

**KEEPING  
IN  
TOUCH**



**December  
2006**

**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

**Correspondence to:** Secretary, PO Box 20, Putney NSW 2112.  
Email: [jennyrollo@bigpond.com](mailto:jennyrollo@bigpond.com)

**KIT Editor:** Joanne Argent,  
Email: [jargent@library.mq.edu.au](mailto:jargent@library.mq.edu.au)

**Websites:** Australasia: [www.cdlsaus.org](http://www.cdlsaus.org)  
International: [www.cdlsworld.org](http://www.cdlsworld.org)

**Online support groups:** OZ/NZ online discussion group: [oznz-cdls@yahoo.com](mailto:oznz-cdls@yahoo.com)  
(register via the link on the [www.cdlsaus.org](http://www.cdlsaus.org) homepage)

International Online Support Group: [www.cdls-support.org](http://www.cdls-support.org)

**With this issue of KIT:**

**“Research Update – Behavioural Challenges in children and Adults with CdLS” by Prof Chris Oliver et al, UK**

(An online copy can be found on the Medical Page of this site)

**From the Editor**

Wishing you all a very happy and relaxing holiday, Joanne

**THANK YOU** to everyone who have financially contributed to the Association.

**Welcome to new members** from South Australia.

## Snippets

### **Behaviour Article**

As a result of continuing research of behaviour in the UK by Prof Chris Oliver et al, a comprehensive report on present findings has been produced. This article is too large to be included in KIT so is being sent both electronically and by post with this issue. It will also be available on our web site.

Thanks to Dr Oliver and his team for their valuable contributions, and to Alan Peaford (CdLS UK) who kindly included Australian families in his printing run. Very much appreciated.

### **Supported Accommodation for Adults Alliance**

« Taskforce Independence » is an alliance of carer and advocacy organisations around Australia formed with the sole objective of obtaining population-based benchmark Commonwealth funding quarantined for long term supported accommodation for adults with a disability. The funding will be the foundation of a national framework comprised of:

- A single tier system providing a range of accommodation options to all who need it;
- Some parent contribution, not necessarily financial;
- A general levy on a broad base of the population by way of a « safety net » for all.

The Alliance focuses on the one area that can have maximum impact on families which include an adult with a disability. It is not intended to detract from other needs.

The Alliance's proposals will be presented to Commonwealth Ministers over the next few months with a view to changing Commonwealth Government policy on this issue before the next election. If you wish to help effect change, or wish to endorse the Proposal, contact Katrina Clark on 02 9426 1725 or send her an email at [khenty@optusnet.com.au](mailto:khenty@optusnet.com.au)

Please inform any other advocacy or disability groups to which you belong. Supported accommodation ultimately affects every one of us. You can help make a difference to your family's future now.

### **Electronic KIT**

If you prefer to receive KIT in electronic form, please email Jenny and write «electronic KIT » in the subject line.

### **Australian Scientific Advisory Council**

Australia's International SAC representative, Dr Meredith Wilson, and Federation Representatives, Peter Crawford and Jenny Rollo, have begun the formation of an Australian SAC. This will give families access to local expertise in the various disciplines of medicine and therapy, and will enhance and support the existing Ask The Doctor service of the cdlsworld web site.

Do you want to recommend a doctor who has shown particular knowledge and dedication? Contact Jenny.

### **CdLS Clinic Day NSW**

The next adult clinic day for new patients in NSW will be in March 2007. Follow up appointments can be made at any time. For an appointment contact Jenny, or speak to Nicki at the clinic on Mondays and Wednesdays phone 9808 9287.

### **CdLS Clinic Day Queensland**

We are presently working on establishing a CdLS clinic day in Brisbane for adult Queensland residents. To register your interest, please contact Rose Humphrey.

### **Rose Humphrey's volunteer work recognised.**

A very surprised Rose Humphrey was presented with a commemorative plaque at close of conference in September, recognising her invaluable volunteer work for CdLS families in Queensland since 1999. The CdLS Association's inaugural « Distinguished Service Award » also recognised Rose's contributions to maintaining the web site, setting up the online group « oznz », and active support on the Management Committee of the Association. Thank you, Rose. The Association would not be where it is today without you.

### **Collis Curve Toothbrushes**

We still have a few collis curve toothbrushes available for purchase \$5 which includes postage in Australia. Limited choice of colours. Contact Jenny.

### **Australian Pacific Islands Disability Support (APIDS)**

APIDS is a not for profit company that is seeking to work with disabled peoples' organisations to improve the lives of people with disabilities in the Cook Islands, Federated States of Micronesia, Fiji, Kiribati, Nauru, Niue, Palau, Papua New Guinea, Republic of the Marshall Islands, Samoa, Solomon Islands, Tonga, Tuvalu and Vanuatu. These are the island states of the South Pacific Forum.

Joining as a member for \$20 will make a huge difference to the quality of life of disabled people in the Pacific. This includes enough food to eat, the chance of getting a job, obtaining the necessary equipment to aid mobility. For example, in Fiji, \$20 will pay the salary and expenses for one day for the Advocacy Officer with Fiji Disabled Peoples Association.

