

Dear Members,

Welcome to our Autumn 2003 Newsletter!

We held our second annual Get Together in Brisbane last October. It was a wonderful weekend and a fantastic opportunity for our members to get to know each other and put a face to a name. We are busy planning this years Get Together to be held in Perth. We have more information on both of these latter on in this newsletter.

Our newsletter finally has a name! After a number of suggestions, the most popular name was...drum roll please...

CHERUBS under the Southern Cross.

This month (May) in Sydney, the Westmead Hospital hosted two International meetings, which included a focus on CDH. Two of our members delivered presentations at these meetings and reported back that the meetings were fantastic. They left our members feeling positive that the medical community is looking at ways to change the treatment of CDH babies to increase the survival rate here in Australia. Look out for an article on this in our next newsletter!

Our membership has continued to grow this year and we would like to say a special welcome to all of our new members.

We would like to encourage all of our members to contribute to the newsletter with letters, stories, photos, poems etc. You can send all contributions to:

CHERUBS Australia
PO Box 515
Morwell 3840
Victoria

Or email them to

kessam@austarnet.com.au

Until our next edition J

Danielle – President, CHERUBS Australia

Everything that is done in the world is done by hope - Martin Luther

THIS NEWSLETTER IS IN MEMORY OF.....

Kyan Andrew Meer Bolin
Julia Clare Foley
Jonathon James Kilby
Zack Anthony Motbey
Celeste Spardo
Harry Brian Tabbernal
Lachlan Christopher Matthew Wood

WELCOME TO THE FAMILIES OF OUR NEW MEMBERS.....

Alex Bennett
Kyan Bolin
Jack Burns
Nathan Clarke
Rani Costello
Kelsey Glindeman/Smith
Jonathon Kilby

Dain Kingston
Zack Motbey
Tory Piperno
Rebecca Reid
Harry Tabbernal
Lisa Warnock
Lachlan Christopher Matthew Wood

NEW ARRIVALS

Rebecca Jade Reid
Lachlan Christopher Matthew Wood

NEW SIBLING ARRIVALS

Samuel Mark Carroll
Gemma Hope Ross

THANK YOU FOR YOUR HELP....

Alicia Wood
Wayne & Lynda Viset
Chris Bowring
Sue Wilkinson
Joanne Kjaersgaard
Linda West
Caroline Gould
Kirrily Hanlon
Ken McKay
Caitlin Robilliard
Kristine Ross
Helen Harrison
And ALL of our WONDERFUL Volunteers!

DAD'S PERSPECTIVE



My wife had her regular scan at 28 weeks and my work commitments kept me away. However, I was able to leave work and I arrived at the radiologists 10 minutes into the appointment. The scan seemed to last for hours and the radiographer did well to disguise her concerns (haven't we heard that before!). She blamed her lack of success in scanning the stomach on Jackson's movements. We didn't think anything of it because he was an extremely mobile baby. She left the room to consult with the radiologist on her findings and was gone for quite a while. After what seemed like a very long time, but was probably less than half an hour, the radiologist made an appearance, followed closely by the radiographer. The radiologist explained that because of Jackson's movements, the radiographer had been unable to clearly scan his stomach. Therefore, she wanted to clarify the situation for herself.

After a few minutes, she broke the news to us. Congenital Diaphragmatic Hernia. What was that? We had never heard of it. She briefly explained the situation but neither of us actually took anything in at this point. However, back in her office the situation was made abundantly clear to us. Our unborn son had a 50% chance of survival. We were left alone in her office while she went to gather some further research on CDH. During that time there was very little to say to each other as our minds were scrambled with the overload of information, and our hearts were shattered. How could this be happening to us? What can be done? Will he be one of the lucky ones?

Needless to say the following few weeks were anxiety ridden. All I knew was that I had to keep myself positive for Wendy and the kids. She couldn't see any positives in the situation. The radiologist made it perfectly clear that we had to go as long as possible with the pregnancy, and I had to keep Wendy's spirits and mine up. My way of looking at it was: the cup was half full, not half-empty. Explanations also had to be given to our four year old son, Connor. Life had to go on as normal as possible for everyone else.

