

Dear Members,

This is our first official newsletter as “CHERUBS Australia” and I would like to take this opportunity to welcome you all to our support group.

It is an exciting and busy time for CHERUBS Australia. We are currently in the process of becoming a non-profit organisation in our own right. This involves such things as creating new membership forms, brochures and business cards and learning about the legal requirements we must meet as a group. Hopeful, all of our hard work will result in lots of new members from around Australia!

In November 2001 we held our inaugural National Get Together in Melbourne. This was a very successful event and you can read all about it in this newsletter.

Please send in your stories, poems and letters to us here at CHERUBS Australia so that we can share them with the all of our members in our next newsletter.

Christmas is not always a joyous time for everyone. For those families that are struggling with the so-called “festive” season, you are in our hearts and thoughts.

CHERUBS Australia wishes you all a safe Christmas and New Year and looks forward to our first “official” year in 2002.

Danielle – President, CHERUBS Australia

THIS NEWSLETTER IS IN MEMORY OF.....

Noah Edward Kelly
Hannah Kate Bowring
Jack James Willshire
Starr Castronova
Damien Smith
Rhian Robilliard
Brodie Bennett

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

Noah Edward Kelly
Hannah Kate Bowring
Starr Castronova
Adam Joseph Vella
Anna Fogarty
Harrison Alan Lovell

We forget the people we laugh with but we never forget the people we cry with. - Unknown

BIRTHDAYS AND MEMORIALS

Brodie Bennett	3/12/01 – 12/12/01
Paul Noble	22/12/66
Minya Kjaersgaard (cherubs sibling)	30/12/92 (Stillborn)
Jack Willshire	31/01/99 – 31/01/99
Matthew Bailey	6/02/00 – 8/02/00
Sean Eason	16/02/99–17/02/99
Starr Castronova	16/02/99
Natalie Whittle	9/02/00

NEW CHERUB ARRIVALS

Brodie Bennett	3/12/01 – 3/12/01
Adam Joseph Vella	22/08/01
Harrison Alan Lovell	20/09/01

THANK YOU FOR YOUR HELP.....

Sue Wilkinson	Nicole Smith
Llona Noble	Linda West
Viv Fogarty	Fiona Frew
Judy Scherrenberg	Caroline Bowditch
Joanne Kjaersgaard	Eilis Hughes

Name Our Newsletter!

If anyone has any ideas on a name for our newsletter please send them in. The CHERUBS International newsletter is called The Silver Lining. We would like to come up with something original that reflects our Australian Group.

Sue's Views

Ho Ho For Who???

How is it possible that Christmas has come around again? For some of us this is the first year we have to endure without our child, for myself it's the third year I have contemplated wringing Santa's neck, throwing reindeers into my open fire and directing large shopping centres to put tinsel where it was never intended. But, like all other public celebrations it can be so very hard to deal with the fact that our special person isn't here to wake us with screams of delight – even if it is at 4 in the morning! So what do we do? I guess we could hide ourselves away, investing in large reels of hessian, growing extreme lengths of facial hair and reappearing at some stage in January, or we can find ways of celebrating. Here are some suggestions that might not cost as much as 50 metres of hessian and a bag of bic razors.

- Decorate a star or Christmas ornament, put a photo on it, and place it proudly on the tree where everyone can see it (including those friends and family who think we should just 'forget')
- Donate some money to a favourite charity in honour of your child
- Release a balloon or several balloons according to the age your child would be at Christmas this year
- Send out Christmas cards – including a significant logo (I always add a star)
- Buy a special toy that can be added to a special memory box. If you haven't already got a memory box – maybe you could buy a chest, paint it and start putting in special memory items
- When opening presents put on a special piece of music
- name a star after your child. Go to www.starregistry.com
- Do something special for a needy child – from your child
- Visit a special place – the cemetery, the train station, fairy land etc.

