



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  
[www.au.geocities.com/ozcherubs](http://www.au.geocities.com/ozcherubs)

International Contact  
Information:  
270 Coley Road, Henderson, NC  
27537, USA  
dawn\_torrence@cherubs-  
cdh.org  
[www.cherubs-cdh.org](http://www.cherubs-cdh.org)

**Issue No. 1**

**2007**

## From the President....

Dear Members,

Welcome to the first edition of our newsletter for 2007!

Our member forum held in Brisbane last year was a great success and many thanks are sent to the organisers Joanne Kjaersgaard, Wendy McKay and Linda West. For all the details and some great photos please read the article featured in this edition. We are all looking forward to our 2007 CHERUBS Australia Annual Forum to be held from 19<sup>th</sup> – 21st October in Sydney. We are seeking NSW members who live reasonably close to Sydney to be on the planning and organising committee for the forum. Please contact me if you are interested. Details for this year's forum will be confirmed and members notified in the coming months.

A small committee of members have been working incredibly hard behind the scenes to help our group achieve an official status. In the past we have had numerous discussions on this topic and some debate on how we can best achieve this – all amounting to nothing! Great news though...a national law firm, CORRS, CHAMBERS, WESTGARTH lawyers (<http://www.corrs.com.au/>) have made the generous offer to represent us pro-bona and help us with all the legalities surrounding our incorporation. Our Constitution is almost complete along with a number of other necessary steps. We will have full details for you in the next edition of our newsletter (or a special bulletin will be sent out earlier if needed).

Work is still being done on our new website. This often takes a back seat to other jobs but it has not been forgotten. Your patience is much appreciated as all work done for CHERUBS Australia is by volunteers who have family and work commitments. If anyone is able to (or knows someone who is willing to) host our website for free please contact me. As soon as we are incorporated we will be applying to obtain a new domain name and hoping to post our new website shortly after to its new address.

Until our next edition ☺

Danielle Kessner – President, CHERUBS  
Australia  
[kessam@tpg.com.au](mailto:kessam@tpg.com.au)

**WARNING:** Please note that on page 8, as part of our Medical Matters article, there is a colour photo of a bowel adhesion. This may be disturbing to some readers.

**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.

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

Joanne Kjaersgaard  
Danielle Kessner  
Wendy McKay  
Maryanne Reid  
Alicia Wood  
Fiona Rice  
Linda West  
Carl & Maryanne Reid  
Damon & Sharon Knott

***CHERUBS Australia wishes the following cherubs a very happy birthday.***

***Adam Whitelock  
Chloe Lysaght  
Haideen Smith  
Sarah Hogg-Keeling  
Harlee Timms  
Chloe Towne  
Kelsey Glindeman-Smith  
Rebecca Reid  
Arti Hodgeson  
Paul Noble  
Kirra Graham  
Nathan Clarke  
William Tripoki  
Natalie Whittle  
Bailey Viset***

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

***Caleb Geaghan***

*Noah Kelly  
Alec Bonser  
Brodie Bennett  
Jonathan Kilby  
Jack Willshire  
Harry Tabbernal  
Matthew Bailey  
Sean Eason*

**CHERUBS Australia  
Annual National Forum**

**for**

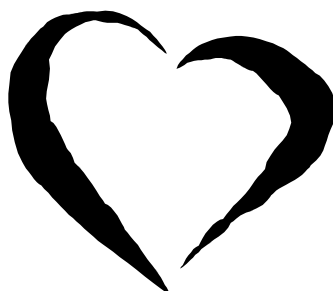
**2007**

**will be held in**

**Sydney**

**October 19 - 21**

**Mark it on your calendar!**





PRESS CLIPPINGS

Liam's American Story

We left Perth bound for Kluge Children's Rehabilitation Centre, Charlottesville, Virginia on 5th October. After many problems with airlines we arrived full of excitement and extremely tired. Liam started his 2 week intense feeding clinic on Monday 9th October. We all met Miss Polly (speech pathologist) and instantly warmed to her.

Miss Polly sat us down in the cafeteria and started to get a bowl of yogurt ready for Liam and some Cheeto chips (twisties). We wondered how will this go? Then Miss Polly explained to Liam what to do and to use his "big boy teeth" and he did what she asked and he was eating, this was all within the first 10 minutes... Wow!!!!!! How good will this be?

The day was taken up with breakfast, mid morning snack, lunch and afternoon snack, in between this there was recreational therapy, occupational therapy and school. The activities revolved around touch, smell and tasting of food and all in a fun way, there was no pressure and the specialists were happy to help and they loved what they did. For 2 weeks this routine would be our world.