The next five weeks were hard. I plunged myself into my work. Being self-employed, at a time like that was unfortunate. I had nothing to fall back on. There was no one to take my place and no one to bring in the money. I internalized the pressure throughout that time, to show no weakness towards my wife or my colleagues. I knew it was going to get harder when Jackson and Chelsea were born. However, I had

committed myself to more work (before we had the diagnosis) and this was now compounding my troubles. Clients didn't let up. Deadlines to meet, people to pay, debts to collect. My only solace was one understanding client who gave me the freedom to where I had to be, when I had to be there and paid their bills on time. I don't believe I took it out on anyone; therefore the pressure increased. But I had to handle it and I couldn't show it to Wendy.

Once the twins were born, emotions went wild. One child was healthy and one was not. I felt so lucky and unlucky at the same time. I still had to maintain my positive attitude for Wendy.

Over the next sixteen weeks my emotions rode one hell of a rollercoaster. We are all well aware of the ups and downs of CDH babies. I found safety in watching the monitors and the nurses. At first, every beep, every chirp made me jump and squirm. After constantly asking the nurses about this machine and that machine, I familiarized myself with them and was able to relax more when alarms sounded (which was constant). I even started to understand them and was able to decide for myself whether Jackson had improved or not, just by looking at the numbers. His chart became my bedtime reading and it was the first thing I would look at upon entering his room.

During his 16 week hospital stay, I missed 5 days. Every other day I was able to visit him (sometimes twice a day). I felt guilty each time I wasn't able to get there, but not as bad as the day I took time for myself and played golf. I didn't enjoy the game at all as I couldn't get him off my mind.

Luckily for us, Jackson was one of the lucky ones. However, I would advise everyone to find someone that they can talk to, outside of the family. I needed someone who was not emotionally attached to the situation and was there whenever I needed him. If there is one thing that I have learnt from all of this is that family comes first and everything else will take care of itself.

Ken McKay

INNER STRENGTH

Author Unknown

Although you may doubt,
That your baby will live.
Don't abandon her there,
In that glass covered crib.

Your visit, your presence,
Your tears that you show-
The touch of your hand,
Your pulse she will know.

The sound of your voice,
Your softens of song,
Will help make her choice-
Keep her heart beating strong.

The warmth of your breath,
The deep love that you give.
She will fight against death,
You have helped her to live!

Sue's Views

Grief and Healing?

Why are the words 'Grief' and 'Healing' always put together? Why is it that the whole grief process with all its warts and endless cavities associated with a word that seems completely opposite? It would be great to come up with some fabulous alternative, but seeing as this is a newsletter article, the use of expletives is somewhat frowned upon. Let's just say that I associate the word grief with something completely different to healing.

I am coming up to the five year mark now. It's been such a long time. I have no idea where some of the time has gone and am completely aware of certain minutes, hours and days. Very strange. But am I healed? No. Am I healing? Perhaps, but unlikely. Am I angry? Definitely. How can I heal such a loss? Ok, in my own way I have, and continue to deal with living without my son, but is that healing? I am now able to hold myself back from the screaming woman scenario when I look at the small photos on my walls, I can also coo away at little newborn baby boys and best of all can now sing Happy Birthday all the way through (this is somewhat of an achievement for me) but does that mean I am healed?

Having this whole grief thing tag along with me every day is something that I have just got used to. Somewhat like a spider, sometimes we just live together doing our own thing in our own ways trying not to disturb each other, but on some days those cob-webs need to be brushed out, and pity anyone or anything that gets in the way. But I must say, that on other days the whole thing is a little comfortable. I cringe using that word, but it's hard to describe. Grief is now a part of me, of who I am, of who I will be in the future.