Christmas can be seen as yet another opportunity to publicly or privately acknowledge our child while showing that he or she is a part of a very loving family. Of course you could ignore any suggestions and head straight to a material outlet, buy up hessian, and when on the way back pop into a large shopping centre and head for the Customer Service Department. Hey, we need to keep all options open!

Have a safe Christmas, and through the sadness allow yourself to smile.

I believe that imagination is stronger than knowledge, that myth is more potent than history. I believe that dreams are more powerful than facts, that hope always triumphs over experience, that laughter is the only cure for grief. And I believe that love is stronger than death. - Robert Fulghum

The Future of CHERUBS Australia

As mentioned at the start of the newsletter, CHERUBS Australia is in the process of becoming a non-profit organisation in our own right. We currently have 40 families and 2 medical professionals as members. CDH affects approximately 1 in every 3000 babies – imagine how many people around Australia have been affected by CDH and don't realise that CHERUBS Australia is here to offer them support! In order to reach more people we need money to print written material such as brochures, business cards and membership forms, to cover postage costs and other general administration costs.

After discussing this at the Get Together in Melbourne we all agreed that we really did need to become a group in our own right. The International CHERUBS have offered us every support and will help us as much as possible each step of the way. The Genetics Support Network of Victoria (GSNV) is currently helping us in set up. The GSNV are a group that are there to offer assistance to support groups in various ways – from referring families on to us right through to helping us establish a constitution and become incorporated.

It will be a slow process. We are all volunteers with family and work commitments. As things develop we will call on members to volunteer in various positions. Not everyone will be able to volunteer, and we understand that, but for those that might be interested, we will have more details in our next newsletter.

I will contact you all individually with your membership details to ensure I have correct information for you all. I will hold the Australian membership database from now on. If you do not wish to be a part of CHERUBS Australia and only wish to belong to the International group then please let me know ASAP and I will make sure that is sorted. The rest of us will remain a part of both the International group and the Australian group. You can also pull your membership from the International group if you want, however, Dawn Torrence and I both believe that it will benefit us all if we belong to both. We get the benefits of two websites, two newsletters, two listservs, two chats etc. We are also able to match up with families internationally. When it comes time for our research survey we can have an Australian perspective and still help Dawn to gain an international one. The choice is yours though.

The Autumn edition of our newsletter should contain some more detailed information on where we are at and we will most likely be shouting out for donations by then!

To help us get things up and running, the following people have taken on these roles until we hold our first AGM in Brisbane at the 2002 Get Together:

President: Danielle Kessner
Secretary: Viv Fogarty
Treasurer: Llona Noble

Thank you all for your support!

Jo's Thoughts

The grief that goes with a living Cherub.

As strange as that sounds, that is what happens. Coming to grips with the thought that the baby you carry may die within hours of birth is a nightmarish idea. That is what women who know they are carrying a CDH baby have to face. The 'pre-grieving' that occurs during pregnancy is something that each of us deals with in our own style. What is not discussed as much is the 'post-grieving' that occurs when that cherub lives. Let me explain:

You have 4 ½ months or maybe more, of preparing yourself. The baby that kicks inside you now will be born with massive hurdles to overcome. Not only do you have to prepare for birth, you have to prepare for a most abnormal 24hrs after birth, a scary, no one can tell me what is going to happen, unknown. You have to focus on that cherub getting through CDH from the time you find out. The fun of buying baby clothes evaporates, you get to tour the intensive care nursery, you can't let yourself think too long on the negative, it may not happen, but you do think of the worst every now & again.

Then it all happens, the cherub is here, the outside world stops for you as you hone in on the life that hangs by a thread. The stress of the few days after birth, surgery, recovery, drugs, lights 24hrs a day, the weird noises of intensive care, even the unrealistic constant temperature in a hospital, all take their toll. But you can't deal with this because there is one thing only that takes top priority, your baby.

