



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

CHERUBS Australia Newsletter

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2007

From the President....

Dear Members,

Welcome to the second edition of our newsletter for 2007!

We are all looking forward to our 2007 CHERUBS Australia Annual Forum to be held on the 20th October in Sydney. For full details on this please see the article on page 2 of this newsletter. Please also read the article on page 3 that contains information on the CDH conference that will be held the day before our forum on the 19th October. This is a wonderful opportunity for parents to listen to some of Australia's leading medical professionals presenting and discussing various aspects of CDH. For members attending either of these days PLEASE email me to get a copy of a questionnaire we have prepared.

As I wrote in our last newsletter, a small committee of members have been working incredibly hard behind the scenes to help our group achieve an official status. Please read the article on page 5 for more details and to see how you can volunteer to help our group in the future.

We are still looking for a host for our website so please contact me if you are able to help.

Until our next edition ☺

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

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 Member

Natalie Sheridan

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

Danielle Kessner
Maryanne Reid
Alicia Wood
Angela Logozzo
Linda West
Jo Kjaersgaard
Lynda Viset
Wendy McKay
Tanya Quirk

CHERUBS Australia wishes the following cherubs a very happy birthday.

***Tory Piperno
Anna Fogarty
Angus Matsen
Samuel Gambin
Fallon McClelland
Claire Oakley
Dain Kingston
Jackson McKay
Henry Nancarrow
Justin Keeling
Jack Augustson
Liam Knott
Louis Ericson
Jack Burns
Ariana Kjaersgaard
Madeline Dryburgh
Sebastian McErlean
Hayley Ginns
Thomas Nash
Lisa Warnock
Anthony Moschilla
Natalie Sheridan***

CHERUBS Australia is thinking of the following cherubs and their families on their birthdays and anniversaries.

*Braydon Ross
Leon McDermid
Emma West
Hannah Bowring
Noah Kelly
Scarlett Bailey
Maddison Carroll
Joshua Baker
Lysa Ienco
Max Logozzo
Kyan Bolin
Alyssa Kessner
Rowan Keating
Blake Hanlon
Chloe Mitchell-Greenfield*

**CHERUBS Australia
Annual National Forum**

for

2007

will be held in

Sydney

**October 20 at the
Beaumont Hills Community
Centre.**

Mark it on your calendar!



CHERUBS Australia Annual Forum Sydney 2007

This year, the CHERUBS Australia annual Forum will be held on Saturday 20th October 2007 at the Beaumont Hills Community Centre in Sydney. Its location is close to Westmead Hospital and the venue for Friday's CDH conference, and has great facilities for the children to make use of.

We have invited some special guest speakers to attend on the day.

They include:-

- Dr Peter Barr - A neonatologist from The Children's Hospital at Westmead who also has a special interest in neonatal bereavement.
- Professor William Tarnow Mordi - from Westmead Hospital NICU
- A/Professor Nadia Badawi (yet to confirm) - From the Grace centre of Newborn Care at The Children's Hospital at Westmead.
- Dr Dominic Fitzgerald (yet to confirm) - who runs the CDH clinic at Children's Hospital Westmead.

Babysitting will be available on the Saturday with the hope that the children will have access to the centre's enclosed play area and toys (we are currently seek permission with the local playgroup). Parents will be able to access their children at all times but rest assured that they will be kept busy with lots of activities & toys to play with.

Morning and afternoon tea will be provided for at the centre & we will take a break for lunch, eating out at the nearby 'Aberdeen House'. Or if the children prefer there is always the option of McDonalds etc., which is also close by.

We are busy looking into accommodation however the Crown Plaza Norwest looks like a good choice as it's close to our venues, has nearby shops, restaurants & an ice skating rink. It is located 40 minutes from Sydney CBD. We have also secured a great rate on this motel (see box below). A number of other options you

could look into if necessary are The Hills Lodge Grand Mercure (Castle Hill), Best Western Wesley Lodge (Westmead) and Skyton Le Fairways Apartments Quest (Castle Hill).

So if you are thinking of attending this year's Forum PLEASE email Danielle Kessner to get a copy of a questionnaire we have prepared to let us start getting some ideas of numbers. We are happy to answer any questions or concerns that you may have.

It promises to be a great day - Hope to see you there.

Angela, Alicia and Lynda

BOOKING INFORMATION

Alicia Wood's friend, Sheree, has approached the Reservation Manager and General Manager at the Crowne Plaza Norwest where she works and has secured Cherubs a family and friends room rate of \$88 per night.

This is quite fantastic as it is a 4.5 star hotel!!

When you book YOU MUST contact Sheree Faux directly so that she can organise the discount.

sheree.faux@crowneplazanorwest.com.au
Ph: 02 9634 9613

You can get rooms with either one Queen bed or two Single beds. If you are bringing a couple of children you can book two connecting rooms. If you only need one additional bed in a Queen room the motel is prepared to waive the normal cost associated. Contact Sheree and she will discuss all of your options.