Day 4 was the best. We were able to feed our son for the first time in 3 and a half years, what an experience!! It made our decision to take our son Liam and his big sister Chelsea-Rose half way around the world worth it. Why though, did our very own Princess Margaret Hospital not give this service. After witnessing first hand how the program worked we could see NO reason WHY this clinic couldn't be done in our own City, let alone our own country.

Liam took to feeding like a duck to water and he was enjoying it. Liam needed to eat yogurt, pudding and other pureed food that equalled the amount of formula that went down his tube.

Monday of the second week saw the biggest event of all. After a weight check and a team talk, our amazing little man was to lose his companion – that nasty little nasogastric tube came out and Liam said

"bye bye" and threw it into the bin. Liam loved not having the tube, he kept touching his face and his first nights sleep with no tube and feeding pump was so funny as he must have gone around the bed 3 times in his sleep. For the rest of the week, he kept trying all foods that were put in front of him and managed to hold his weight as well, we finished the 2 weeks in absolute awe as our son and brother was eating. We all had the biggest smiles.

We left Charlottesville to have some fun in Disneyworld for 3 and a half days. Unfortunately Liam became sick and wouldn't eat or drink so that nasty tube had to be reinstated. The temperature was extremely high and we had to keep him hydrated. We have been home for two weeks and Liam's bug turned into an inner ear infection. He is still on antibiotics but after getting into a routine the eating has started again and he is eating the required daily amount. Within days that nasty tube will again go!! It is still a long road ahead and it will be a while until he eats a piece of steak but we finally have something to work forward to and we are no longer stuck in a black hole.

**Damon & Sharon Knott 0433 349 800**  
**shamon2@optusnet.com.au**

**Update on Liam:**

Liam's tube has been out again for 3 1/2 weeks and is doing really well with his eating of soft foods. He is practising his crunching on yummy food such as: twisties, burger rings, fruit bars and apples. Liam has found a new confidence in himself and holds his little head up high when we are out and about - nobody stares!! Onwards and upwards... our light is burning much brighter at the end of the tunnel:))

**Liam with no tube and Miss Polly**



## Rebecca's American Story

*For all our members who did not get to attend this year's Forum in Brisbane, Carl and Maryanne gave a wonderful slide presentation on Rebecca's clinic treatment. Below is a summary of their presentation and an update on Rebecca.*

We traveled to Charlottesville Virginia in the USA, in October of this year, so that Bec could attend the Kluge Children's Rehabilitation Hospital. They run an intensive feeding program that would help to initiate the weaning process from her tube feedings.

The course lasted two weeks, but by the end of the first day, Bec was already eating more food than she ever had. When we left, we had managed to reduce Bec's dependence on her tube by 90%.

At the moment we are still giving her 200mls at night, as she has had a cold over the last couple of weeks and Bec always takes things to the extreme. While you would expect a cold to put a child off food for a couple of days, it put Bec off for a couple of weeks! She has now started to eat again, so hopefully sometime in the near future we will be able to stop the 200mls at night.

Rebecca has come a very long way in just a few months, and we are certainly further ahead than if we had stayed in Perth.

Carl and Maryanne Reid

### MEMBER PROFILES

#### Damon & Sharon Knott



We met while working at Perth's only Sunday Newspaper "The Sunday Times". We eloped to Las Vegas and married in The Little White Chapel, in 2007 we will have been married 9 years – time flies... We have 2 kids our beautiful daughter Chelsea-Rose and our Cherub Liam, oops forgot our other kiddies Holly –

**Sharon:** I'm home with the kids and dogs full time and LOVE IT... I enjoy going to the gym, cooking, going to the beach with the kids, listening to great music, shopping and being with my family, oh and I love a good drop of chardonnay.

**Damon:** I own a small business and love working for myself. I am fanatical about Christmas – love to spend hours decorating our house with lights etc each year. Love being with the kids and the wife and love drinking beer.

#### Maryanne and Carl Reid

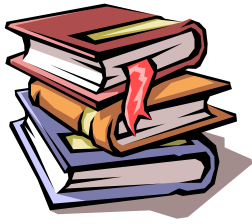


Carl and I have been married for 7 years. We met at a friend's 30<sup>th</sup> birthday, actually we were set up! We have two children, Rebecca 4yrs (LCDH) and Nicholas who is nearly two.

We live in Perth, where I grew up; Carl is originally from Kalgoorlie.

I am a registered nurse and am currently on maternity leave which runs out in January, Carl is an auto electrician and he is just about to finish a second apprenticeship to become an electrician.