Then you go home with your cherub. Now the demands of a new baby are upon you, but you haven't really prepared yourself for the mental & physical strain of this. Then the other half of your brain kicks in & says to you, 'what are you on about, your baby is alive, don't be so petty'. The tiredness sets in, you are feeling down, but that's not possible, your baby is alive. You have the priorities in order, life at the top, why aren't you floating every second of the day?

As enjoyable as they can be, the first few months of a baby's life is also an exhausting, tension filled (why are they crying now?), life changing learning curve. What normally takes us 7 odd months to prepare for, you have now done overnight. There has been no time to understand & come to terms with everything that has just gone on in your life.

We grieve because of loss. What have you lost? The joy of a problem free pregnancy, the innocence of thinking 'everything will be fine', those first moments straight after birth of holding & bonding with your newborn. Not being able to 'mother' your baby in the first few weeks of life, having a stranger tell you when & how often you can & can't do things with your baby. Never being alone with your baby for weeks, knowing others have more control over what happens to your baby than you do.

We know we are privileged to have this cherub, life is precious, but we are only human. You've just witnessed a life/death struggle that you had no control over, your body has been through hormone party overload. You don't get to live the stereotype happy mum/family scenario.

The downward feelings don't happen straight away, in fact it takes months. You are too busy adapting to your new life, dealing with all the well wishers, maybe even still dealing with hospitals, Dr's & the system, getting the feeding & sleeping pattern worked out. It happens as you start to come out of this busy, all intense time that you may start to feel it.

See it for what it is. Talk with someone who understands. Often we relate grieving with the death of a person, but it can be just as valid to grieve over other losses, such as those first precious moments with your newborn. It goes without saying that the grieving talked about here is not on par with death, but important non the less to recognise the loss, have a cry, have a sigh, then plan for tomorrow.

Joanne

Inaugural Get Together - Saturday 10th November 2001



L to R Back - Judy Scherrenberg, Linda West, Lachlan Dryburgh, Richard Dryburgh, Llona Noble, Bailey Viset, Wayne Viset, Lynda Viset, Karen Vella, Michael Vella, Viv Fogarty, Danielle Kessner.
L to R Front - Andrea Dryburgh, Madeline Dryburgh, Sue Wilkinson, Anna Fogarty, Anabel Silva.

After a lot of interest was shown throughout the CHERUBS Australian group, a decision to hold a national Get Together was made. A lot of effort went into planning and organising the get together held in Melbourne, Victoria, resulting in a wonderful day.

Our group is still relatively small with approximately 35 families. We had a total of 23 people attend the get together, with not everyone being able to stay for the whole day as well as dinner. We were very happy to have such wonderful support from our members. Australia is a large country making it difficult for members to attend when it is held so far from home. Our future plans include holding an annual get together in a different state each year.

We spent the morning of the get together sharing our stories and getting to know each other over coffee and cake. We broke for lunch returning to a ceremony held to honour and celebrate all of our cherubs.

The ceremony began with the lighting of a candle followed by a reading of a poem written in memory of one of our cherubs, Rhian. Next we played a song, "Together Again" by Janet Jackson, in memory of the Aussie cherubs who could not stay with us. A Dedication written for one of our cherubs, Harlee, was read to celebrate the lives of our surviving cherubs and the highlight of the day followed. One of our survivors, 4-year-old Madeline, performed a song and tap dance for us. The number chosen was Twinkle Twinkle Little Star, however OUR little STAR threw in a number of encores that included Baa Baa Black Sheep and Rock a Bye Baby. We won't be surprised to see Miss Madeline's name up in lights one day – but to us, she will always be a star J . All of our Aussie cherubs names were then read out with a lovely piece of music played in the background. The ceremony was completed with a slide show presentation. This included photos of our Aussie cherubs, their names and the song "The Best Thing That Ever Happened To Me" by Gladys Knight & The Pips. A number of our members took part in the ceremony and did a wonderful job. The ceremony was simply beautiful with tissues being passed around throughout!

