We will have a separate room for the children to spend the day in with babysitters (they will still be able to 'access' their parents as needed). Children will have activities to do, videos to watch, toys to play with etc.
- Morning and afternoon tea will be provided (plus some goodies for the children)
- We will break for lunch - gives the children a chance to get outside and run off some energy!
- Plus more!

We will go out for dinner on the Saturday night and if there is enough interest, on the Friday night as well. We are also planning a family 'fun' day on the Sunday.

We really need to start getting some idea of how many people plan on attending. Our Melbourne members are busy organising the day and looking into accommodation etc.

If you plan on attending this year's Get Together and have not let CHERUBS Australia know, please do so as soon as you can. Please let us know numbers attending (and ages of any children). If you have any questions, let us know!

Hoping to see you in Melbourne!



The Association of Congenital Diaphragmatic Hernia Research,
Advocacy, and Support

CHERUBS Australia Newsletter Deadlines

<u>Edition</u>	<u>Final date for submission of material to editor</u>
Spring	October 9, 2005
Summer	January 15, 2006
Autumn	April 16, 2006
Winter	July 16, 2006

**Please send all submissions (stories, photos, poems,
birthday messages, letters, etc.) directly to our editor,
Wendy McKay, at:**

k_wmckay@samford.net

or

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