To donate, join, or for further information contact Robyn James on 0410 085 140 or email [apids@aapt.net.au](mailto:apids@aapt.net.au)

### **CdLS Fundraising**

A major fundraising event will be held in Sydney during the second half of 2007. More details next KIT. Items for raffle and auction are being collected now. Donations of suitable items for prizes and auction can be made by contacting Jenny. Volunteers to help with organising, and during the event, are very welcome.

### **Committee 2007**

The CdLS Association's AGM was held during the conference in September. The management committee for 2007 was elected during this meeting. The volunteers who will be guiding the Association through to the end of 2007 are:

President	Peter Crawford (ACT)
Vice President	Steve Sandilands (WA)
Treasurer	Brett Howe (NSW)
Secretary	Jenny Rollo (NSW)

### **Ordinary Members:**

Rose Humphrey (QLD), Claudia Dale (VIC), Carol Duffee (NZ), Joanne Argent (NSW) and a very warm welcome to our newest volunteer, Lynne Wood (VIC).

Thank you to all those who served the interests of the membership so well in 2006.

Cornelia de Lange Syndrome Association  
(Australasia) Inc  
President's Report  
2006

Last year I began my Report by asking "How does one judge the health, the efficiency, the well-being of an association?" and went on to detail some factors that perhaps suggested that as an association we were fit and well.

With confidence, I can report that those indicators continue to suggest our well being.

- Our state co-ordinators, Joanne Argent, the editor of *Keeping in Touch*, our committee, our website manager, Rose Humphrey, our wonderful Secretary, Jenny Rollo, our Treasurer, Brett Howe have continued to serve our CdLS community with dedication and skill.

The OZNS on-line group is growing and providing mutual support to its participants.

Last year, I also asked some questions, the answers to which might not only give some insight on the state of the association but also point the way ahead. I think they are worth repeating:

- Can we do more to identify more people who have CdLS?
- Can we increase our membership?
- Do we have throngs of people eager to take on leadership roles on the committee?
- As a small organisation, can we access government/community help in reaching out to present and future members?
- Are there better ways to bring our members together for that reviving, exhilarating, comforting experience of mutual support?

The National Conference provides a wonderful vehicle for attaining some of these objectives of revitalising our association.

Since our last Annual General Meeting, I draw your attention not only to the continued ordinary running of the association referred to above but also to the courage of the committee in deciding to hold a National Conference, at which this report is to be presented.

- We were successful in obtaining some funding support from the federal government for the Conference. A lot of work went into making several other submissions for funds, some have been unsuccessful while for others we are still awaiting results.

- NSW continues to hold CdLS Clinic Days and attempts continue to be made to hold similar events in some other States.
- Queensland and NSW held their annual picnic day.
- Jenny Rollo successfully completed a long running project which she had set herself in distributing to all of us the template to contain the personal history/medical information of our CdLS family member.
- Jenny also distributed the behavioural surveys for the research that Professor Chris Oliver has been conducting. We are looking forward to getting the results from that in the near future, perhaps even at the National Conference.
- Our New Zealand group report a quiet 12 months since their mini conference in July last year. Activities have enabled new members to be introduced to the group and Liz and Vernon Molloy attended a conference for families with intellectually disabled members with the theme: Strong Families Strong Voices. Carol Duffee the NZ member on our Association Committee has been busy this year having a membership drive ensuring everybody has committed to the CdLS group. Personal medical folders and the questionnaire compiled by Chris Oliver have been sent to all NZ members. They are looking forward to the continued association and support of the Australian CdLS group which is greatly appreciated. Looking to the future they are hoping to have a few New Zealanders attend the Canadian conference in July 2007.

On the international level I can report:

- The Council of the International Federation of CdLS National Support Groups has further developed the world website: [www.cdlsworld.org](http://www.cdlsworld.org).
- The Council has continued to address the two major issues identified at the last meeting – language and the database of answers to Ask the Doctor questions.
- The Federation executive is fine tuning the draft constitution which was presented to the last Council meeting for acceptance at the next meeting.
- Germany and Spain have been accepted into the Federation as new members.
- Preparations seem to be well in hand for the next International Conference in Canada in July 2007.

We can perhaps summarise the past year as both consolidation and as preparation for our 2006 National Conference. The challenge remains to achieve better outcomes for our CdLS community.

Peter Crawford  
President



## Love Ella



Mark, Madeleine and Chelsea Witham with CdLSA Patron, Nick Farr-Jones

The launch in July of "Love Ella" by Madeleine Witham was a resounding success. CdLS Association Patron, Nick Farr-Jones officially launched the book, with a moving speech in support of the Witham family and the thousands of others who deal with disability issues in Australia. Nick admitted that although he knows the Witham family well, he had no real idea of what daily life is like for parents and siblings. He told of reading "Love Ella" during a plane flight across Australia, causing him to spend the trip in tears. Nick bought a number of copies to send to politicians to read.