Our lives have been a little restricted over the last few years as we have had a lot to deal with, with Bec not eating. Now that that is finally starting to resolve itself, we are looking forward to a more 'normal' family life without so many restrictions.



## From the Bookshelf

### In My Own Way - A Bereavement Journal

By Dianne & Mal McKissock

"...A beautiful and thoughtful alternative to sending flowers (or maybe as well)..."

If you don't know what to do for a bereaved person or you don't know what to say that will convey what you feel in response to their grief, Here is an answer - send them a copy of 'In My Own Way - A Bereavement Journal'.

This book, written by Dianne & Mal McKissock who are respected internationally for their innovative work with bereaved people, contains information on the experience of grief and directions for using the journal as a helpful part of the process. "Beautiful to look at and inviting to use. In My Own Way is the most thoughtful and comforting gift that will continue to be there, helping recovery, long after the flowers have faded and friends have dispersed"

Danielle Kessner



## Family and Friends

**Keeping A Diary** - Some people find keeping a diary is a good outlet for their mental health. Recording your feelings and your baby's progress can become an important part of your family history later. Whatever may happen, you can always look back and see how far you've come. You can get other people

to write in the book as well (e.g. grandparents, siblings, and partners). One of our members kept a diary whilst sitting beside her baby's bed, and with her permission, the night nursing staff would read her entries. They said it gave them an insight into the parent's feelings. This can be a wonderful way to vent your emotions. You could also write a letter to your baby!

Another way to do this is to set up a website. During your pregnancy you can keep an online diary, including pregnancy and ultrasound photos. After the baby is born, someone can update the website on a regular basis with photos and diary entries. This is not only therapeutic, but allows communication with all family and friends who have Internet access at once. Sometimes one of the parents manages it; sometimes another family member or a friend will do this for the parents. If someone else manages the website for you, there is still the option of writing the diary entries yourself. Simply type them up on your computer and send them to your 'website manager' who can do all the work from there. You will find lots of free websites around which are relatively user friendly for those who have no experience in this area. Simply type 'Free Websites' or 'Free Baby Websites' into your search engine to investigate the options and choose the one that best suits you.

Taken from the CHERUBS Australia "Expecting a CDH Baby" booklet by J Kjaersgaard, M Reid and N McErlean.

## CHERUBS Australia Needs You!

If you feel you can contribute to any of the jobs that need doing in CHERUBS Australia, please do so. Remember, any bits you can do, will lighten the workload of other members. Many hands make light work.

Everything done with CHERUBS Australia is done on a voluntary basis. To make sure this group will continue as it grows, we are going to have to think about sharing and rotating the jobs. So put your thinking caps on as to how you can help, and let's work together.

# CHERUBS AUSTRALIA FORUM Brisbane 2006

The sun shone on Friday, the day before our Cherubs Forum. We arranged to meet anyone who would be in town, to gather up at South bank Parklands. South Bank is a public area that has food galore, great areas of grass, kids' playgrounds and a wonderful free beachside pool, well protected by a lifeguard.

People started arriving around lunchtime. Before long we had several kids with several adults, eating a yummy lunch and looking forward to a swim in the pool. After lots of sunscreen and a few hours in the pool, it was decided we all meet for dinner in Browns Plains. In those few short hours we managed to gather a few more members, so dinner turned into a 20 person affair.

It was a perfect sunny Queensland day topped by a great dinner. Thanks to all those who came and made our Forum a very successful one.

Jo Kjaersgaard

Wow what a day, well done to all our Brisbane organizers. For those of you that were unable to attend the "Forum" in Brisbane this year it was at the Greenbank RSL on Saturday 19<sup>th</sup> October 2006. We all got to have a bit of a chat before our day got started. We met up with old friends and create new ones as well.

Once the kids went off to the Kids' Room we got settled into the first half of our day. We started off with a Welcoming from Jo and then watching a CHERUB Dedication where we saw photos of our CHERUBS whilst listening to a beautiful piece of music. We also had our child's name on a stick which we all stood in some sand

We had a guest speaker Dr Frank Carmody an Obstetrician / Gynecologist who had some very interesting information on Nuchal Translucency Testing. This test is done between 11 and 13 weeks of pregnancy. The aim of the test is to determine if you are at high **risk** of having a baby with a chromosomal abnormality. It does not **diagnose** an abnormality; it only finds those who are at high risk who may then opt for further testing. Dr Carmody also spoke of some of his other experiences within his practice. Dr Carmody stayed for morning tea and a chat.

Then we got the kids and had our group photo and scrapbooking time for those who needed to add their

CHERUB to the Album.

Then we divided into our groups for discussion time (Surviving and Grieving).

