

KEEPING  
IN  
TOUCH



JULY  
2012

Cornelia de Lange Syndrome Association (Australasia) Inc.  
Authority to Fundraise: NSW CFN 15201  
Donations of \$2 and over are Tax Deductible  
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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@yahoogroups.com](mailto:oznz-cdls@yahoogroups.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)

## CDLS CLINIC DAY - SYDNEY

The date of the next Clinic day at the Developmental Disability Clinic in Putney has been changed to **Wednesday August 22<sup>nd</sup>**.

There are two appointments with Dr Jane Law for new patients and 3 for follow-up patients. New patients have an extended consultation for 2 hours.

This clinic is funded for adults with disabilities, but adolescents are welcome as well. Younger people need to see their paediatrician.

The Developmental Disability Clinic is presently a little oasis of a building amongst extensive building works, but directions are clear and there is still plenty of parking available.

For an appointment please contact Jenny Rollo ASAP. Appointments not taken up by CdLS patients can be given to other people on the clinic's waiting list.

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# The CdLSA National Conference Sydney

**Friday 28<sup>th</sup> and Saturday 29<sup>th</sup> September.**

Information and Registration papers are in this issue.  
Learn from the speakers, consult with doctors, meet and relax with other families.  
We look forward to seeing you there.

## Queensland Picnic Day

by Rose Humphrey

Queensland families gathered for their annual picnic on Sunday 27<sup>th</sup> May 2012 at Orleigh Park on the Brisbane River.

Isabella (8), Katie (21), Krystal (18) and Laura (15) in the main kept to themselves but were happy to eventually pose for photos.

Katie was not feeling very well so she was fairly laid back all day; Krystal was a bundle of energy and happily told us of her new adventures, post school.

Shy Bella sought the protection of big brother Justin's lap and played with baby Oliver (almost 2); whilst Laura showed off her new bike when she wasn't taking photos on her iPad.

Dianne and Richard updated the group on their grandson Sean's progress.

See everyone again next year on Sunday, 26<sup>th</sup> May 2013.



Bella



Katie



Krystal and Laura

Reprinted with kind permission from the Winter 2012 issue of *Reaching Out*, CdLS Foundation, USA.

## Oral Health Issues Facing Individuals with CdLS

*by Dr. Richard Mungo, D.D.S.*

*CdLS Foundation Clinical Advisory Board Member*

A daunting task facing parents of a child with multiple physical and developmental challenges is assembling a strong healthcare support team that can guide them through the maze of therapies, treatments and unknown difficulties.

Very important members of that team are the dental specialists who can address the oral health concerns affecting children and adults with Cornelia de Lange Syndrome (CdLS). Common oral and dental abnormalities can have a profound effect upon the overall health of patients. Feeding struggles (associated with a high prevalence of oral clefting), delayed eruption of the teeth, and proper swallowing, demand an early establishment of a “dental home.” An early consultation with a pediatric dental specialist is important. Pediatric dentists are trained in all aspects of assessment and treatment associated with children who possess special health care needs.

### **Physical Issues**

CdLS presents an array of different abnormalities affecting the mouth and craniofacial structures. The jaws, teeth and oral soft tissues can be altered due to poor growth and development. Children with CdLS are at a higher risk for cavities, orthodontic problems and self-inflicted oral injuries.

It is common to have clefting of the palate, which can affect infant feeding, speech development and proper jaw growth. Ankyglossia, or tongue-tie, is found in many children and can greatly affect speech development and proper eating. This condition can also be a factor in excessive drooling, making it difficult to swallow effectively. Periodontal, or gum, disease can be detected in a great number of individuals with CdLS. This becomes a serious threat to good oral health well into adulthood and can cause the early loss of the permanent teeth.

The lower jaw can be short. The upper jaw can be very narrow and positioned forward on the skull, causing misalignment and crooked teeth.

The upper and lower jaws are also usually quite narrow with a very high arch to the palate. This kind of arch configuration makes for very crowded teeth. Some people feel that this contributes to tongue thrusting due to such a small space for tongue positioning and resting.