So, I guess in all of this it has to be said that healing isn't as simple as a band-aid over a sore, (we all know that there aren't band aids big enough for this!) It's not something that will just happen just because time passes, and it won't happen just because the rest of the world seems to think that it should. What has happened for me is that there is some sort of a process going on, but I'm not that inclined to call it healing.

But before I get a barrage of Psychiatrists knocking on my door citing Freudian associations, I do have to say that I have met people who seem to be 'healed' and have a completely different perspective to me about this whole grief and healing process. Hey, that's great, but at the moment, Fred (the spider) and I are doing just fine.

**Something to live for came to the place,
Something to die for maybe,
Something to give even sorrow a grace,
And yet it was only a baby!**

- Harriet Spofford

Together We Are Strong

Written By Ashley Stuart Morrell for his wife Mariella, in memory of their son 13 May 2001

A Woman knows not where a Man's heart truly lies
 Till there is a little piece of him from within which dies
 You can't imagine how ripped apart your man feels
 When there is a part of him, which he can never heal
 There is a time when he needs your support
 A time when you are strong and hold down the fort
 A time when the man flounders, a lost ship at sea
 A time when he is weak when others might flee
 He is tossed and tormented by wild and crashing waves
 When the torrent is over who knows how he behaves
 He understands your needs, your sorrows and pain
 Now it his turn to hold onto the reins
 He also knows that your pain is real
 He knows your grief and the feelings you shield
 The day will come bringing us a dawn of new hope
 Understanding our strengths together we cope
 Together we are unique we are strong like the cliffs
 Where waves crash continuously, trying to break us to bits
 Weathered years of stone sea and sand
 Moulded with hope and forged by the hands
 Of a force greater than we ever dream to be
 Greater than the universe more vast than our seas
 A force all knowing of our weaknesses and our strengths,
 Who has placed us together bound through all events
 Together means life of this you are assured
 Through all life's tests we will always be secure
 Secure in the fact that time mends all wounds
 New life will evolve like a bud comes to bloom
 This poem is for you my sweetheart my dear
 Let me help heal your pain let me quash all your fears
 I will be there when you are well when you are ill
 I will be there when no one else will
 So just remember the strength that we find
 Whilst standing together when life is unkind
 Tomorrow comes fast and we will be prepared
 To be joyous and happy with what will be there
 With this in mind we can let life go on
 Knowing inside that **Together We Are Strong**

Jo's Thoughts

The Cherub spice!

Ingredients: 1 or 2 eggs

Some Pond Endo Reviving Milk

A bucket of genes

Some nutty brain cells (given to parents)

Blend:

Some heavy mixing with a tinge of weakness in the diaphragm area

Stir well until inside is upside down

Cook for approx 9mths with a dose of stress & tests for good measure

That's my recipe for a cherub. Where is the spice I hear you ask? Well my friends, that is something that comes from within the cherub. You don't get to taste it, you only get to smell it when the spice is working overtime but you will see it every day in the 'not so normal' goings on with your cherub.

It starts at birth, the 'not so normal' goings on, the spice will show itself almost from that moment. The spice is strong & does it's magic. The cherub has leapt over all the tall hurdles & is now on the home straight, surely the spice is depleted?

ARE YOU KIDDING! The cherub seems to have a boundless supply of this incredible ingredient. Where did that cookbook go??? I need to re-read the recipe. What are those words down the bottom.....'after cooking, good luck, you're on your own.'

Why is it, I ask myself whilst scratching my head, that this baby is crawling straight for the stereo even though the floor is strewn with great baby toys? How did she get out that locked security front door at the age of 3? (Kindly returned by our neighbour) Why did I hear her footsteps on the roof at the age of 7 when she only had the fence & the guttering to do this? Why can't she sit still long enough to finish a meal? Why did she think lighting a whole box of matches in one hit was an interesting thing to do? And this was all before she was 8! I won't scare you with her 'up-to-now' other bits, but there has been a few, quite a few!