After lunch we put the kids back into the Kids' Room and we had a Surprise guest speaker to talk about their Journey. Much to our surprise it was Maryanne and Carl, they had just returned from the USA where they spent sometime in a Clinic with Rebecca and Damon and Sharon Knott and their son, Liam. The focus was to get their children to want and start to eat. They finally had success at the clinic and returned home to share this experience and to really put in place what they had learnt and accomplished. By 4 pm the day was drawing to the end we had a quick afternoon tea with the kids then the cleaned up the wonderful room we were able to use.

Lynda Viset



I would just like to take this opportunity to thank our Queensland members for organising a wonderful member forum. I had a great time catching up with old friends and was delighted to meet a number of new families. For the first time I sat with the surviving families during the group split which allowed me to develop a greater insight into the struggles some of these families face on a daily basis. Thank you to all the members for sharing their stories with me and increasing my knowledge of CDH. Can't wait until next year's forum rolls around!

Danielle Kessner, Victoria



## MEDICAL MATTERS

By Maryanne Reid RN

### Small Bowel Obstruction

This is one potential problem that can occur following the repair of a congenital diaphragmatic hernia and is caused by adhesions.

#### **Definition of Adhesions**

Adhesions are bands of scar tissue that bind together two parts of tissue that are normally unconnected. They can cause loops of your small bowel to “stick” together, which can pull the intestines out of place and can cause an obstruction. They are a common post operative complication following surgery that involves the abdomen, as scar tissue begins to form within hours of surgery as part of the body’s healing process.

#### **Symptoms of a bowel obstruction**

The majority of adhesions are painless and will not cause an obstruction, but if a bowel obstruction is suspected the following symptoms could be present.

- Crampy abdominal pain that can come in waves
- Vomiting
- Bloating and tenderness
- Inability to pass gas
- High pitched tinkling bowel sounds may be heard over your stomach
- Constipation or loose stools

The adhesions can cause either a partial or complete blockage of the small intestine. Small bowel obstructions can correct themselves, but if an obstruction is suspected you must see your doctor. If the obstruction progresses, further symptoms may develop. These can include.

- The pain becoming severe and constant
- No bowel sounds as bowel movement stops altogether
- Distended abdomen
- Fever

Perforation of your bowel which can cause peritonitis.

#### **Diagnosis**

Your doctor can order a number of tests to determine whether a small bowel obstruction is present. These include

- Abdominal X-ray
- Barium contrast studies
- Cat scan

#### **Treatment**

Sometimes adhesions go away by themselves and cause no symptoms. But for those that don’t resolve by themselves medical intervention will be needed. This can include the insertion of a nasogastric tube to relieve the distension that is already present, and prevent further bloating. The NGT can also help to relieve pain and nausea, and prevent vomiting. You would also have to fast and have IV fluids.

Surgery to divide the adhesions. This can be done using a laparoscopic although sometimes larger incisions are required to divide the adhesions.



This is an adhesion between loops of small intestine. Such adhesions are typical following abdominal surgery. More diffuse adhesions may also form following peritonitis.

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## STATE CONTACTS

### GRIEVING CONTACTS

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

### SURVIVING CONTACTS

State	Name	Phone Number	E-mail Address
NSW	Lynda Viset	(02) 4393 6454 (ph) (02) 4393 9372 (fax)	<a href="mailto:lynda@micromac.com.au">lynda@micromac.com.au</a>
Sth QLD	Joanne Kjaersgaard Ken & Wendy McKay	(07) 3372 8687 (07) 3882 2375	<a href="mailto:no_sew@bigpond.net.au">no_sew@bigpond.net.au</a> <a href="mailto:k_wmckay@samford.net">k_wmckay@samford.net</a>
Nth QLD	Judy Scherrenberg	(07) 4774 1535	<a href="mailto:jscherre@bigpond.net.au">jscherre@bigpond.net.au</a>
TAS	Sabine and Lindsay Kingston	(03) 6250 3493	<a href="mailto:barlou@bigpond.com">barlou@bigpond.com</a>
WA	Maryanne Reid	(08) 9309 2192	<a href="mailto:mpreid@bigpond.net.au">mpreid@bigpond.net.au</a>
ACT	Sandy Graham	(02) 6452 7390 0412 999 816	<a href="mailto:sandygraham@ripnet.aunz.com">sandygraham@ripnet.aunz.com</a>
VIC	Jasmine Burns		<a href="mailto:scottburns@optusnet.com.au">scottburns@optusnet.com.au</a>
VIC	Karen Vella	(03) 9748 9644	<a href="mailto:mkvella@optusnet.com.au">mkvella@optusnet.com.au</a>