



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

CHERUBS Australia Newsletter

Australian Contact Information:

4 McLean Street
Morwell, Victoria 3840,
Australia
(03) 5135 6999

kessam@tpg.com.au

<http://au.geocities.com/ozcherubs/>

International Contact

Information:

270 Coley Road, Henderson, NC
27537, USA

dawn_torrence@cherubs-cdh.org

www.cdhsupport.org

From the President...

Issue No. 1

2008

Dear Members,

Welcome to the first edition of our newsletter for 2008!

A wonderful weekend was held in Sydney last year at our 2007 CHERUBS Australia Annual Forum. A very special thank you to Alicia Wood, Angela LogoZZo and Lynda Viset for all of their hard work organising such a successful event.

We are all looking forward to our 2008 CHERUBS Australia Annual Forum to be held Perth. For details on this please see the article on page 5 of this newsletter.

Work has been progressing on CHERUBS Australia registering as a non-profit organisation. Our board of directors are currently signing our lives away. Make sure you check out our volunteer opportunities – we would love to have you help out our group in whatever way you can!

A special welcome to Sharon Knott, our new Australian Co-Representative for CHERUBS. Having a Co-Rep has taken an enormous amount of pressure off me and eased my work load substantially.

We are currently working with Damon Knott who is revamping our logo and helping to come up with some additional graphics that we intend to use for fundraising purposes. Watch out for our new and improved look.

Until our next edition ☺

Danielle Kessner – President, CHERUBS
Australia
kessam@tpg.com.au

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

The Board of Directors would like to thank:

Sharon and Damon Knott
Maryanne and Carl Reid
Wendy McKay
Alicia Wood
Angela LogoZZo
Lynda and Wayne Viset
Dr Michael Stewart
Professor William Tarnow Mordi
A/Professor Nadia Badawi
Professor Danny Cass
Dr Dominic Fitzgerald

If you have recently changed your contact details please let CHERUBS Australia know so that we can update our records.

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.

Welcome to our new Members

Rebecca Mills
 Catherine Lucre
 Kate Dyer
 Charity Caldwell
 Jenny Dance
 Danielle Golding
 Dominic Nash
 Jaana Rosenlund
 Andrea Labudda
 Fiona Rice
 Mel Nicol
 Cathy Ferries
 Alethea Walker
 Kylie Beswick
 Sonia Stafford
 Lesky S
 Mei Tay
 Robyn Milcallef
 Jenny Kruger
 Petrina B
 Leanne Brooks

We also extend a very warm welcome to those new members who have requested that their information remain private.



Public Benevolent Institution

Working has been progressing in our bid for CHERUBS Australia to become a legal entity. We have come across a number of obstacles along the way but have finally reached the stage where our solicitors at **Corrs Chambers Westgarth** are ready to submit our paperwork with ASIC and the ATO.

Due to family commitments Linda West was unable to take up the position of Secretary.

Thank you so much to the members who showed interest in this position. We are delighted to announce that our new Secretary will be Sabine Kingston.

We are also very pleased to announce that the vacant position of Funding/Fundraising Co-

Ordinator (Director) has been filled by Lynda Viset.

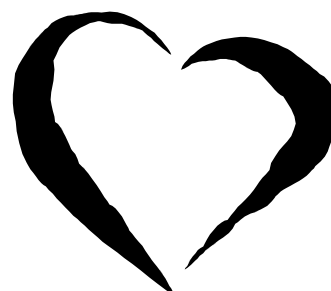
Our Board of Directors would like to take this opportunity to thank Damon Knott for providing his business address for use as our registered office. We would like to thank all of the other members who volunteered to help out in this area.

We had great difficulty obtaining the services of a registered company auditor and we appreciate all members who spent time trying to help us find someone. Many thanks sent to Carl and Maryanne Reid for securing the services of an auditor for us.

Updates will be sent out by the Board of Directors over the coming months once CHERUBS Australia has become officially registered. Thanks to all of our members for their patience and support during this long and difficult process.



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



Introducing our new Australian Co-Representative for CHERUBS.....

Hi, I'm **Sharon Knott**, mother of 2 kids CHERUB Liam and Chelsea-Rose and wife to Damon and the new co-rep for CHERUBS Australia.

I have been busy getting to know the new CHERUBS International website... WOW!! This new site is amazing! I love a chat and have made many new International friends who have or are experiencing the CDH journey.

Have you managed to take a look at the new site yet? Personally, as a family, my husband and I have used the NEW CHERUBS site to ask many, many questions we have had and continue to have. The posting boards are a great way to ask anything and every single member understands the road our family is on. It's also a safe place to express how you are feeling as so many of our members will understand exactly what you are going through.

CHERUBS Australia also has a Facebook page. If you are on Facebook please add CHERUBS Australia and say "g'day" on our wall. You can post pics and videos on our page. Facebook is also a great way to raise CDH awareness, so once you have added us, please get your friends to add us too.

Looking forward to reading Aussie posts on CHERUBS and Facebook.

Shaz

If you have any questions about using either the CHERUBS member boards or Facebook contact Shaz via email: shamon2@optusnet.com.au

...and our new Fundraising Co-ordinator for CHERUBS....

