

KEEPING
IN
TOUCH



DECEMBER
2010

Cornelia de Lange Syndrome Association (Australasia) Inc.

Authority to Fundraise: NSW CFN 15201
Donations of \$2 and over are Tax Deductible
DGR 419321 ABN 97 070 990 653

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Australasia: www.cdlsaus.org
International: www.cdlsworld.org

Online support groups:

OZ/NZ online discussion group: oznz-cdls@yahoogroups.com
(register via the link on the www.cdlsaus.org homepage)
International Online Support Group: www.cdls-support.org

From the Editor

Wishing you all a very happy, relaxing Christmas, ready to enjoy the new year. It can be a time of great change for families, so congratulations and best wishes to those of you starting preschool, school, day programs, work programs or another of life's big steps. And if you'd like to tell us about it, we would love to hear. My email address is on the front page.

Joanne

Fundraising Events



Madeleine Witham has put her new interest in baking cupcakes to good purpose by raising funds for CdLS! SHORE School in North Sydney hosted a fundraiser "Cupcake" morning tea for the staff, one of which is Mark Witham (father of Ella). The staff members were required to make a donation in order to be able to eat! There was also information available on CdLS and many staff showed an interest in the syndrome. They raised a total of \$120 for the CdLS Association.

CdLS Association Major Fundraiser

Join us at our second MANCINI's CdLS FUNDRAISER to be held late February/Early March 2011.

The generous staff of Mancini's award-winning Italian restaurant at 21 Burwood Road, Belfield (in Sydney) has again decided to support our association.

A three course meal is included in the ticket price. Drinks extra, and charged on consumption. You will be able to try their variety of delicious pasta dishes and gourmet pizzas! Magnifico!

There will be a silent auction, raffles, door prizes and lots of surprises. Children and people with CdLS (at reduced price) are welcome. Seats are limited so please book early to avoid disappointment. For tickets contact Jenny (02)9809 0287.

International CdLS Conference

The venue and dates have now been decided for the CdLS conference, Denmark: July 26th to 31st 2011 at the Radisson SAS Scandinavia Hotel in Copenhagen. The SAC will meet 26th, Professional Symposium and Federation Council on 27th, Professionals Conference on 28th, and Families and Siblings program 29th to 31st.

The main focus of this conference will be:
Gastroesophageal Reflux, Behaviour, Genetics, and
Clinical Picture and Different Health Aspects.



To see the electronic brochure

<http://www.cdlsworld.com/xwiki/bin/view/CdLSWorld/World+conference?language=en>

To register (online only): <https://www.scandinavia.mci-group.com/weraform/receive.csp?kgid=70101&lang=2>

To book accommodation at the conference hotel: www.radissonblu.com

Victorian News

Victorian CdLS families have just recently had a get together in Melbourne. A family picnic in the park was scheduled but due to Melbourne's typical unpredictable weather, we had to change our plans and move indoors. Never the less it was still nice to catch up with a few families, enjoy lunch together and have a chat. All the kids enjoyed a play in the playground (although got a little wet). It was lovely to see Ben, Sean and Corey together – such gorgeous little men and so well behaved. We do plan to have future get togethers so I am more than happy to take any suggestions and hopefully encourage more families to take the time to come and join us.

Lynne Wood

Victorian Co-ordinator

Siblings Australia has again had to close its physical doors due to government funding cuts. All the workings of the office will be put into storage, but this does not mean that Siblings Australia is out of business. Far from it! The Director, Kate Strohm, will continue to provide essential services to thousands of siblings around Australia from her home. Kate will also keep applying for funding. You can help by writing to disability ministers in your state – copying to the SA minister – and federal governments. Tell them how important it is that siblings are supported and how your own children have benefited from the services of Siblings Australia. Kate and Siblings Australia has supported the siblings of people with CdLS in this country and overseas for many years. We must keep this service operating.

CdLS Clinic days

Dr Jane Law (pictured) will be conducting two clinic days for patients with CdLS in the first half of 2011 - Wednesday 13th April and Wednesday 29th June – at the CDS clinic rooms at the Royal Rehabilitation Centre in Putney (Sydney).

Adult and adolescent patients with CdLS from anywhere in Australia are welcome to attend for a complete health check. Referrals are given for specialist and allied health services as needed, and a full report is given to you and your GP to ensure follow-up is monitored. Each clinic day there are two, two hour appointments for new patients in the mornings and two, one hour follow-up appointments in the afternoons.



