



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

CHERUBS Australia Newsletter

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Summer/Autumn Edition

2006

From the President....

Dear Members,

Welcome to our first edition of 2006! I hope you enjoy our new look newsletter and CHERUBS Australia sends their appreciation to our newsletter editor, Wendy McKay for all her hard work J .

After a much-deserved break over summer, we are all slowly getting back into the swing of things. Work is continuing on booklets for surviving families and grieving families so please let us know if you are interested in contributing to either of these. Our website is still undergoing its revamp and should be up within the next month.

We hope to see lots of you at this year's CHERUBS Australia Annual Forum, previously known as the CHERUBS Australia Get Together. Further details can be found on page 5 of this newsletter.

Please read the letter on page 6 and complete the attached questionnaire to help our surviving cherubs get the most effective ongoing care.

Until our next edition J

Danielle Kessner – President, CHERUBS Australia

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

Sarah Hogg-Keeling
Justing Keeling
Baby Girl Mair
Noah Wiesel

NEW ARRIVALS

Liam Bolin (sibling to Kyan)
Leon McDermid
Georgia Coyle

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

Saskia Ericson
Joanne Kjaesgaard
Wendy McKay
Maryanne Reid
Judy Scherrenberg
Alicia Wood
Sabine Kingston
Chris Bowring
Fiona Rice
Karen Vella
Helen Harrison
Tabatha Barrett

*Before you were
conceived
I wanted you
Before you were born
I loved you
Before you were here an hour
I would die for you
This is the miracle of life.*

Maureen Hawkins



PRESS CLIPPINGS

The Australian, Wednesday April 19, 2006
From correspondents in New York
April 19, 2006

PREM BABIES 'NEED FLIGHT CHECK-UP'

AUSTRALIAN doctors said infants who are born prematurely and have impaired lungs should probably have their respiratory function checked out before being taken on a flight.

That's because more than 80 per cent of preterm infants with a history of so-called neonatal lung disease would require supplementary oxygen during air travel, according to a small study.

Air travel involves a low-oxygen environment, which is known to increase the risk that adults with respiratory disease will develop low blood levels of oxygen. However, relatively little is known about the oxygen requirements of infants with neonatal lung disease who are scheduled to fly.

To investigate, Dr GL Hall, from the Princess analysed data from 47 infants who had undergone

low-oxygen challenge tests as part of a fitness-to-fly assessment.

As described in the medical journal "Thorax", the children, who all had a history of neonatal lung disease, were given a nitrogen-oxygen mixture to breathe via a facemask, with the oxygen concentration set at 14 to 15 percent, for 20 minutes.

The normal concentration of oxygen in air is 21 per cent. Initially, blood oxygen levels in all of the infants were at more than 95 per cent of the saturation point.

During challenge testing, however, 38 of the infants had levels that fell below 85 per cent of saturation, a point at which supplementary oxygen would be indicated, the report said.

The younger children were more likely to fail the low-oxygen test and require supplemental oxygen, the researchers said.

Further information is needed, they said, to determine "the clinical significance of failing current guidelines for safety during flight for infants with a history of neonatal lung disease".

From Neonatal News. The Royal Children's Hospital, Melbourne. Autumn 2006. Edition One. Page one.

Our achievements.

...We provide the best outcomes in the country for a condition called Congenital Diaphragmatic Hernia. This is where a baby is born with a large hole in the diaphragm resulting in the intestines being present in the chest thus compressing the lungs. The condition requires the combined skills of neonatologists, nurses, cardiologists and surgeons. Our outcomes for this previously lethal condition are second to none in the world. Survival of this condition provides a normal life for these babies..."

From the Melbourne Herald

The following article appeared in the lead up to the Royal Children's Hospital Good Friday Appeal.

Excerpt from "World Leader Saves Tiny Levi"

Melbourne doctors are saving a record number of babies with diaphragmatic hernias.

Continued on next page...

Royal Children's Hospital neonatal experts believe their way of treating these newborns is the best in the world.

