



*Supporting families and
medical professionals
along their CDH journey*

CDH Australia Newsletter

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Winter issue

2010

From the President....

A lot of exciting things have been happening for our group so far this year. We officially became CDH Australia on 23.03.2010. The impetus for changing our name came about for a couple of reasons.

- 1.) We are in the process of having a new website built and felt it was a good opportunity to increase awareness of our existence by changing our name and branding to something that is easily recognisable and remembered for new families and medical professionals seeking information and support in our region. CDH Australia clearly states that our group is for people affected by CDH, whereas our experience in Australia has shown that the name CHERUBS requires explanation as to what it stands for and is harder for people to remember the connection.
- 2.) There was also some confusion amongst families about the organisational relationship between CHERUBS, CHERUBS UK and CHERUBS Australia. We operate as separate groups yet families often believe if they are a member of one group they are a member of all three groups. One of our aims as an organisation is to increase membership and we believe by having an independent name, it will be obvious that we are a separate organisation and therefore have separate membership.
- 3.) Our name change will not affect the way in which our organisation operates in any way or our objective to continue working with other CDH organisations to advance research on CDH treatments and support. We would like to thank CHERUBS for the support shown to us during the setting up our group CHERUBS Australia Organisation and we will continue to fondly call our CDH children 'cherubs'.

We were hoping our new website would have been up and running by now but we have been very careful to ensure all aspects are set up correctly from the start. This has caused a

delay but once it is up and running I am sure you will all be very impressed.

This year's CAAF will be held in Brisbane and should be a wonderful event to attend. You can find all of the relevant information in this newsletter. We hope to see you there.

We have plenty of room left within our group for volunteers. If you are interested in helping contact our Volunteer Coordinator Shaz (volunteer@cdh.org.au) who will be able to fill you in on the different roles that are vacant.

Until our next edition ☺

Danielle Kessner – President, CDH Australia
president@cdh.org.au

Thank You!

The Board of Directors would like to thank the following people for their hard work and support:

Joanne Kjaersgaard
Damon Knott
Kevin Lizars
Angela Logozzo
Wendy McKay
Rebecca Mills
Caron & Frank Mugica
Karen Vella
Amanda Vidic
Linda West
Alicia Wood

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. CDH 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 by contributors to this web site are their personal views are not necessarily the views of CDH Australia, or its members or staff.

Membership

Membership to our group is separate to membership with the International group of CHERUBS. We charge a membership fee of \$20 per annum to help cover the administrative costs of maintaining our group. We do not want to use donations and fundraising to cover day to day items such as postage – we feel these funds should be spent on supporting families and research efforts. Membership fees are not tax deductible. We can only provide tax deductions for donations under our Deductible Gift Recipient endorsement. Membership fees will be re-evaluated at the end of each financial year by the board of directors to determine if we are able to reduce this cost.

For more information on our membership please email us at membership@cdh.org.au or visit our website: <http://www.cdh.org.au/membership.htm>

CDH Australia would like to welcome its newest member:

Danni Downie
Sophie Franet
Simone Ramsay-Spence



CDH Australia wishes all our Cherubs who have recently celebrated a birthday or who have an upcoming birthday, a wonderful day!



CDH Australia is thinking of all angel cherubs and their families on their birthdays and anniversaries!

Fundraising for the CAAF

Calling out to our Queensland members! Help make our CAAF in Brisbane this year a great event by helping us raise money to fund the forum. Some of the things you can do to help out are:

- Sell fundraiser Cadbury chocolate or Jolly Goat Coffee
- Host a social event:
 - trivia night
 - cinema night
 - morning tea.
- Arrange a casual clothes / fancy dress day at your work or school for a gold coin donation
- Participate in an organised public event – fun run, marathon, triathlon, cycling course, and ask people to sponsor for your efforts through donations to our website.
- Come up with other great ideas to fundraise!