The clinic appointments are covered by Medicare. Your travel/accommodation expenses (if necessary) are your own responsibility. Contact Jen for help with information about the clinic and travel/accommodation, as well as making a booking for an appointment with Dr Law. It's time for follow-up appointments for a number of her CdLS patients!

Committee Members for 2010-2011: The Association's AGM was held during the weekend of the Brisbane Clinic in September. We are very appreciative of the many, many hours of volunteer work our committee members give for the benefit of all our families. Often they have dual/multiple roles as State Coordinators/ KIT writers & editors/fundraisers/web guru, etc. Thanks to all the members of our new committee: President – Peter Crawford (ACT), Vice President – Steve Sandilands (WA), Treasurer – Brett Howe (NSW), Secretary – Jenny Rollo (NSW), and Ordinary Members: Rose Humphrey (Qld), Lynne Wood (Vic), Claudia Dale (Vic), Jo Argent (NSW), Carol Duffee (NZ) and re-joining the committee is Madeleine Witham (NSW).

International Rare Disease Day is being acknowledged in Sydney on 28th February by a gathering on the steps of the Opera House. If you are interested in attending to help represent CdLS please contact Jenny. Details will be finalised closer to the time. Keep an eye on the press.

Our Web Site has been Revamped!

Sincere thanks to Rose Humphrey who spent many months this year giving our web site a complete overhaul. With professional direction from Ken Anderson of Accent Web Design, our site is not only looking great but is much easier to navigate.

Please visit the site soon. Rose will be happy to consider your contributions to the site, although we don't do links to private sites, blogs, etc. Photos for the gallery are welcome, as is all feedback. We want our families to have easy access to the latest information from around the world.



Ken Anderson and Rose displaying the updated CdLS web site

Brisbane clinic

by Rose Humphrey

Saturday, 25 September 2010, Brisbane became the hub for CdLS families from Australia & South East Asia

Our brilliant Prof Chris Oliver gave a presentation on his latest findings on behavioural issues with people with CdLS and Dr Barry Lipschitz spoke on gastrointestinal disorders in CdLS. Both doctors worked tirelessly all day giving individual consultations to families.

We saw Chris Oliver to discuss Laura's obsessive compulsive behaviours – carrying two Wiggles guitars **EVERYWHERE** – the yellow in the right hand and the red in the left hand. With Chris' help and hints we have managed to limit the times she now carries these guitars and have actually replaced them with a digital camera. Thank goodness for digital because we can simply delete the 200 odd photos she takes every day.

Laura had an extremely difficult year with her bowels. On one of our two trips to the Casualty Department of RCH this year, she had a mass in her bowel which the doctor could feel on examination. So a consultation with Dr Lipschitz was timely. He gave us a very practical process to follow if Laura's bowels begin to play up again and his advice was prevention instead of cure. To date, touch wood, we have not needed to put the process in place as she has been extremely regular.

We were again fortunate to have the Everton Park Girl Guides to provide support and entertainment for our CdLS kids and younger siblings. They are a wonderful group of young Australian women who jumped at the opportunity to again spend time with our loved ones. Feedback from the guides was very positive – “very rewarding”; “I had so much fun”; “tiring but so worth it”. And from the parents – “it was great to see the kids have so much fun”; “I was able to listen to the doctors without having my daughter climbing all over me”.

We ended the event in typical Australian style – with food, music and good cheer. Dinner at *Gilhooley's* was a noisy but delicious affair. Families took the time to meet others who they knew by name only. We sat with the Nor family who travelled all the way from Malaysia to attend so that they could better support their daughter Lina.

Looking back on that day now – 2½ months ago – I realize how extremely lucky we are to be living in Australia with a child with CdLS. As members of the Australasian CdLS Association we receive up to the minute medical information through regular newsletters and the website; we attend National Conferences and Clinic Days where we have access to private consultations with world renowned specialist in their fields – all for the cost of a \$25 annual membership or in today's ever financial savvy world - \$2.10 per month.

However, membership fees form a very small part of the Association's regular income and fundraising events are crucial to ensure this level of subsidy to members continues. We all need to play a part in ensuring the strength of the Association which, after all, is staffed by volunteers – parents just like me.



Chelsea and Madeleine Witham with Prof Chris Oliver and Maddi's mum, Sandy Harbison in Brisbane



Sophia stole the show with her dyed red hair and "attitude"!