Each year they treat five to 10 babies with the potentially fatal hernia. From 1981 to 2003, children with diaphragmatic hernias had a 66% chance of surviving.

In the past three years survival rates have soared to 97%. Dr Michael Stewart said no other hospital had reported such high survival rates.

By reducing the oxygen and increasing the carbon dioxide, babies' lungs were protected and their breathing was restored faster. Dr Stewart said the hospital also used a drug called prostaglandin E1.

"There's an enormous effort put into looking after these babies. A lot of them are diagnosed during pregnancy, so it's a long journey for the mothers and for the babies," he said. "A 87% survival rate is unheard of anywhere else, so it's pretty exciting."

The research was presented at a Perinatal Society of Australia and New Zealand conference in Perth yesterday.

CHERUBS Australia wishes the following cherubs a very happy birthday.

Harlee Timms

Chloe Towne

Kelsey Glindeman-Smith

Rebecca Reid

Arti Hodgson

Paul Noble

Kirra Graham

Nathan Clarke

William Tripodi

Natalie Whittle

Bailey Viset

Tory Piperno

Anna Fogarty

Fallon McClelland

Claire Oakley

Dain Kingston

Jackson McKay

Henry Nancarrow

Justin Keeling

Jack Augustson

Liam Knott

Louis Ericson

Jack Burns

Ariana Kjaersgaard

Madeline Dryburgh

Hayley Ginns

Angus Matsen

Sebastian McErlean

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

Noah Kelly

Alec Bonser

Brodie Bennett

Jonathan Kilby

Jack Willshire

Harry Tabernal

Matthew Bailey

Sean Eason

Brayden Ross

Emma West

Hannah Bowring

Leon McDermid

Scarlett Bailey

Maddison Carroll

Joshua Baker

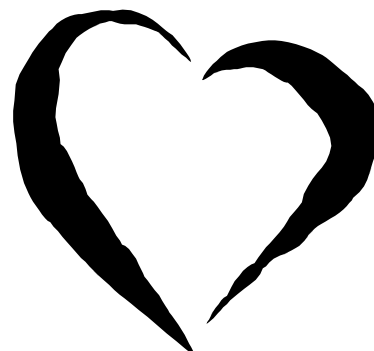
Lysa Ienco

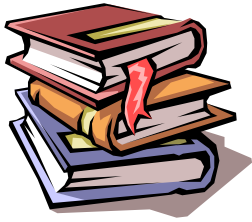
Max Logozzo

Kyan Bolin

Alyssa Kessner

Rowan Keating





From the bookshelf...

Expecting Adam by Martha Beck

Penguin Publishers

Review by Amy Coffin

Expecting Adam documents Martha's extraordinary pregnancy. The Becks were already experiencing many personal difficulties when they found their unborn child had Down Syndrome.

Martha writes candidly about her feelings during this time. She also discusses the reactions and perceptions of others. Relatives had a hard time accepting the diagnosis. Medical personnel and Harvard colleagues didn't think Adam should be born at all.

As readers, we see the dramatic change in the couple's perception of what's important in life. The author goes back and forth between her pre-Adam and current outlook. The birth of this special child made the couple realize that multiple college degrees did not provide the happiness they were seeking. As readers, we learn the family gave up the Harvard academic life and moved closer to their families. They credit Adam for showing them what mattered most in this world.

Beck's memoir is poignant. Humour flows freely and makes the story shine. Beck's words are refreshing. You don't have to be a parent to be moved by her story.

With absolute wit and grace, Martha Beck tells a very inspirational story.

Editor's Note: I loved this book. I read it during my pregnancy with the twins and I found that although the diagnosis was different, Martha's roller coaster ride was parallel to my own.

Listserv Courtesies

Welcome to the new members of Cherubs Australia and a hearty greeting to all our 'oldies'. As the group grows larger, now would be the time to go over some things that will see this group moving along with its growing size. Love that old adage about prevention being better than the cure, so please take the time to read the following regulations.