Linda Viset. I live with my husband Wayne, and our son Bailey, in Hamlyn Terrace on the NSW Central Coast. Our home is also an office for our Computer Business, which we both operate and keeps us extremely busy. I enjoy scrapbooking but haven't had the chance to do any for a very long time. I would like to get together with a couple of friends and do card making etc. I also play indoor volleyball and try going to water aerobics but that hasn't happened lately. Wayne was playing indoor cricket but can't for about 9 months due to a knee reconstruction. Bailey has been playing tennis since he was about 3 and just loves it. He is also playing cricket. We enjoy going away camping whenever we can, swimming in our pool, gardening and spending time with our family and friends. Oh just one more thing I'm going to be an aunty in March and Bailey is very excited about having a cousin.

Fundraising and Funding

I would like to invite anyone interested in volunteering to join either our Fundraising Committee or our Funding Committee. These committees are essential to make CHERUBS a success in raising funds to benefit research, CAAF (CHERUBS Australia Annual Forum), getting CHERUBS known, CDH Awareness etc.

If anyone has previous experience in Funding applications, it would be fantastic to have you on the committee. Please if you are able to give some of your time to either one of these committees it will be greatly appreciated.

It's so exciting to see so many different opportunities out there for fundraising and fundraising events. My vision is to have each state hold a fundraising event once a year with other smaller fundraisers throughout that year.

I would love to see CHERUBS have one fundraiser each year that all states would do the theme on the same day. I held a "CHERUBS in Pyjama Day" at Bailey's school; yes everyone even the teachers and executive staff came to school in their PJ's with a gold coin donation.

The more devoted committee members we have the lighter the work for everyone involved. So let's put our heads together and make Funding/Fundraising a success.

Lynda Viset
Fundraising/Funding Director
CHERUBS Australia
lynda@micromac.com.au

CHERUBS 2007 National Forum, Sydney



We were all a little tired after a full Friday but it was really good to see everyone there. The Sydney girls did a great job of organizing and running the Forum. I can tell you it's a little daunting to get around Sydney if you don't live there, but those Sydney folk were very nice to us and helped us by driving in convoy to the venues. Thanks guys!

I think everyone that went got something out of the day. Tears, smiles, meeting interesting people and learning about their lives. This was the first time we didn't break into separate groups, and many of us learnt much about others. We learnt about research and how it affects us as a group, we learnt about grief and post natal depression, and at the end of the day, I think we all re-learnt how wonderful and fragile life is.

Seeing faces and putting them to names is always wonderful. The guests, the new and the old faces, the new structure of the kids another year older, it all came together and made it the Sydney experience. Thanks to all who put it together and made it happen.

Jo K.



...Update on mothers to be from the Sydney Forum...



Remember our mum's to be from Sydney?

Here are their updates:

Angela (mum of angel Cherub Max) gave birth to a healthy boy named **Dominic** on 1st December 2007. He arrived 2 weeks early and weighed in at 2.8kg.

Linda (mum of angel Cherub Emma) gave birth to a healthy boy named **Jack** on 2nd May 2008. He arrived 1 week late and weighed in at 4.490kg.

All well!

Congratulations from everyone in CHERUBS
Australia!

A video has been created featuring photos from all of our past CAAF's. You can view this video on YouTube by following this link:

<http://www.youtube.com/watch?v=keOCsSK48Z0>

For additional CHERUBS videos:

<http://www.youtube.com/user/cdhsupport>





CHERUBS Australia Annual Forum

Will this year be held in **PERTH**

On *Saturday 18th October 2008*

At the Sorrento Beach Resort
www.sorrentobeach.com.au

A family day will be organised for Sunday the 19th October

Sorrento beach is located 20 kms north of the city on Perth's sunset coast. The hotel is across the road from the beach and within a 5 minute walk of Hillarys Marina. The marina has a sheltered family beach along with a large number of restaurants, cafes, shops and the Hillarys Great Escape leisure centre which has a waterslide, minigolf, bumper cars and other family activities. www.thegreatescape.com.au
AQWA (Aquarium of WA) is also located within a 5 minute walk. www.aqwa.com.au

Any queries or acceptances to

Maryanne Reid
mpreid@bigpond.net.au
0439954008

Or

Sharon Knott
shamon2@optusnet.com.au
0408695113

More details re accommodation are on the next page. Please contact the resort directly to make your booking.

Sorrento Beach Resort

www.sorrentobeach.com.au

Phone: 08 9246 8100

Resort Manager:

admin@sorrentobeach.com.au

All Reservations Inquiries:

reservations@sorrentobeach.com.au

Address Details: 1 Padbury Circle
Sorrento, Western Australia 6020

Hotel Studio Room (resort view)
\$ 164.00 * room only

Hotel Studio Room with Ocean View
\$ 194.00 * room only

Luxury 1 Bed Spa (Resort View)
\$ 213.00 * room only

Luxury 1 Bed Spa with Ocean View
\$ 243.00 * room only

2 Bedroom Apart (shared apart/own
room) \$ 206.00 * room only

Continental Breakfast Basket in-room @
\$8.80 per person.