Every little bit helps. For further information and help with your fundraising efforts please email Margaret Polacska (Fundraising Coordinator) at fundraising@cdh.org.au.



Member's Profile

Hi! My name is Kath Murphy and I've recently taken over as Treasurer for CDH Australia.

I live in Tintenbar on the far north coast of NSW (near Byron Bay).

My husband Peter and I have four beautiful children, Sam – 10, Hannah – 8, Zac – 5 and our angel cherub, Jessica Kate, (born sleeping 9th September, 2008).



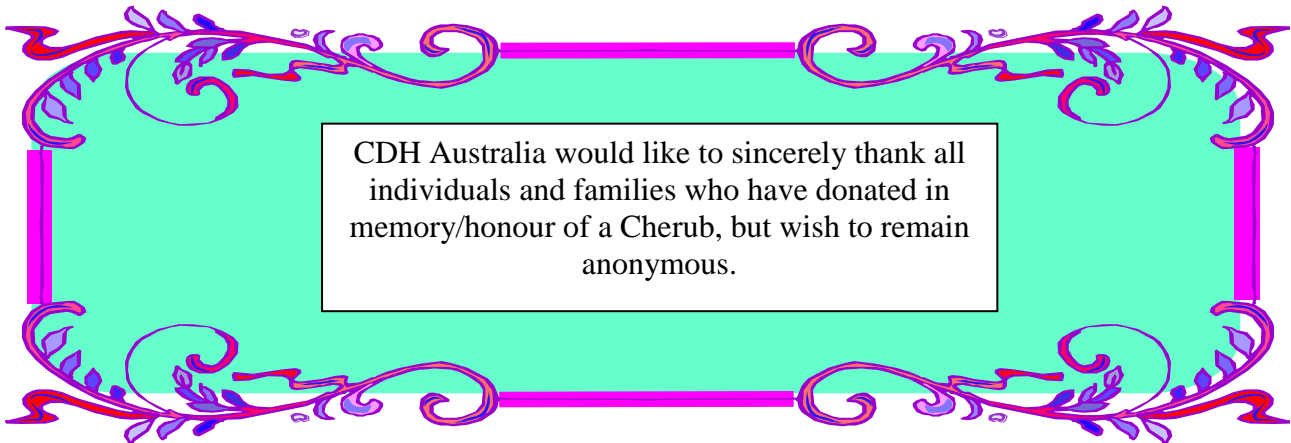
I recently attended my first CAAF in Melbourne, which was fantastic. I met so many amazing people and was able to put faces to names finally, which was lovely. We had a great time and I look forward to seeing those familiar faces as well as some new ones, in Brisbane this October.

Donations

CDH Australia would sincerely like to thank the following people for their contributions. A special thank you goes out to Frank and Caron Mugica, parents of angel Cherub Oskar, for their incredible efforts in raising over \$5000.00 in memory of Oskar.

J & D Kessner	In memory of Alyssa Catherine Kessner	In memory of our beautiful daughter, Alyssa
United Way	In honour of Gabriel Reza Kia	
Barry Quirk	In memory of Alyssa Catherine Kessner	Our beautiful baby granddaughter - loved forever.
Damien Arboit Progressive Wealth Solutions	In memory of Oskar Matteo Mugica	
Amber Kite	In memory of Lewis Moore	Lewis you were a strong little baby, right through your mum's pregnancy, birth and beyond. Ingrid, Anthony and Harry, we know that Lewis will always be with you and a part of your family. Much love, The 16-30th Due In Group
Margaret & Lorre Polacska	In memory of Noah Polacska	In loving memory on Noah's second angelversary.
McCathie's Real Estate	In memory of Oskar Matteo Mugica	
Eileen & Jenny List	In memory of Oskar Matteo Mugica	
J & D Kessner	in the name of Bob Kessner	In memory of your beautiful granddaughter Alyssa Kessner
J & D Kessner	In the name of Tara Kessner	in memory of your beautiful sister Alyssa Kessner
J & D Kessner	In the name of Barry & Gae Quirk	Merry Christmas in memory of Alyssa
????		
George Fotinos Chemist	In memory of Oskar Matteo Mugica	
BQC Quarries	In memory of Oskar Matteo Mugica	
John Honeycombe	In memory of Oskar Matteo Mugica	
Home Hill Stockfeeds	In memory of Oskar Matteo Mugica	
Larry Hudson Engineering & Welding	In memory of Oskar Matteo Mugica	
Tony Castrejana	In memory of Oskar Matteo Mugica	
Tanya McConnell	In memory of Lily Allison Downie	In loving memory of our precious niece & cousin. Love Aunty Tanya, Uncle Stuart, Brayden & Keely

