



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

CHERUBS Australia Organisation

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Spring/Summer issue

2008

From the President....

Welcome to the last edition of our newsletter for 2008.

CHERUBS Australia can FINALLY say we are an officially registered non-profit group! For full details see page 3 of this newsletter.

A fantastic weekend was held in Perth last month at our 2008 CHERUBS Australia Annual Forum (CAAF). A very special thank you to Sharon Knott and Maryanne Reid, for all of their hard work organising such a successful event. Next year's CAAF will be held in Melbourne and details will appear in a newsletter next year.

A special welcome to Angela Logozzo, our new Australian Co-Representative for CHERUBS. Angela is the grieving representative and is working closely with Sharon (surviving/expectant representative) to offer support to the Australian members of the CHERUBS International group.

We have a new website up at www.cdh.org.au There are still a lot of pages under construction and a few teething problems, however I think you will agree it is a big improvement on our previous site. We are still looking for a web designer to create us a professional and user friendly site for CDH families to use. If anyone knows of anyone willing to work with us on this please get in touch with us at information@cdh.org.au

You will notice our new logo on this newsletter and on our new website. A huge thank you to Damon Knott, from As One Advertising and Marketing, for creating this for us. Damon and his team have also created designs for a number of other documents.

Until our next edition ☺

Danielle Kessner – President, CHERUBS Australia
president@cdh.org.au

Thank You!

The Board of Directors would like to thank:

Joanne Dwyer and Alison Chappell at Corrs Chambers Westgarth
Damon Knott and Kevin Lizars at As One Advertising & Marketing
Printwest Printing & Packaging
Sharon Knott
Maryanne Reid
Damon Knott
Carl Reid
Wendy McKay
Angela Logozzo
Sabine Kingston

A special thank you to our husbands for all their support and patience over the past months while we spent hours and hours glued to our computers.

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 Organisation 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 by contributors to this newsletter are their personal views and are not necessarily the views of CHERUBS Australia Organisation, or its members or staff.

Membership

Now that CHERUBS Australia is officially registered we are able to call for membership. Membership to our group will be separate to membership with the International group of CHERUBS. Over the coming months CHERUBS Australia will be sending out membership forms to all of our Australian CDH families and medical professional contacts. We have chosen to do this in small batches to ensure we can process all memberships efficiently without being overwhelmed with a large number of applications at any one time.

We will be charging a membership fee of \$20 per annum. This fee is not tax deductible. We can only provide tax deductions for donations under our Deductible Gift Recipient endorsement. Membership fees will be re-evaluated at the end of the financial year by the board of directors to determine if we are able to reduce this cost. Membership fees will be used to cover the administrative costs of running our group. We do not want to use donations and fundraising to cover day to day items such as postage – we feel these funds should be spent on supporting families and research efforts.

For more information on our membership please visit our website:

<http://www.cdh.org.au/membership.htm>

CHERUBS Australia would like to welcome its very first members:

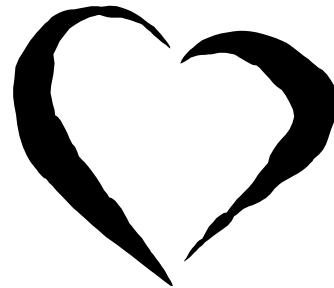
Danielle Kessner
Lynda and Wayne Viset
Tanya Quirk
Fiona Rice
Joanne Kjaersgaard



Cherubs Australia Organisation wishes all members a happy and safe Christmas. Our next issue will be published in March 2009.



CHERUBS Australia wishes all our Cherubs who have recently celebrated a birthday or who have an upcoming birthday, a wonderful day!



CHERUBS Australia is thinking of all angel cherubs and their families on their birthdays and anniversaries!

MEMBERS' PROFILE

Hello! I'm Tanya Quirk, I'm married to Anthony and am Aunty to Alyssa Kessner (and sister-in-law to Danielle)... confused yet? Danielle and I have been friends since high school and Anthony



(Danielle's brother) and I have been married for 2 ½ years.

We are both mad Carlton supporters, have a spoilt cat (named Bronte) and have been working away on our "renovators delight" for almost 2 years... should be done in about 4 months (yah!).

I work full time in Melbourne and am Treasurer for CHERUBS Australia. I've recently returned from the CAAF in Perth which was fantastic. It's a great place and it was lovely to catch up with everyone who attended.

Health Promotion Charity

We are finally registered!!! Our official name is CHERUBS Australia Organisation. The Organisation had to be added to our name as there is already a business called Cherubs Australia registered.

As most of you will be aware, CHERUBS Australia has been working closely with our solicitors at Corrs Chambers Westgarth to complete the necessary paperwork to allow us to become a registered non-profit group. We have encountered a number of problems along the way and it has been a long and drawn out process. All of our hard work has paid off though. A very special thank you to Joanne and Alison from Corrs Chambers Westgarth for all of their hard work, support and patience.