QUEENSLAND CHRISTMAS PARTY – 2010

The old adage that absence makes the heart grow fonder was certainly true last weekend when, after years of absence from CDLS events due to distance, we were able to attend the 2010 Brisbane CDLS Christmas party near Brisbane. It was marvellous to see faces, old and new, who shared a common bond.

Despite my navigational ability getting us well and truly lost, (BE WARNED: entering the correct street but wrong suburb into the NavMan *isn't* advisable!) it was lovely to *eventually* pull up outside John and Margaret Wood's house to see a happy gathering of CDLS families.

Many thanks to John and Margaret for hosting this event once again and willingly carrying



out so much of the 'behind the scenes' preparation that helped make the occasion so successful.

Guests in attendance were: Margaret and John Wood with Isabella; Margie, Larry and baby Oliver; Mary-Ellen and daughter Katie; Richard and Di Tetley, grandparents to Sean Bartholomew and their beautiful grandchildren; David, Rose & daughter Laura and

the Dolinski family.

Wow - all of our children have grown up so much and were so well behaved! It was wonderful to see how much they had developed into charming individuals, each with a unique personality. Laura acted as official photographer with her digital camera; Katie was the social butterfly who cruised past us all with a smile, checking out what was going on; baby Oliver looked as cute as ever; Isabella investigated the scene thoroughly; whilst Helen enjoyed the extra attention and a good feed of sausages. If you ever need an expert sausage sizzler, then John is your man!

There was great delight in cutting the Christmas cake, which looked and tasted superb. During the afternoon the CdLS children, their siblings and young relations were thrilled to each receive a bag bursting with Christmas goodies. Sincere appreciation is expressed to Brookfield Multiplex who sponsored the gifts and, of course, Margaret and John who were the industrious shoppers.

The hours spent together passed as a blur of chatter and laughter. The value of these CdLS events was impressed on me once again. Stories were shared and support was given; it's amazing how a small comment or piece of information can reassure or allay many concerns. I am sure that we each walked away with our own special memory or tit-bit of useful information to file away. Despite absences, the CdLS connections always

remain strong and our thoughts and conversations included fellow Queenslanders who couldn't be there on the day.



2011 diaries already have the date of Sunday, 29 May pencilled in for our next get together at a location to be confirmed – maybe even Bundaberg. Until then, the Queensland crew wish you all a very happy Christmas and a new year that is filled with happiness, good health and oodles of love.

By Dawn Dolinski



LAURA BECOMES A GIRL GUIDE

When CdLS Australia held its 2006 National Conference on the Gold Coast, I approached our local Girl Guides to see whether they were interested in providing entertainment and general supervision for our CdLS kids and their younger siblings. They readily accepted and arrived with toys, DVDs and lots of enthusiasm. However, as most of you know our kids can be exhausting with their challenging behaviours, and by the end of the day the guides were looking more than a little weary.



So it was with some trepidation that, early this year, I dropped into the Guides' hut one Saturday afternoon to again appeal for assistance at the Brisbane Clinic Day. As luck would have it, Nalkari, my oldest daughters' Brownie guide leader, was on duty. After catching up on each other's families, and discussing the reason for my visit, Nalkari asked why I had not followed through with signing up Laura as a girl guide.



Over the years Laura often accompanied me when dropping off her sisters at guides and Nalkari grew to know her. As mums we sometimes shared stories of our kids and I often talked about our hopes that Laura could have similar experiences to her sisters. At the time, Nalkari offered her assistance if we decided that guides was a suitable activity for Laura.

Unfortunately, around that time my daughters left guides and project “Laura – Girl Guide” was put on the back burner – until that day when Nalkari again pledged her support.

So with support Laura started attending girl guides and was initiated as a fully fledged girl guide on 14 August. She already has a number of badges on her sash. It hasn't always been smooth sailing, as some weeks she is not as keen to attend and protests loudly. At other times her infectious laugh can be heard around the group and draws the other girls to her like a magnet. So far canoeing has been her favourite event.



The Girl Guides have been a part of our family for many years and like her sisters, Laura may eventually decide that she has outgrown them. But whilst she is still happy to go and wonderful people like Nalkari are willing to pledge their time and support, we will continue – one Saturday at a time!

Rose Humphrey – Brisbane

DISCLAIMER

This newsletter is not intended for diagnostic purposes or self treatment. The Cornelia de Lange Syndrome Association and its committee do not necessarily endorse or recommend any products, services, methods or literature mentioned within. Any questions about treatments should be discussed with your child's doctor.