There are many other factors involved with tongue thrusting, such as a constricted airway, large tonsils or neurological abnormalities leading to a poorly developed swallow mechanism. This can also lead to excessive drooling. Tongue thrusting and drooling are common in children with CdLS. A consultation with a speech pathologist, myofunctional therapist or physical therapist could be helpful.

### **Erosion**

Enamel erosion can be seen in individuals who experience gastroesophageal reflux disease (GERD). The upward flow of stomach acids constantly bathe the teeth and cause the protective layer of enamel to dissolve away. This allows cavities to develop. When pitting of the enamel is seen on the backside of the front teeth, due to the acids, the pediatric dentist will use various medications, like fluoride, to control or even reverse the acid damage.

Tooth grinding, known as bruxism, compounds the erosion problem, causing further loss of tooth structure. The pediatric dentist can make a retainer-like device that can be worn to prevent the bad effects of tooth grinding.

## **Teeth Growth**

Children with CdLS do have a great number of orthodontic concerns. The growth and development issues associated with the syndrome not only affect the height and weight of the children, but the growth and maturity of the mouth and dentition.

The primary, or baby, teeth have a tendency to come into the mouth later than we would typically expect. These teeth often do not fall out when they should. This causes the permanent teeth to erupt in an abnormal position and can block the permanent teeth all together. Sometimes it is necessary to remove the baby teeth when they stay in too long. The dentist will determine if and when the over retained baby teeth, or even some of the permanent teeth, must be removed for a better bite.

## **Hygiene & Behavior**

Home care and dietary concerns must be addressed early on. Appropriate oral hygiene practices can be taught to parents and other caretakers. Special toothbrushes, toothpastes and devices to help in the brushing process are available. Prevention of early childhood cavities, usually due to nighttime infant feeding practices, must be addressed as soon as possible. Monitoring for habitual retention of food in the cheeks, a common practice of children with CdLS, must be met with oral cleansing after each feeding. This can prevent the molars from decaying rapidly.

Self-inflicted oral and facial trauma may be noticed and addressed with various dental appliances and referrals to behavioral therapists. Routine six-month check-ups can assist in monitoring changes, detecting pathology and reinforcing proper home care.

## **Visiting the Dentist**

An orthodontic consultation around the age of six years old is recommended. It can then be determined if the child is a good candidate for orthodontic care and when it should be started.

Compromises are often the answer. Obtaining a moderate improvement may be all that's needed or accomplished. When working with the pediatric dentist or orthodontist, we always need to be practical. We want to help improve the health of the child but, as always, we must weigh the risks and the benefits and come to a wise decision as to how to safely proceed.

The medical and developmental complications associated with CdLS make the delivery of dental therapy a challenge. When dental treatment, such as fillings, extractions and even some preventive procedures like dental sealants, are required, the best approach to accomplishing these tasks must be determined. Some children with CdLS receive their care in the dental office alongside their typical siblings with ease. For many others, this is not possible.

Conscious sedation, deep sedation and even general anesthesia are adjuncts to care that are often necessary in order to obtain cooperation and can take place in the dental office, surgery center or hospital environments. Airway abnormalities and the general health of the child must be taken into consideration to determine the safest approach to care.

The pediatric dentist can determine the best avenue to pursue in order to deliver the highest quality of care in a safe and effective manner. It's helpful to alert all of the child's healthcare providers any time the child will be placed under general anesthesia. Other physicians and dentists might desire to take advantage of the sedation and join together to perform multiple treatments, thus minimizing anesthetic experiences.

## **In Summary**

The oral and dental concerns associated with CdLS necessitate early evaluation and intervention. A "dental home" must be established as early as possible so the child can consistently receive oral health care and prevention that is culturally sensitive, comprehensive and easily accessible.

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# CdLS National Conference

Our venue booking is confirmed, details are being finalised and people are becoming very excited about meeting again at conference!