Originally, we thought we would be registered as a Public Benevolent Society with the ATO. In the end it was determined that we were better suited as a Health Promotion Charity. We have also been endorsed as a Deductible Gift Recipient (DGR) which means all donations over \$2 are tax deductible.

You can view all of our official documentation on our website at:

<http://www.cdh.org.au/officialdocumentation.htm>

You can also conduct a search for us at the Australian Business Register:

[http://www.abr.business.gov.au/\(abvsssetaoozwb45owf5v345\)/main.aspx](http://www.abr.business.gov.au/(abvsssetaoozwb45owf5v345)/main.aspx)

Just type in our name CHERUBS Australia Organisation

Our Secretary, Sabine Kingston, had to resign due to family business commitments. We would like to extend our thanks to Sabine for all her hard work over the past months.

We are delighted to announce our new Secretary, Fiona Rice. Fiona has extensive experience working in the administration field and has jumped right into her new role with CHERUBS Australia.

Over the coming month we will be adding photos and profiles to our website of our Board of Directors. Our inaugural AGM will be held next year on the same weekend as our CAAF.

Here is a quick glance at who will be running our group until our inaugural AGM is held:

President – Danielle Kessner, Victoria. Mum of angel cherub Alyssa.

Secretary – Fiona Rice, Queensland. Mum of angel cherub Leon.

Treasurer – Tanya Quirk, Victoria. Aunty of angel cherub Alyssa.

Volunteer Coordinator – Joanne Kjaersgaard, Queensland. Mum of surviving cherub Ariana (aka Wild Child).

Fundraising/Funding Coordinator – Lynda Viset, New South Wales. Mum of surviving cherub Bailey.

Donation of Hospital Information Packs

CHERUBS Australia has put together information packs for hospitals, doctors and clinics to be given out CDH families who they come into contact with. The packs include a cover letter (that contains extracts from our past newsletters), a brochure, our state contacts listing, a membership form and a donation form. They are all held in a coloured gloss presentation folder. <http://www.cdh.org.au/informationpacks.htm>

We are offering families the chance to donate packs in honour or memory of their cherub. The cost per pack is \$5.00 (all donation over \$2 are tax deductible) and sticker containing a personalised message of your choice will be included in the pack/s.

Our state contacts will be distributing these packs to relevant hospitals and clinics as needed.

We will do our very best to accommodate all special requests such as wanting your folders to go to a specific hospital/ultrasound clinic/doctors or wishing to distributing your packs personally.

A donation form, examples and details of personalised labels and photos of the packs can be found on our website:

For further information on donating these packs in memory or honour of your cherub please contact us at: information@cdh.org.au

Fundraising/Funding

I have got our CafePress Store up and running for anyone wishing to purchase CHERUBS Australia merchandise. At the moment we have only one image (CAAF Perth) on a range of products e.g. Shirts, Cups, Bibs plus much more. I am looking at upgrading our CafePress Store so we would have a wider range of images on multiple products. If you wish to purchase or just have a look at what's on offer in our store please follow this link -

http://www.cafepress.com/CHERUBS_Aust . I would love to hear as much feed back as possible.

Funding Applications are on hold for the moment until we can get a committee formed. For the fundraising committee we will need volunteers from the different states/territories. Each State/Territory has its own legal requirements hence the need for a volunteer in each.

I am still in need of volunteers to join either our Fundraising Committee or Funding Committee, if you are interested could you please either email me at fundraising@cdh.org.au or our Volunteer Co-ordinator Joanne at volunteer@cdh.org.au There are no special requirements needed but if you have had any previous experience in fundraising activities or funding applications we would *love* to hear from you. I know we don't get much time these days for family and doing the things we love to do but I would really value anytime you would have spare, to be a part of one of these committees. We really do have a range of opportunities out there to raise money for CHERUBS Australia.

Thanks
Lynda
Fundraising/Funding Co-ordinator

Lily Golding's 1st Birthday Spectacular!



As CHERUBS Australia was about to get its DGR status, my husband Brenton and I thought it would be great if we could get donations in lieu of gifts for Lily's birthday.

Lily's 1st Birthday was such a special milestone to reach and the more we talked about it, we quickly realised there was no better way to celebrate than to have a CHERUBS themed birthday party.

We held the party at our property at Lake Cargelligo on the 2nd August 2008, two days after Lily's actual birthday. Lily's birthday cake was a butterfly, decorated in pink, yellow and blue to represent CHERUBS. I displayed information about CDH and CHERUBS and we also had helium balloons in pink, yellow and blue. Some members allowed us to display their CHERUBS names and family and friends released the balloons in memory and honour of all our CHERUBS. It was such a lovely way to finish off the day.

I'd just like to say a special thank you to all of our friends and family! We raised just under \$900 for CHERUB Australia, which is simply amazing.

Calling all volunteers!!!