Our other kids don't tempt fate or their parent's mental capacity, in fact, they are often standing beside me, vigorously shaking & scratching their noggins along with me. It has even been known to turn from scratching to screaming at the antics, I believe this is where she is 'sharing' the spice, but it's hard to see the sharing part as you stomp on a small fire in the garage, envisioning the part on the insurance claim form that you have to write "my daughter did it".

Then I think about those first weeks, and then the 2nd operation & her recovery. Then of all the times she bounced off the concrete instead of splatting, & then of all the times that she's had the same illness that we've all had, as we groan in bed she refuses to be 'crook' & is bouncing on the tramp outside.

Why does the whole family look forward to her going on a week long camp so we can have a little peace & quiet, yet within two days of peace & quiet we all want her back? It's the spice. The spice of our life. The spice that is sometimes too hot, sometimes, but not very often mild, and always adds a zing & spark to everything it touches.

I'd just like to add a note now. Ariana is nearly 13 & is now getting around with a stubbly haircut. She raised just over \$250 for 'Shave for the Cure' Leukemia foundation by shaving off all of her hair. We are very proud that she has raised this amount of money & was brave enough to 'go the whole way'. Although I do think the ulterior motive of having no hair would have been done for free! The scar she has in her hairline that she got from jumping off the roof & onto a thin rail at the age of 3 ½ is clearly visible.

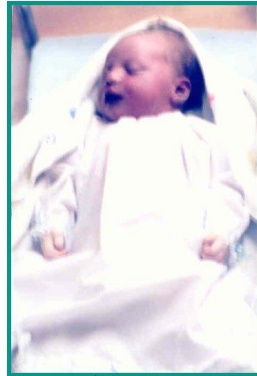
For Harry On Your 3rd Birthday

May you have a Heavenly birthday with all your Angel friends up above.
May they all sing and rejoice on this very special day,
The day you joined them in God's home of beauty and joy.

Today here on earth we celebrate your 3rd birthday
And through Olivia and Luke's eyes we can only image what you'd be like...
cheeky, adorable, beautiful & so full of life...
I know in God's care you are loved
And with God's grace we know where you are.
Keep watch over us as we miss you every day.

Sending you millions and trillions of kisses your way;
Catch them all – for they also contain my tears.

Happy birthday my baby,
Love Mummy



2nd Feb 2003

Volunteers

We have had a wonderful response to our call for volunteers and we would like to thank each and every one of you who has offered your time and support to CHERUBS Australia. Our state contacts will begin to make contact with the members in their state over the coming months. If you are interested in volunteering but see that we already have a member in the position you are interested in, get in touch with us. A lot of the positions can have more than one or more people in them. We really do need a few more state contacts. The states/territories that have no representation at the moment are:

Victoria, South Australia, Western Australia, Northern Territory and the ACT.

So if you are interested in volunteering for any of the above positions (or any positions at all), get in touch with us here at CHERUBS Australia and we will answer all of your questions and help you get started.

Another area that we would like to open for volunteers is the Card Committee. We will need one co-ordinator and as many committee members as we can get! The idea is that we send out hand made birthday and/or anniversary cards to the cherubs/cherubs parents on behalf of everyone at CHERUBS Australia. If arts and crafts are your 'thing', this is the ideal position for you! For further details, contact us here at CHERUBS Australia.

STATE CONTACTS

GRIEVING CONTACTS

State	Name	Phone Number	E-mail Address
NSW	Kirrily Hanlon	(02) 9548 3360	khanlon@nswtrb.com.au
Sth QLD	Linda West	(07) 3314 1015	Linda_West@corr.com.au
Nth QLD	Helen Harrison	(07) 4742 2213	Helen.Harrison@mim.com.au

SURVIVING CONTACTS

State	Name	Phone Number	E-mail Address
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Sth QLD	Joanne Kjaersgaard	(07) 3372 8687	not_sewing@iprimus.com.au
Nth QLD	Judy Scherrenberg	(07) 4774 1535	beach_shack@iprimus.com.au
TAS	Sabine and Lindsay Kingston	(03) 6250 3493	barlou@bigpond.com

