



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

CHERUBS Australia Newsletter

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From the President....

Dear Members,

Welcome to our second edition of 2006!

The new look for our newsletter was well received after our last edition and I am sure you have all been eagerly waiting this second edition. Wendy (editor) has come up with another great idea - to profile members so we can all get to know each other a little better. I look forward to learning more about our members in the future. Please remember to send in contributions for our newsletter – articles you may have seen, reviews on books you have read, etc.

There is only 6 weeks until our annual member forum. I am looking forward to meeting lots of our members and catching up with those I have previously met. Watch out in our next edition for photos and accounts from this special event.

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.

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

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

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.

There is a grief that ages the face and hardens the
 heart
 Yet softens the spirit....
 A grief that casts shadows on the eyes
 Yet broadens the mind....
 A grief that keeps the pain and has no words
 But increases the understanding....
 There is a grief that breaks the heart
 and wounds the soul,
 That lasts and lasts
 and can shatter in a minute,
 But will inspire for a lifetime

-Laura



CHERUBS Australia wishes the following cherubs a very happy birthday.

Thomas Nash
Lisa Warnock
Anthony Moschilla
Abigail Neu
Benjamin Bogdanovic
Adam Vella
Rani Costello
Kirsten Burgess
Eva Walton
Blake Merrick
Celeste Spadaro
Rhiannon Smith
Nadia Gould
Harrison Lovell
Alex Bennett

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

Blake Hanlon
 Rowan Keating
 Chloe Mitchell-Greenfield
 Scarlett Bailey
 Isaac Pedler
 Henry Faure
 Rhian Robilliard
 Lachlan Wood
 Damien Smith
 Alec Bonser
 Ellie Mair

**CHERUBS Australia
 National Forum - 2006**

Brisbane

October 28/29

Have you:

1. advised Jo of your attendance?
2. booked your accommodation?
3. sent your updated photo of your CHERUB?

If you have already indicated your attendance, you should have received your Forum package. If you have not, please email Jo/Wendy and it will be sent to you.



PRESS CLIPPINGS

*As stated in our previous newsletter, one of our members, Tabatha Hodgson, was asked to contribute a story for **Notebook** magazine. Here is the article for those who missed it.*

Tabatha Hodgson discovered five months through her second pregnancy that her unborn baby had a rare medical condition and might not survive.

“Our first daughter, Hunter, was born in 1998. About four years later, I became pregnant with Arti. My initial ultrasounds all indicated a fit and healthy baby, but in my 20th week, I knew something was wrong just by looking at my radiographer’s face. She left the room hurriedly and reappeared with a doctor who explained that my daughter had a hole in her diaphragm. In normal foetuses, this hole closes after ten to twelve weeks, containing within it organs such as the stomach, intestines, liver and spleen. My baby’s abdominal organs, however, were where her heart and lungs should be – a condition called Congenital Diaphragmatic Hernia that affects about one in every 2500 pregnancies.

I was dispatched to another hospital and put in the hands of a specialist midwife who explained in detail what my husband, Stuart, and I were to expect.

The first issue we had to come to terms with was whether or not to terminate. We were told our baby’s chance of survival was 50/50. If she survived, she would be put on life support immediately; we wouldn’t be able to hold, feed or cuddle her. Once stabilised, she would have to undergo a risky operation to close her diaphragm. It was made abundantly clear to us that CDH involved many complications and we were told to hope for the best, but also, realistically, to plan our baby’s funeral.

Stuart and I digested it all and decided to discuss the termination only after we’d drawn our own conclusions. When we sat down to talk a week later, St said ‘I want to give her a chance’, and I said, ‘Good, so do I’. And that was that.

Arti was born nine weeks premature. She weighed 1.37 kg and measured 34 cm. She went straight on to morphine and a ventilator and had her operation about two weeks later. After her operation, she became seriously ill. The diagnosis was Necrotising Enterocolitis, a serious gastrointestinal disorder that destroys the bowel and mostly affects premature infants. Once again, we were told Arti’s prognosis was poor. My life became a series of basic increments: I would express milk; drive to hospital; visit Arti and sleep.

Miraculously, Arti survived NEC, but then she had a golden staph infection - twice. She also had two brain bleeds, gastroparesis (delayed emptying of the stomach) and three cardiac arrests. I’m not sure how Stuart and I held it together, but we did. Stu took care of Hunter; I was with Arti almost every waking moment. We also had CHERUBS which was amazing.

Arti spent 35 days on ventilation and 42 days in ICU. On day 45, she attempted her first breastfeed and after that she flew through many ‘firsts’. At her final check-up, the surgeon said he’d never seen anyone like Arti before. He’d given her no chance of survival; did I realise most CDH babies didn’t live? He then said Arti was ‘perfectly healthy’ and, apart from some missing lung, ‘completely normal’. He even used the word ‘miracle’.

Walking though the hospital doors with Arti to the car park was cathartic, but also weirdly sad. Arti and I were smiling then, as we were leaving, a chopper came in to land. Someone else’s life had just changed for the worse and, like us, their life would never be the same again.

I’ve always known that family is the most important thing in life, but after what happened to Arti, I have the evidence. It’s amazing how simple life is when someone you love could die. Thank heavens, Arti is as tough as boots and pulled through. For that I’m forever grateful.”