We had a craft activity set up for the afternoon. We made Christmas decorations to be taken home where we were then able to add a photo of our cherub and hang onto our trees come December. During this we discussed the future of our group and how we could best reach other Australian families affected by CDH. Some of the ideas and decisions discussed are currently being implemented and the future for CHERUBS Australia looks bright.

We met for dinner at a local restaurant where Bailey, a 2.5-year-old survivor, stole the hearts of the waitresses with his typical cherub charm J . He even managed to get himself a free bowl of ice cream! Two of our “older” cherubs, Paul 35 and Anna 16, were able to share their CDH stories. It was the first time either of them had encountered anyone else born with CDH. It was wonderful to watch the two of them engrossed in conversation – finally having found someone who could understand what they were talking about!

A tired and emotionally drained group of people finally said good night at 11:00pm. A couple of families met up the next day for an outing, with the rest of us heading for home.

A huge thank you to all of the members who helped organise 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 next years J .

Our inaugural CHERUBS Australia Get Together has officially gone down as a success!



CEREMONY PHOTO'S



Comments from members who attended

I cannot begin to express my gratitude. Saturday was wonderful and personally very needed. Life has a way of sucking you into the mundane things. Although, you know what is important all the other things still need to get done. Like paying the bills, the ironing and you can somehow hide in all this. Thank you again, Anabel, mum of Julia.

Thanks for such a fantastic day on Saturday. Everything was so nicely planned out. It was great to finally put faces to names and meet new people. Everything went smoothly, thanks again. Lynda, mum of Bailey.



I just want to say congratulations - you did a WONDERFUL job with the Get-Together and I know that everyone present appreciated all the hard work that was put into it. Saturday was a truly memorable day (even if it was rather emotional). It was a great success! For my part, it was amazing to see other CDH kids and to spend time with Mums that have been through exactly (and more) than what I went through.... finally!!!! You begin to think you are the only person in the world who knows about diaphragmatic hernias! From just our little family's point of view, you must be able to see the worth of this wonderful support group!!! I have waited almost 35 years to spend time with families who understand what our family has been through... but it was worth it and I am so glad that we found Cherubs. Llona, mum of Paul.

I wanted to congratulate you on organising a successful get together for statewide Australian cherub families. It was wonderful to share our stories with people who actually understood the terminology, and of course the emotional stress. Thanks and Congratulations - I look forward to going to the next one! Sue, mum of Henry.

Thanks so much for giving us this chance to share our grief, our joy and our stories. It means so much to us all! Judy, mum of Harlee

GET TOGETHER 2002

We are in the initial stages of planning our get together for next year. After some discussion it was decided that the best city to hold it in would be Brisbane. We had a mum from Brisbane attend this years get together in Melbourne and she is willing to help co-ordinate the 2002 one. We have a lot of members who either live in Brisbane or who are within driving distant. For the rest of us, start saving your pennies for a Queensland holiday in either late October/early November 2002! We would really like for a Perth family to attend if at all possible. That way we can have the get together in Perth in 2003. It is hard enough to organise everything necessary for these gatherings and it just makes it so much easier if we have someone to co-ordinate it if they have attended a previous one. We will have more details regarding our 2002 Get Together in our Autumn edition.

**Little babe growing
deep inside~
Warm & Secure
in your Mother's Love,
Show the world
your Spirit and Strength.
How dearly
we want to get to know you
and watch you along
Life's Journey.**

**-Written by Judy Scherrenberg for her then expectant cherub,
Harlee James Scherrenberg Timms**

EMMA



19th March 2001 - 22nd March 2001

*You showed courage in the face of adversity
Your spirit shone when dark times loomed*

*You showed bravery beyond your years fighting to the end
Honoring all who loved you*

*Your great heart was evident though you body so small
An inspiration to all*

*And you never gave up though your battle was tough
Unfairly taken from the ones who loved you
Your memory will linger forever in the hearts of all who knew*

*Remembering always with affection
Emma Margaret West
May your precious soul be at peace*

By Mathew May

Emma's Godfather