PHONE SUPPORT

GRIEVING PHONE SUPPORT

State	Name	Phone Number
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QLD	Linda West	(07) 3314 1015
QLD	Helen Harrison	(07) 4742 2213
VIC	Anabel Silva	(03) 9383 4938 0425 735 646

SURVIVING PHONE SUPPORT

State	Name	Phone Number
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QLD	Joanne Kjaersgaard	(07) 3372 8687
QLD	Wendy & Ken McKay	(07) 3264 2753
TAS	Sabine and Lindsay Kingston	(03) 6250 3493
VIC	Karen Vella	(03) 9748 9644
WA	Maryanne Reid	(08) 9309 2192

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Remembering Our Babies
Kristine Ross

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Anabel Silva

WELCOMING NEW FAMILIES

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QLD – Joanne Kjaersgaard (07) 3372 8687 not_sewing@iprimus.com.au
QLD – Wendy McKay (07) 3264 2753 k_wmckay@samford.net

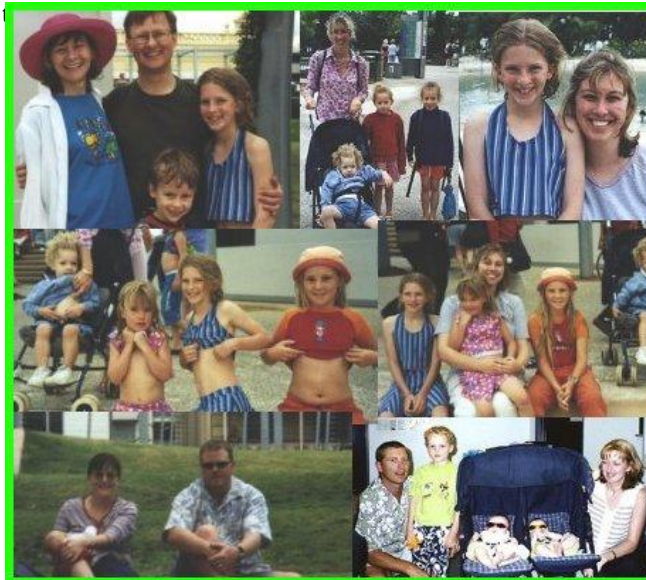
**"Youth fades; love droops, the leaves of friendship fall; A mother's secret hope outlives them all."
Oliver Wendell Holmes (1809-1894)**

Brisbane Get Together Saturday 26th October 2002



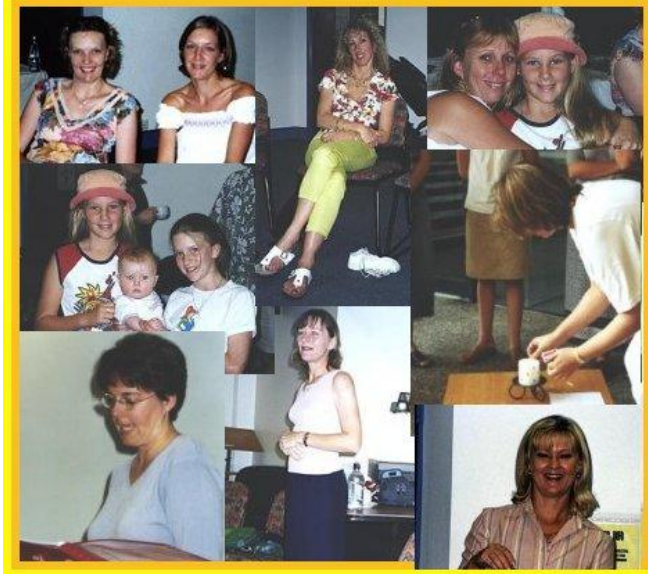
CHERUBS Australia held it's 2nd national Get Together in Brisbane in October 2002. A lot of effort went into planning and organizing the get together resulting in a wonderful weekend. A very special thank you to Joanne Kjaersgaard and Linda West for all of their hard work and to Fiona Frew for her contributions. An extra special thank you to Emma West's grandmother for donating the morning and afternoon tea in memory of her sweet cherub granddaughter.