We love our listserv and to keep it rolling along as it gets busier, we'll need to keep these things in mind.

1. Please remember to be courteous to other members and respect their opinions.
2. Write your story and submit it to the web site. That way, when new members arrive, we can write a short introduction about ourselves and then direct them to the web page.
3. Exchanging information/keeping up to date and in touch on the listserv is fantastic. However, if you find someone you want to chat with, exchange email addresses to keep the listserv traffic down and topics on track.
4. NO swearing or derogatory comments are allowed.

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.

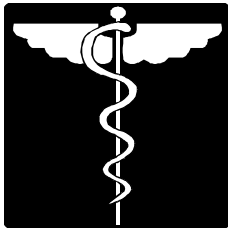


Family and Friends

Often family and friends want to help us but don't know how. The aim of this section is to provide advice for all those wonderful people who encircle us with love and support.

- LISTEN! You don't have to say anything, just lend an ear and a shoulder.
- Avoid saying things like "I understand", "It's God's Will", "You just have to accept it and move on", and other clichés and "words of wisdom". Stay positive and respect the parents' decisions and feelings.
- Offer rides to the hospital, babysitting for siblings, doing laundry, cooking meals, cleaning, picking up mail, making phone calls etc.

Taken from the CHERUBS Australia "Expecting a CDH Baby" booklet by J Kjaersgaard, M Reid and N McErlean.
<http://www.pdf4free.com>



MEDICAL
MATTERS
By Maryanne Reid R.N.

Feeding Difficulties

Babies born with a congenital diaphragmatic hernia, have the potential to develop feeding problems. The main causative factors include ventilation time, the amount of suctioning required, oversensitive gags, gastro esophageal reflux disease (GERD) and oral motor developmental delays, all which contribute to negative associations with the babies' mouth.

Babies who need frequent suctioning while ventilated, are ventilated for extended periods of time and/or experience pain while feeding as a result of having GERD, can develop an oral aversion which will result in feeding difficulties of differing levels.

Some may be "fussy" feeders, who take a lot of convincing to bottle or breastfeed, to those who will refuse the bottle or breast altogether. The introduction of solids may also fail, as the baby is still very defensive when it comes to having something placed in its mouth.

In conjunction with being very defensive with feeding due to pain, some babies may also have oral motor developmental delays that will impede on the babies ability to feed (bite, chew and swallow). An evaluation by a speech therapist experienced in feeding difficulties is needed to assess the baby's oral motor development before effective strategies to help the baby overcome its feeding difficulties can be implemented. Occupational therapy, clinical psychology and dietetics, along with the babies' doctor could also be used to help deal with feeding problems.

The references below discuss in greater detail feeding issues and how they can be resolved.

Elliott C, Clawson S and Bishop A .2003. Strategies for Treating Children with Severe Oral Aversion.
http://www.childrenshosp-richmond.org/professionals/articles/strategies_for_treating.htm

Ashland J. Infants and Young Children Gagging on Textures: Dysphagia or a Sensory Problem.
http://www.massgeneral.org/pcs/heal_lang_art2.htm

Fishbein M, Cox S, Walbert L and Fraker C.
Comprehensive Treatment of Feeding Aversion in Children.
<http://www.empoweredparents.com/pickyteating/pickyteating7.htm>

CHERUBS Australia!

I am seeking much needed help to get our group 'officially' recognised and able to accept donations, conduct fundraising etc.

I have looked into this quite a bit over the past years and always felt overwhelmed and confused as to the best way to go about it. After thinking long and hard I believe the best way to tackle this is to form a small committee of interested and dedicated families - ideally, we would have families from across Australia involved. This way the workload can be evenly distributed and each committee member will only have to give up a small amount of time and effort.

For our group to move forward and achieve what we want to, it is vital that we make these next steps. Any and all help will be greatly appreciated. If you are even remotely interested, please let me know. I will discuss this in greater detail with all interested parties and then you can make an informed choice on whether you are able to help or not. From there a committee will be formed and we can really get things moving.