As in any group such as ours, we go nowhere without our volunteers. An important part of CHERUBS Australia is our parent to parent support. This is mostly done via the internet, which is manned by a volunteer (fear not, this job is being done!). Now I'd like you to think about your first experience with contacting Cherubs Australia

Who did you first talk with? Did it help you? As we have grown, we are finding the need to spread the contact base from one person and share it between several. We are aiming to have two contacts in each state and territory, one to represent the grieving families and one to represent the surviving and expectant families. These will be known as State Contacts. The second tier of volunteers are our Phone Support Contacts.

To be a Phone Support volunteer, all we need from you is a willingness to listen. Your name and contact details will be added on to our website and newsletter. It's as simple as being a person on the end of the phone that really does understand the CDH experience. Do you think you would like to be on the list? Think back to the time you needed to talk to someone, would you like to be there for the next CDH family?

Being a State Contact is not much harder than being a phone contact person. You will have your name and contact details on the CHERUBS Australia state contact list that will go to hospitals as well as being listed on our website and in our newsletter. You may

be asked to do small tasks such as dropping the CHERUBS Australia Hospital Information Pack into your hospital or Dr's surgery. You will also get the opportunity to help organise the Annual Forum if it's in your state (you will be supported from past organisers and helpers)

We have made it as simple as we can by putting together an information package for you to follow with each job. Easy ☺ There is no such thing as too many phone contacts, so don't be shy, you may never be called, but it's always nice to have you 'just in case'!

We need State contacts for:
Survivors – ACT, NT & SA
Grieving – SA & TAS

Forward any questions to me at -
volunteer@cdh.org.au

Joanne Kjaersgaard
Volunteer co-ordinator

2008 Cherubs Annual Forum



This year's CAAF was held on the 18th October in sunny Perth. It was so great to catch up with everyone and meet some new members! We had 3 doctors present to us, and they had ensured that their presentations were linked! A huge thank you to Mr Ian Gollow, Dr Corrado Minutillo and Dr Jacqui Scurlock for coming along and being so involved. I must also thank Sharon and Damon Knott for everything they did in helping organise the day, I certainly couldn't have done it without them! Dinner Saturday night was a great way to finish off the day. Looking forward to next year in Melbourne. Maryanne WA

CAAF Perth 2008 was wonderful! I thoroughly enjoyed the guest speakers, catching up with old

friends and meeting new ones. The children were all beautifully behaved and the location perfect. Thanks so much to the organising committee for making CAAF Perth 2008 such a memorable weekend. Can't wait for CAAF Melbourne 2009! Danielle, Vic

CAAF in Perth 2008 was a new and wonderful experience for our family. It was great to meet other CDH families and to share our stories. Keep up the fantastic work Cherubs Australia! Danielle, NSW

Personally the CAAF was amazing! To meet all the wonderful families who put such a huge effort into support for Cherubs and to make the day such a success, to see the doctors who treated our baby and to listen to other people share their stories and be able to share mine was priceless. Thank-you so much to everyone involved. Lisa, WA.

Thank you to Maryanne and Sharon for a wonderful weekend. It was great to see everyone again and meet new families and share in their experiences. It was terrific to see how much the cherubs have grown and how well they were all doing. Being able to listen to and talk to the doctors was a wonderful bonus. THANK YOU to you Maryanne and Sharon for all your hard work and for a job well done. Tracey WA

CHERUBS Australia would like to sincerely thank the following people for their contributions:-

Ashton & Elijah Kendall in honour of Lily Golding
Lee Alexander in honour of Lily Golding
The Brigden Family in honour of Lily Golding
Mr & Mrs N Stonestreet in honour of Lily Golding
Millicent Thomas in honour of Lily Golding
Lucida Thomas in honour of Lily Golding
The Golding Family in honour of Lily Golding
Mrs R Stonestreet in honour of Lily Golding
The Knott Family in honour of Lily Golding
Camec Pty Ltd in honour of Gabriel Reza
Kia
Danielle & Julian Kessner in memory of
Alyssa Kessner

STATE CONTACTS – GRIEVING

State	Name	Phone Number	E-mail Address
NSW	Kirrily Hanlon	(02) 9548 3360	kirrily.hanlon@cdh.org.au
Sth QLD	Linda West	(07) 3886 9170	linda.west@cdh.org.au
NT	Helen Harrison	(089) 481 304	helen.harrison@cdh.org.au
VIC	Danielle Kessner	(03) 5135 6999	danielle.kessner@cdh.org.au
North Qld	Robyn Mills	0412 089 189	robyn.mills@cdh.org.au
ACT	Rebecca Mills	0420 524 550	rebecca.mills@cdh.org.au

STATE CONTACTS - SURVIVING

State	Name	Phone Number	E-mail Address
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Sth QLD	Joanne Kjaersgaard	(07) 3372 8687	joanne.kjaersgaard@cdh.org.au
Nth QLD	Judy Scherrenberg	(07) 4774 1535	judy.scherrenberg@cdh.org.au
TAS	Sabine and Lindsay Kingston	0419 578 495	sabine.kingston@cdh.org.au
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