CBA - Arana Hills	In memory of Lily Allison Downie	
Sunnybank State High School	In memory of Lily Allison Downie	
Susan & Les Peterson		
Alexis Vella & Gloria Downie	In memory of Lily Allison Downie	In loving memory of our great niece and great granddaughter
Ayr Rotary Club	In memory of Oskar Matteo Mugica	
Ayr Lions Club	In memory of Oskar Matteo Mugica	
Bill Buckby	In memory of Oskar Matteo Mugica	In loving memory of Oskar Matteo Mugica, and in the heartfelt and loving support of his parents Frank & Caron Mugica.
Joyce Tough	In memory of Lily Allison Downie	
Jand & Kevin Smith	In memory of Lily Allison Downie	
Val & Keith Mills	In memory of Lily Allison Downie	
CSR Sugar Burdekin Region	In memory of Oskar Matteo Mugica	
B. Jackson	In memory of Oskar Matteo Mugica	In loving memory of Oskar. Love Nana and Grandad



CDH Australia would like to sincerely thank all individuals and families who have donated in memory/honour of a Cherub, but wish to remain anonymous.



Calling all volunteers!!!

Are you interested in volunteering? If anyone is interested in helping out with projects we will be working on from time to time, please contact our Special Projects Coordinator Ali Moxham.

alison.moxham@med.monash.edu.au

State Social Groups

One of the things we learnt at this year's CDH Australia Annual Forum (CAAF) is how important exercising, eating well, getting adequate sleep and having peer support are when dealing with the stresses of trauma and grief. So to put this concept into practice we are organising social groups for our CDH families around the country to encourage exercising and chatting with each other. Our new Volunteer Coordinator, Sharon Knott, is currently working with our State Contacts to get in contact with our families. The aim is to get a group started in each area where we have a number of people interested to meet up at the same time each month to walk around a designated track and enjoy a picnic lunch together. We hope this is an initiative that takes off as it's a great way of extending the support we offer each other at our annual forums to a more regular and sustainable activity. And what better way to exercise than in a group where you can chat along the way and before you know it you've worked off that irresistible chocolate bar.

For further information please contact our Volunteer Co-ordinator, Shaz on volunteer@cdh.org.au

NEEDED – STATE CONTACTS for

Victoria – Grieving
 South Australia – Surviving
 Tasmanian – Grieving
 ACT – Surviving
 Outback – Grieving
 Northern Territory – both



CDH Australia, on behalf of its members, would like to send a huge THANK YOU to *Sharon Knott* and *Angela Logozzo*. Both ladies were the Australian co-representatives for CHERUBS and have had to relinquish their positions due to personal reasons. During their time as co-representatives, Ang and Shaz volunteered tirelessly to support Aussie families. They have done amazing jobs and we are so proud of them. Thank you Ang and Shaz for being the kind and caring people you are!

A Father's Perspective

By Julian Kessner, dad of Alyssa Kessner
21st – 22nd May 1992



I guess in some ways I'm the stereotypical man when confronted with stressful situations. I try to bury my head in the sand and not give too much thought to the issue by trying to forget or ignore it rather than confronting it. This was me for about 16 years after Alyssa, my first child, passed away due to CDH in 1992.