There is a Lollipops (a playcentre) which is within walking distance of the Crowne. Occasionally they have a program where you can drop off older children for a fee. This may assist those who have small children and don't think that they will last the whole day on Friday. If there is enough interest in this option we will contact the centre to see if we can arrange something so please let us know if you are interested.

CDH Conference

Professor William Tarnow Mordi of Westmead Hospital NICU and A/Professor Nadia Badawi of Grace Centre for Newborn Care from The Children's Hospital at Westmead have very kindly offered to organise a CDH conference on Friday 19th October 2007. The conference will discuss CDH epidemiology and the intended audience is a mixture of professionals and parents.

The conference will review the latest NSW statewide figures and recent trends of Congenital Diaphragmatic Hernia and speakers will present current figures and trends from other Australian states and New Zealand geographically defined populations. Speakers such as Dr Michael Stewart from Melbourne will present, Professor Danny Cass (surgeon) and Dr Dominic Fitzgerald from Sydney will discuss the CDH clinic providing some data based information which I'm sure will provide subsequent discussion on the day. A research parent survey (which you will receive shortly) will also be presented by a High Risk Obstetrician. The 2007 conference will also provide a base for organising a larger 2008 International CDH conference, which will be very exciting for us all.

At the moment the cost for the day will be \$50 for catering (morning and afternoon tea, lunch, tea and coffee) and unfortunately childminding facilities will **not** be able to be offered. However, if you need to bring your children, please be considerate of other attendees by taking the children outside if they need a break or become noisy. Please see the last paragraph in the box on the previous page re: playcentre.

I will try and negotiate lower fees however I cannot promise a reduction. The conference we held in 2003 was a catalyst for change and whilst sometimes confronting the conference is an extremely important part of improved survival rates for CDH.

Alicia Wood



From the
Kitchen

Easy Bake Brownie Slice

By Rosie (kindly made for Mother's Day by Miss Rosie who is Chelsea McKay's White class teacher aide)

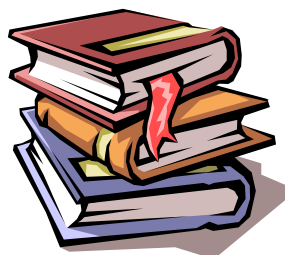
1 cup self raising flour
 ½ cup soft brown sugar
 ½ cup desiccated coconut
 2 tbl cocoa powder
 1 x 400g can sweetened condensed milk
 125g butter melted
 1 x 200g block dark/milk chocolate broken into squares

Grease slice pan. Line with baking paper.

Combine flour, sugar, coconut, cocoa powder, condensed milk and melted butter into a medium bowl. Mix well. Pour into pan. Press chocolate squares into mixture about 5cm apart.

Cook in moderate oven at 180° C for about 20 mins or until lightly browned. Cool slice in pan before cutting into squares.

Enjoy!



From the
Bookshelf

CHICKEN SOUP FOR THE GRIEVING SOUL

By Jack L Canfield & Mark Victor Hansen

This collection of inspirational stories will undoubtedly touch many hearts. Written by authors who have lost loved ones, these stories offer comfort, peace and understanding to those going through the grieving process. Individual people deal with grief in their own ways and within their own time, but the guidance and support they receive from others is what helps them through it.

One of the key messages of "Chicken Soup for the Grieving Soul" is that togetherness and sharing are the keys to moving on. In these stories people share their experiences with coping and they share deep memories. Each one has found that putting thoughts and feelings into words is not only cathartic; it allows them to reconnect with their loved one and others.

Words of encouragement are plentiful in this edition and they go straight to the heart. Chapters encompass the complete grieving experience and include: Final Gifts, the Power of Support, Coping and Healing, Those We Will Miss, Special Moments, Insights and Lessons, and Living Again.

Readers will be comforted and inspired by the stories of regaining strength and hope, such as holding meaningful services, performing thoughtful deeds and cherishing special memories. Most important, just as the writers have come to appreciate life through the grieving process, readers will discover how to do the same. This soothing bowl of stories is the perfect gift to bring comfort, strength and courage.

Children's Hospital at Westmead. Store owner, Kylie Foxall, chose to raise money for the very special Grace ward in memory of her friend's son, Lachlan Wood, who passed away in 2002.

Lachlan had a condition called Congenital Diaphragmatic Hernia (CDH), a birth defect that occurs when the diaphragm does not fully form, allowing internal organs from the abdominal cavity to enter the chest cavity thereby preventing lung growth. Survival rates have improved markedly as new and improved ventilation and management techniques have been introduced.

Further research into CDH is actively pursued at Grace with some encouraging results; and the new follow-up multidisciplinary lung clinic coordinated by the Department of Respiratory Medicine has proved a blessing for many CDH families who need specialised long-term care.

Every year, 20–30 ladies attend the Scrap-a-thon. Scrappers are invited to the store to create their pages throughout the 24-hour period and are 'sponsored' by family and friends for the number of hours they complete. So they get to work on their much loved hobby and raise money at the same time! Last year, an amazing group of eight ladies scrapped continuously for 24 hours straight! The Scrap-a-thons have raised a total of \$11,500 so far – these funds have helped to fund neurodevelopment assessments of children who have had CDH repaired.