Our group, although still relatively small, has almost doubled in size this past year and now has approximately 60 families. We had a total of 34 people attend the get together. Not everyone was able to attend on Saturday, but caught up with us either at dinner that night or for the family day on Sunday. It was wonderful to see such a large turn out and great support from our members. Our future plans include holding an annual get together in Sydney the 2004.



After introducing ourselves to each other upon arrival on Saturday morning, we broke into separate groups. One for the surviving families and one for the grieving families. This allowed all members to discuss their experiences with CDH openly and honestly without risk of upsetting others who had not experienced the same outcome. After breaking for lunch we returned to have a short ceremony to honour our cherubs. A candle was lit and the names of all of our Australian cherubs were read out. To complete the ceremony, we

watched a slide show that featured photos our Australian cherubs. It was a beautiful way to end a lovely ceremony.



After the ceremony, we held a discussion on the future of our group and the possible legalities involved as we moved forward. Some of the ideas and decisions discussed are currently being implemented and the future for CHERUBS Australia is looking brighter than ever.

Throughout the day the older cherubs and cherubs’ siblings helped out by baby-sitting the younger cherubs. This allowed the parents to relax (at least a little bit!) and get to share their CDH experiences. The children were truly wonderful and made everyone very proud.

We met for dinner at a local restaurant and were given a good laugh by the confused looks of the staff. The parents of one of our cherubs ordered a bowl of ‘plain pasta’. We all know how fussy children can be with food and our cherubs are certainly renowned for this! “Plain pasta?” came the confused reply. “Yes, just pasta with nothing on it. Just cook it and put it in a bowl.” A tentative “OK” was given. Everyone received their meals and still no ‘plain pasta’. We could all picture the staff standing around in the kitchen scratching their heads and trying to figure it out. Finally the ‘plain pasta’ arrived – sprinkled with a green garnish! “YUCK, I don’t like that green stuff,” cried the cherub. In the end, we worked it out J



The next day we met for a family day at South Bank. The children got to swim in the beautiful man made lagoon with the dad’s keeping guard while the mum’s hit the outdoor market. After a lovely day, our tired and emotionally drained group said their goodbyes.

A huge thank you to all of the members who helped organize the day and thank you to those that attended to make it the great success that it was. We are all eagerly looking forward to Perth 2003 – hope to see you there J .



PERTH 2003 Get Together

Our annual Get Together this year is to be held in **PERTH!** For all those who have not visited the delights of WA before, this is a good opportunity to come and see our big sky and sunshine and meet some other CHERUBS Australia members.

The day of the meeting will be **SATURDAY 4th OCTOBER** and will be held at the Gumnut Montessori School in Claremont. Lunch that day will be donated to us by friends of CHERUBS Australia in Perth, and dinner will be at the Ocean Beach Hotel in Cottesloe – you will need to allow \$20 - \$25 for this.

An outing is planned for Sunday 5th October at the Kings Park Ivy Watson Playground. There is an excellent café at the park that does fabulous food at very reasonable prices or for those who live in WA, you may want to bring a picnic. There is lots of space for us to sit and enjoy the children and to chat!

For those of you who will need accommodation, the Ocean Beach Hotel is a really good value hotel and is in the heart of the Cottesloe Beach strip. Prices for rooms start at \$120 per night up to \$165 (if you want a few of the sea or a spa!).

The venue for the Get Together is ideal for children and we will organise the appropriate number of babysitters when we know how many will be attending. There is also free parking available at the school.

We will need to start firming up numbers sooner, rather than later so have a good think and come along!! Nearer the time we will provide you with a more detailed timetable for Saturday 4th October, together with a map of Perth and the areas concerned.

Looking forward to meeting you all.....

Cazz
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