Thank you so much to you all for the support given to our group over years.

Danielle Kessner
President

CHERUBS Australia would like to invite all of its members to the

**CHERUBS Australia
Annual Forum for
2006**

Date : October 28 & 29, 2006

Where: Sunny Brisbane

More details to follow soon.

Community Awareness.....

Hi All,

Just wanted to let you all know that there will be an article about CDH and my cherub Arti in the July edition of Notebook magazine.

The opportunity to do this came through some work contacts of mine, and once approached, I have to admit to not being too keen to take part. Being not too fond of the limelight, I agreed to do it so that affected families may gain some acknowledgement, and help our 'communities' get a better understanding of how deeply it affects us all.

Yes, I feel very guilty about boasting about my miracle baby. But after confronting some of my survivor guilt, and counselling some very knowledgeable experts on the subject :), I think it's OK to say 'wow'.

The article is part of the 'Turning Points' section of the magazine, and you'll find the story (and me looking very uncomfortable in a huge woolly jumper in a 40 degree studio), in early June.

I apologise if the article causes any heartache to those members on the listserv whose Cherubs didn't survive. My heart was firmly in my throat with thoughts of you when I was interviewed and photographed. I struggled with doing it for fear that it would cause you pain. But I also did it in the belief that it may help us all. Somehow. In some small way.

Tabatha - Arti's mum LCDH 15th Dec 2004

Special Note: this story will also be able to be read online at www.notebookmagazine.com.au from the on-sale date (early June).

We will include the article in our next edition for all members not online.

Editor's Note:

Hi Everyone

I hope you enjoyed this new newsletter format. Please feel free to email me with suggestions/submissions for future editions. My email address is

K_wmckay@samford.net

If your Cherub's name has been omitted please accept my sincere apologies and email me asap with relevant details so that our records are kept up to date.

On the following page you will find details of our state contacts. If you are interested in becoming a state contact, please email Danielle so that she can forward information to you. I will begin to collate information for the next

edition immediately so please send in all material as soon as possible.

Thank you so much to all of those members who sent in news articles and stamps, wrote columns and generally helped me with ideas. We cannot achieve any of this without you.

Wendy

CDH Study

Dear Parent,

The management of congenital diaphragmatic hernia remains a significant challenge with considerable mortality and morbidity despite modern intensive care techniques. To date, survival has been the main focus of research but increasingly the emphasis is shifting to the long term complications for these children. Historically these children have received follow-up in surgical clinics where the focus has been on the actual surgical repair. Other medical care has been fragmented. Some investigators have recommended the establishment of multidisciplinary clinics comprising paediatric surgeons, neonatologists or intensive care specialists, developmental specialists, nutritionists, respiratory physicians, occupational therapists and dieticians. Proponents of such clinics argue that this is essential to provide overall care for what is a very complex condition and thereby improve the long term outcome of the children and their families.

We are commencing a multidisciplinary follow-up clinic at the Children's Hospital at Westmead and to help us cater for the needs of children who have undergone surgery for a congenital diaphragmatic hernia we would be grateful if you would complete the attached questionnaire.

Please email Pip with your completed survey on pjam5193@med.usyd.edu.au

If you prefer to mail it to us then the best address is

Nadia Badawi
Department of Neonatology
Children's Hospital at Westmead
Locked Bag 4001
Westmead NSW 2145

Thank you for your help,

Nadia Badawi
Phillipa Jamieson
Consultant Neonatologist
Medical Honours Student
Clinical A/Professor
University of Sydney
University of Sydney

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

SURVIVING CONTACTS

State	Name	Phone Number	E-mail Address
NSW	Lynda Viset	(02) 4393 6454	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

NB

1. If you wish to be added to this list of contacts, please email your relevant details to kessam@tpg.com.au
2. If you are on this list, please double check all details and email any corrections to the above address.