Congratulations to Kylie, the staff at Scrapbook Superstore Penrith and all the participants for their hard work and contribution towards making this event such a great success!



**PRESS
CLIPPINGS**

**Superstore does it
again!**

In September this year, Scrapbook Superstore Penrith will hold their 24-hour Scrap-a-thon for the fifth consecutive year to raise money for the Grace Centre for Newborn Care at The

Scrap-a-thon 2007

22 September – Scrapbook Superstore,
Penrith

You could win the prize giveaway of a
Scrapbook Storage System worth over \$1,000.

For more details or to purchase raffle tickets,
please phone (02) 4722 2152.



Public Benevolent Institution

CHERUBS Australia has been fortunate enough to secure the pro-bona services of a National law firm **Corrs Chambers Westgarth** to assist our group in becoming a legal entity. Their advice was that the best way to go forward, particularly if we wish to receive tax-deductible donations is to incorporate a company limited by guarantee, which is a public benevolent institution.

A small committee was formed and we have been doing a lot of work setting out our objectives and creating a constitution (which is almost finalised) that will best meet the group's needs.

CHERUBS Australia will be 'run' by a board of volunteer directors. We will also have other volunteer positions (e.g. State Contacts) and a couple of sub-committees (e.g. Fundraising Committee) to ensure our group runs smoothly and the large workload is spread evenly around.

We are almost at the stage where more volunteers are needed to help prepare our group as it gets ready to register and in the months that follow. We felt the best way to go forward with this was to ask members to let us know if they are interested in helping us set up the following roles. This does not mean that you will have to volunteer in that role after we have held our first AGM.

Please contact CHERUBS Australia (kessam@tpg.com.au) for more detailed information about the role of Directors.

If you are interested, please stick you hand up. We would rather have lots of members

helping instead just a couple doing all the work.

The positions we need help with are listed below. I have included most of the positions – even those that we know certain people are interested in or are currently volunteering in (as noted). So even if you are currently working a role and want to keep doing it, let us know! You may even be interested in a couple of roles e.g. Funding AND Fundraising committee member.

President (Director) *Danielle Kessner*

Secretary (Director) *Linda West*

Treasurer (Director) *Tanya Quirk*

Volunteer Co-Ordinator (Director) *Jo Kjaersgaard*

Funding/Fundraising Co-Ordinator (Director) *Vacant*

Assistant Secretary *Vacant*

Newsletter Editor *Wendy McKay*

Newsletter Secretary *Vacant*

Research Co-Ordinator *Vacant*

State Contacts *Some Vacancies*

On-Call Volunteers *Some Vacancies*

Fundraising Committee Member *Some Vacancies*

Funding Committee Member *Vacant*

A very special thanks to Danielle Kessner, Linda West, Maryanne Reid, Joanne Kjaersgaard and Lynda Viset for all of their hard work in getting us to this point in the process.



MEDICAL MATTERS

By Maryanne Reid RN

Complications associated with Congenital Diaphragmatic Hernias – Part One

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.

Pulmonary Complications

50-60% of CDH babies will have chronic lung disease, although most lead normal lives by the age of 5. Babies with chronic lung disease may require oxygen and/or medications to help them with their breathing. This could be needed for a few weeks, months or years. Asthma is more common in children who experienced lung problems in infancy. Respiratory infections may also affect them more severely in the first few years of life.

Developmental delays

Some babies with CDH will have developmental delays. These can include the inability to roll over, sit, crawl, stand and then walk. Early intervention with the help of a physiotherapist and/or occupational therapist can help these babies to gain muscle strength and coordination and thus catch up to their peers.

Reflux and feeding problems

Many babies will develop gastroesophageal reflux, and recent studies suggest the incidence can be between 45-85% of surviving infants. Gastroesophageal reflux is where the stomach

contents come back up into the oesophagus. This can lead to vomiting, heartburn, feeding problems and aspiration into the lungs. Most babies can be treated with medication but some with severe reflux may require surgery.

Failure to thrive

Some babies will have difficulty in growing. Studies have shown that more than 30% of babies are below the 5th percentile for height and weight during their first 12 months of life. Those with the most serious lung conditions are more likely to have problems growing as their calorie requirements are very high. As a result they made need a feeding tube to supplement their calorie intake.

To be continued in the next issue.....

Member Profiles



Ken & Wendy McKay

Ken and I were married in 1996. We were engaged 5 weeks after meeting and got married 9 months later. We have 3 children, Connor (8) and Chelsea and Jackson (both 5).

Ken has his own building company and I am a teacher. Last year I took leave to help Ken with the business but it looks as though I won't be going back. I don't regret this as I felt it was time for a change and I now enjoy the freedom of being able to help in the kids' classrooms, attend all school functions, as well as manage the household and assist Ken.

We both enjoy soccer. Ken has previously coached for a number of years and we now love to watch Connor play. I don't play but I do enjoy watching (I'm a total gummy when it comes to sport). We also support our own Queensland team, the Roar. Go the Roar!

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) 3882 2375 | 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 |