Consists of 2 bread, cereal, fruit juice, fruit
snack, muesli bar, various spreads, coffee
& tea making supplies

Alternatively guests can present their room
key to Voyage Café & charge their room
account (anything from \$5 to \$25 for a full
breakfast)

**CHERUBS Australia Vacant
Positions**

CHERUBS Australia has a number of
vacant volunteer positions that will need to
be filled once we are incorporated. If you are
interested in any of the following roles
please contact our Volunteer Coordinator or
Fundraising Coordinator for the
fundraising/funding committees:

Joanne Kjaersgaard (Volunteer Coordinator)
no_sew@bigpond.net.au

Lynda Viset (Fundraising Coordinator)
lynda@micromac.com.au

Assistant Secretary

Assist the Secretary as needed

State Contacts

Ideally one surviving member and one grieving
member per state.

Welcome new members

Inform new members of services we have

Distribute published info to hospitals, doctors
etc.

On-Call Parents

Ideally at least one surviving member and one
grieving member per state. A listing of surviving
parents who were diagnosed in utero would also
be good to have listed for expectant parents.

Welcome new members

Be a phone contact for families that need
someone to talk to.

Research Co-Ordinator

Conduct CDH research to keep the group
informed on latest treatments and statistics. This
would involve online research and where
possible, keeping in touch with medical centres
around Australia who deal with CDH.

Newsletter Secretary

Send out newsletters to offline members

Assist the Editor as needed

Funding Committee

Complete funding applications

Fundraising Committee

Decide and co-ordinate fundraising events



Medical Matters
By *Maryanne Reid RN*

**Complications associated with
Congenital Diaphragmatic Hernias –
Part Two**

Babies who survive being born with a congenital diaphragmatic hernia (CDH) may face ongoing problems. The long term medical outcomes vary from baby to baby and are usually dependent on the severity of the defect and length of hospital stay. Some babies will progress well, have few ongoing problems and be discharged within a few weeks, while others will need to be in hospital for many months. Those babies that stay in hospital longer may have the potential to develop chronic problems.

Reherniation

Reherniation can occur following repair of the diaphragmatic hernia and the timing of this appears to vary. Symptoms associated with reherniation include respiratory distress such as coughing or wheezing and feeding difficulties. If reherniation is suspected the child should be assessed by a doctor without delay.

Scoliosis

The incidence of scoliosis tends to be higher in those babies who had a large diaphragmatic defect. Studies have stated that this may be caused by the tension created following the repair. CDH children should be monitored for signs of scoliosis. Other skeletal abnormalities include pectus excavatum and chest asymmetry.

Hearing loss

Babies born with a CDH are at risk of developing hearing loss that is not obvious at the

time of discharge from hospital. It occurs in about 5% of them. Causative factors include low birth weight, medications that are ototoxic such as some antibiotics and lasix, hyperventilation, persistent pulmonary hypertension and long ventilation times. The hearing loss can be progressive and normal results on discharge do not mean that they won't develop later. Therefore these babies should have their hearing tested every 6 months until 3 years of age.

Bowel Obstruction

Bowel obstructions can occur at any stage due to the formation of adhesions following surgical repair of the CDH. A suspected bowel obstruction must be assessed immediately as a hospital admission could be necessary with the potential for surgery to be required.

Although not all babies will develop these problems, regular follow up with the baby's doctor is essential. This will ensure that potential problems are identified quickly and early intervention can occur to optimise the baby's outcome.

On the following page you will find our list of State contacts. If you would like to add your name to this list, please provide the following information to our Volunteer Co-ordinator, Jo Kjaersgaard via no_sew@bigpond.net.au

*Name
State/territory where you live
Home phone no. (optional)
Mobile no. (optional)
Email address*

STATE CONTACTS

GRIEVING CONTACTS

State	Name	Phone Number	E-mail Address
NSW	Kirrily Hanlon	(02) 9548 3360	kirrily@hn.ozemail.com.au
Sth QLD	Linda West	(07) 3886 9170	dwest@smartchat.net.au
NT	Helen Harrison	89481304 0427 059 104 (mob)	hel_31@hotmail.com

SURVIVING CONTACTS

State	Name	Phone Number	E-mail Address
NSW	Lynda Viset	(02) 4393 6454 (ph) (02) 4393 9372 (fax)	lynda@micromac.com.au
Sth QLD	Joanne Kjaersgaard Ken & Wendy McKay	(07) 3372 8687 (07) 3264 2753	no_sew@bigpond.net.au k_wmckay@samford.net
Nth QLD	Judy Scherrenberg	(07) 4774 1535	jscherre@bigpond.net.au
TAS	Sabine and Lindsay Kingston	(03) 6250 3493	barlou@bigpond.com
WA	Maryanne Reid	(08) 9309 2192	mpreid@bigpond.net.au
ACT	Sandy Graham	(02) 6452 7390 0412 999 816	sandygraham@ripnet.aunz.com
VIC	Jasmine Burns		scottburns@optusnet.com.au
VIC	Karen Vella	(03) 9748 9644	mkvella@optusnet.com.au