Last year as part of a holiday to the USA my wife Danielle and I attended the CHERUBS conference in Texas. I thought that I would attend maybe just one or two sessions/presentations being initially reluctant to get involved, particularly in the discussion groups. To my surprise I found it to be a great experience and of great benefit to myself, almost like a pressure had been released from inside me. Listening to the doctors and guest speakers was informative and gave me great insight into CDH, something I knew little about despite Alyssa having been born with it. Much to my amazement I even participated in the group discussions, something I thought I wouldn't do and I also found these to be of great benefit.

One year has since passed and I have also attended the CDH Australia Annual Forum in Melbourne last year. I found this to be even more enlightening and informative, no bias there at all! One of the main things I have gained is that my experiences can be of help to others which makes me happy that I have attended these forums.

I have found myself thinking more about my beautiful daughter Alyssa and I am looking forward to being a part of the Brisbane CAAF in October. I wish I had started attending the CAAFs years ago but better late than never. If there are any dads out there who are unsure about attending a CAAF I would highly recommend that they give it a go. There is no pressure to contribute to discussions if you don't want to and you are always free to leave and go for a walk if you need to.

Victorian CDH Sunday Lunch

On Sunday 27th of March, a number of our Victorian families gathered for our first CDH Sunday Lunch. We had a total of 23 people meet at a restaurant with a great indoor playground for the kids, and a great pool room for the big kids (the dads)! It was an amazing turn out considering many families have sick children at the moment. We all had a lovely time and it was a great chance for families to share their CDH experiences. We will be planning a picnic lunch at a park for summer, and we've had so much interest from families we think we may need to schedule a gathering for Spring!





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10th Annual Forum 2010

15 October: AGM 4pm start followed by a social drink and dinner

16 October: Medical and support workshops 9:00am – 4.30pm
Venue: Chermide Library, Hamilton Road, Chermide
The library is behind Westfield Chermide Shopping Centre which is on Gympie Road, Chermide
Dinner - Kedron Wavell Services Club 6pm

17 October: Family fun day - Australia Zoo 9:00am – 4:00pm
(transport will be provided)

Accommodation: Our Accommodation of choice for the CAAF is:

The Chermide Apartments

Please mention CDH Australia when booking as a medical group discounted rate applies.

www.thechermide.com.au
self contained PLUS a gorgeous pool
22 Thomas St Chermide
1800 829 291 07 3123 5600

If you would like further information on the CAAF or to find out about other accommodation options
Please contact Linda West: linda.west@cdh.org.au or Sharon Knott: volunteer@cdh.org.au

information@cdh.org.au
CDH Australia ABN (60 131 315 145)

STATE CONTACTS – GRIEVING

State	Name	Phone Number	E-mail Address
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Sth QLD	Linda West	(07) 3886 9170	linda.west@cdh.org.au
SA	Helen Harrison	0427 059 104	helen.harrison@cdh.org.au
VIC	Danielle Kessner	(03) 5135 6999	danielle.kessner@cdh.org.au
WA	Lisa Bonser	(08) 9203 7204	lisa.bonser@cdh.org.au
North Qld	Robyn Mills	0412 089 189	robyn.mills@cdh.org.au
ACT	Rebecca Mills	0420 524 550	rebecca.mills@cdh.org.au

STATE CONTACTS - SURVIVING

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Sth QLD	Joanne Kjaersgaard	(07) 3372 8687	joanne.kjaersgaard@cdh.org.au
Nth QLD	Judy Scherrenberg	(07) 4774 1535	judy.scherrenberg@cdh.org.au
TAS	Sabine and Lindsay Kingston	0419 578 495	sabine.kingston@cdh.org.au
WA	Maryanne Reid	(08) 9309 2192	maryanne.reid@cdh.org.au
VIC	Karen Vella	(03) 9748 9664	karen.vella@cdh.org.au
Outback	Mel Nicol	(08) 8091 6626	mel.nicol@cdh.org.au