CdLS President, Peter Crawford spoke about how the Association has been supporting families for the past 20 years, and our aims for the future.

Ella was taken home early because she wasn't coping with all the fuss, but David Rollo carried the baton of dodgy behaviour in her stead, giving all the guests an insight into some of the social restrictions families face. Many copies of the book were sold on the night, and donations were also made to the Association in support of our work.

Madeleine has since done the rounds of TV and radio shows, conducting interviews, as well as speaking to audiences in Sydney. You can check out some of the interviews by logging on to the book's web site and following the links.

[www.love-ella.com](http://www.love-ella.com)

# COREY'S DOLPHIN EXPERIENCE

By Corey's Mum, Lynne

This year Corey was very fortunate to be granted a 'wish' from the "Make - A - Wish" foundation of Australia. Corey is a bit of a daredevil thrill seeker, so we thought a trip to the Gold Coast to visit all the theme parks and experience some of the heart pumping rides would be something he would thoroughly enjoy.

And thoroughly enjoy he did. This little lad seems to have no fear. He was just so excited and always eager to get to the next ride. It was great to see his face just light up with excitement all day and to see him having such an enjoyable time.

One part of his experience at Seaworld was to have a wade with a dolphin. What an amazing experience for Corey. Corey was a little hesitant at first but after a little while he was quite fascinated with the feel of the dolphin's skin. Corey thought it was a real laugh when the dolphin splashed him. I'm sure he would have been quite happy to jump on and go for a ride.

We are very grateful to the "Make - A - Wish" foundation for granting Corey his wish and sending us on such a wonderful holiday. An experience we will never forget.



Corey "swims" with the dolphins at Seaworld



Corey, held by Mum, Lynne, acquaints himself with a dolphin at Seaworld



## CdLS Conference - Canada 2007



Are you planning to attend the CdLS conference in Niagara Falls in July? The CdLSA Management Committee has decided to help **Australian members'** attendance by paying for their registrations, conference fees and gala tickets, as well as submitting registration papers. There will also be some help with accommodation available. BUT there are conditions:

1. You **MUST** send your registration papers to the CdLSA Secretary by January 20<sup>th</sup> 2007. Late applications will not be considered, as we will be doing only ONE money transfer to Canada.
2. Accommodation support is for the conference hotel only, one room per family, and for the duration of the family conference.

You can download conference registration papers from the CdLS Canada web site or from the world site – [www.cdlsCanada.ca](http://www.cdlsCanada.ca) or [www.cdlsWorld.org](http://www.cdlsWorld.org)  
Any questions please ring or email Jenny Rollo.

CdLSA Management Committee recognizes the importance of the CdLS International conferences and the Federation of National CdLS support groups. Continuing to share knowledge and experience is invaluable to families and professionals.

## NSW Developmental Disability Health Unit

The NSW DDHU, which runs the CdLS adult health clinic, has received a moral boost this year by receiving the support of the NSW Government. The Hon. John Watkins, Deputy Premier of NSW and Member of Ryde, recently presented clinic staff with a guarantee of two more years' service provision for their clients, while a more permanent plan for the future is prepared by Prof. Trevor Parmenter and clinic doctors.

This is an essential service for people with disabilities in NSW which deserves Government support and full funding.



Jen and David with NSW Deputy Premier, The Hon John Watkins at the DDHU presentation

# Membership Form: CdLS Association (Australasia) Inc.

Date: \_\_\_\_\_ Enclosed is a Donation of \_\_\_\_\_

\_\_\_\_\_ I wish to become a Financial Member (Membership Fees \$25)

\_\_\_\_\_ I wish to become an Associate Member (Professionals) (Membership Fees \$25)

NAME: \_\_\_\_\_

Telephone: \_\_\_\_\_ Email: \_\_\_\_\_

Fax: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

State: \_\_\_\_\_ Postcode: \_\_\_\_\_ Country: \_\_\_\_\_

NAME and birthdate OF PERSON WITH CdLS: \_\_\_\_\_

NAME(S) & Birthdate(s) of siblings: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

I am a parent \_\_\_\_\_ : Grandparent \_\_\_\_\_ : Relative \_\_\_\_\_ :

Professional (incl. Field) \_\_\_\_\_ :

Other (specify) \_\_\_\_\_ .

I wish to receive the KIT newsletter - by mail by email not at all (please circle choice)

I give permission for the release of my name to other families for the purpose of mutual support: yes / no

Signature: \_\_\_\_\_

## Payment Method:

**Cheques** made payable to CdLSA can be sent to The Secretary, P.O. Box 20 Putney, NSW, 2112, AUSTRALIA.

## Credit Card:

Mastercard \_\_\_\_\_ Visa \_\_\_\_\_ Bankcard \_\_\_\_\_ (Please tick) Card Number \_\_\_\_\_

Cardholder's Name (Full name as it appears on card): \_\_\_\_\_

Card Expiry Date: \_\_\_\_\_ Total: \_\_\_\_\_

Signature of Cardholder: \_\_\_\_\_

## 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