MEMBER PROFILES



Danielle Kessner
CHERUBS Australia
President/Founder

I am married to Julian and we have had three children; Alyssa (our cherub 21/05/92 – 22/05/92), Tara (almost 13) and Ethan (10). We live in a relatively small town in Gippsland Victoria.

I am currently working full-time doing administration work in a Quality Assurance department for Melbourne's Eastlink Motorway project.

I enjoy going to the gym and taking long walks. I am an avid reader and love to watch good movies. I gain a tremendous amount of satisfaction from my volunteer work for CHERUBS Australia and love to hear all about everyone's gorgeous cherubs.

I love life and intend to make the most of mine while I am here J



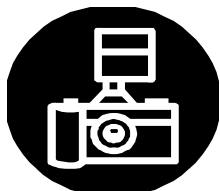
Joanne Kjaersgaard

I'm married to a man named Lars, and we've managed to produce 5 children (can't believe it myself!). As I write this they are; Yolanda (20), Tarni (18), Ariana (the wild child, LCDH, 16), Minya (stillborn, 1992) and Ryan (10). We live in Forest Lake, a suburb of Brisbane.

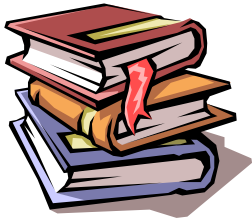
I like to think of myself as a goddess, though not a domestic one (obviously from the state of the house). I earn money being a sign language interpreter, a dog obedience instructor, and a cheerleading coach.

I have to play tennis once a week for sanity reasons and I have delusions of being an amateur photographer. I love scrapbooking when I can get to it and I will occasionally attack the garden with gusto and then let it all weed over again.....sigh.....oh yeah, and I don't get on with the computer that much!

I have helped out in Cherubs where I can and I've been happy to do so. When I was pregnant with Ariana 17 years ago, there was no support of any kind, so to see this group grow and help others is a real pleasure.



Have you sent in a photo of your CHERUB for the Forum?



From the Bookshelf

Coping With Grief

Mal McKissock and Dianne McKissock

Paperback Book \$11.95 Available from ABC shops (can be ordered online) and other bookstores.



Coping with Grief by Mal McKissock and Dianne McKissock is a small, but powerful book that describes the grief process, what one can expect during one's grief process.

The book describes normal grief, managing anniversaries and special dates, physical and emotional reactions, the funeral, gender differences in grief, children and grief, sexuality and grief, consequences of bereavement, support teams, self-help, and community education.

It is a self-help manual that offers information that would be useful for those who are facing grief and those who work with them.

Pages: 64
Released: 2006

I have found this book to be very useful. I have loaned it out to friends and bought another copy for my parents to keep. Written by an Australian team, clear and easy to read, I would highly recommend this book for parents, family, and friend.

Joanne Kjaersgaard

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.



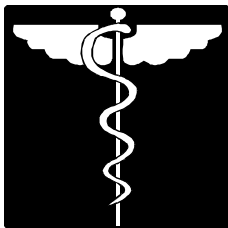
Family and Friends

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.

- **Encourage** the parents to talk about how they feel, but don't push them too hard.

- **Realise** that the parents will need support, comfort, and help for many years, not just weeks.
- **Ask** questions, find information, seek support for the parents- but realize that there are certain boundaries.
- **Bring** food, books, and magazines to the hospital.
- **Take** pictures, videos, and help the parents to accumulate mementos.

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



MEDICAL MATTERS

By Maryanne Reid R.N.

Medical Terms

Arterial Blood Gas (ABG): a sample of blood taken from an artery that allows the medical staff to analyse the gas exchange in the lungs. They are looking at the amount of oxygen, carbon dioxide, and acid in the patient's blood. These measurements are used to determine how much ventilation support is needed. Normal ranges for ABG's are:

- Partial pressure of carbon dioxide (PCO₂) is 35-45mmHg.
- Partial pressure of oxygen (PO₂) is 80-100mmHg.
- Saturation of haemoglobin with oxygen (SaO₂) is 96-100%.
- Bicarbonate (HCO₃) level is 22-26mEq/L.
- pH is 7.35-7.45

Agensis of the Diaphragm: complete absence of the diaphragm.

Alveolus: air sac in the lung.

Amniocentesis: A fine needle is inserted through the mother's abdominal wall and into the amniotic sac, where a small amount of fluid that surrounds the embryo is withdrawn, to test for genetic abnormalities.

Analgesia: medication given to provide pain relief, such as paracetamol (panadol) or morphine.

Antibiotic: a medication given that prohibits the growth of, or destroys micro organisms that cause infection.

Artery: a blood vessel that carries blood away from the heart.

NEWSLETTER SUBMISSIONS

Please send all submissions directly to Wendy at k_wmckay@samford.net

I will be emailing members soon to collate information on profiles for the next edition. Please feel free to say no. However, it is nice to be able to put a face to a name when reading on the listserv.

For the next edition I particularly need submissions for the Book Shelf and Press Clippings.

If you have any suggestions for this newsletter, please don't hesitate to contact me. I'm open to all ideas.

Also, if you find any omissions or errors, please let me know so that I can correct them.

Hope you enjoy this issue.

Wendy

"Hope is the only bee that makes honey without flowers."

Robert Green Ingersoll



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