**Where:** Courtyard by Marriott, North Ryde in Sydney

**When:** September 28<sup>th</sup> and 29<sup>th</sup> 2012

**How do I register?** Conference registration papers are included in this issue of KIT. Post completed forms to **CdLS Conference Registration, PO Box 20, Putney, NSW, 2112**. Don't forget your payment. Receipts will be issued in your conference folder.

**How do I book accommodation?** Go to the Conference web page <http://cwp.marriott.com/sydney/corneliadelange/> that has been set up by the Marriott hotel. Or telephone (02) 9491 9500 and state you are attending the CdLS conference

**Cost:** Details of the conference registration costs are on the next page. We have not been able to apply for any government funding for this conference. However, the CdLS Association is keeping the costs as low as possible to allow families a greater chance of attending. There are very significant discounts for financial members.

**What is on the program?** Included in the program are doctor appointments, speakers, and our AGM. All subjects will be relevant to the medical, social, educational needs of families. Registrants will be sent the program and other details by the end of August.

**Childcare** On-site childcare is available for all children up to the age of 5 years, and all people with CdLS.

**Sibling Outings** to nearby venues will be arranged for all children aged 5 and over attending school. We do not have the capacity to care for younger children on outings. People who have CdLS may attend if they have their own carer (other than sibling). Possible venues: movies; ice skating; wildlife park.

**Optional Dinner On Friday Night** Attendees are encouraged to attend the conference dinner. Previous experience has shown this to be the highlight of the social side of our gatherings. Patrons will pay for their own meals and beverages on the night. Please indicate on the Registration form if you are likely to attend.

**Doctor Consultations** Details will be available to registrants at a later date.

## **Airport Transfers**

Transport options: self drive (free parking at the hotel), taxi (about \$70 one way), train travel from airport change at Central station to North Shore line Macquarie Park station, 5 minute walk from station to hotel. (I wouldn't choose the train option if travelling with kids and bags!)

We are looking forward to seeing everyone in September! Bring your camera!

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# Notice of Annual General Meeting

The AGM of the CdLS Association Inc will be held during the National Conference at the Marriott Hotel North Ryde on Saturday 29<sup>th</sup> September at 4pm.

If you are not able to attend in person there will be a Skype hook-up available. You must apply for this option by September 15<sup>th</sup> to allow time for links to be set up.

New members of the committee are always welcome. If you are interested in nominating for the committee to help with the administrative side of the Association, please nominate yourself on the enclosed form.

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## CONFERENCE REGISTRATION FEES

- There is a substantial discount for financial members of the CdLS Association.
- Financial membership costs \$25 per family per year.
- If you and your family are **not** currently financial members, you are only eligible for the discounted fees if you complete and return the enclosed Membership Form and payment with your Conference Registration Form.

### **MEMBERS**

#### **Registration Fees for Conference – per membership**

People with CdLS	Free
Children 0-5 years	Free
2 Adults (13 years and over)	Free
2 Siblings 6-12 years	Free
1 Adult and 3 Siblings 6-12 years	Free
Extra Adults (13 years and over)	\$65 PER DAY
Extra Children 6-12 years	\$35 PER DAY

### **NON-MEMBERS**

#### **Registration Fees for Conference**

People with CdLS	Free
Children 0-5 years	Free
Adults (13 years and over)	\$65 PER DAY
Children 6-12 years	\$35 PER DAY

# REGISTRATION FORM

Cornelia de Lange Syndrome National Conference

27<sup>th</sup> to 30<sup>th</sup> September 2012

## Families:

Family name: \_\_\_\_\_

## Professionals:

Name: \_\_\_\_\_ Profession: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone: (\_\_\_\_) \_\_\_\_\_ Mob: \_\_\_\_\_

Email address: \_\_\_\_\_

**ATTENDANCE:** FRIDAY ONLY / SATURDAY ONLY / BOTH DAYS (Please circle one)

**ACCOMMODATION.** Are you staying at Courtyard by Marriott North Ryde? Yes / No

## OPTIONAL DINNER ON FRIDAY NIGHT

To get an idea of likely attendance for organising bookings please indicate your interest:

Adults attending: \_\_\_\_\_ Children attending: \_\_\_\_\_

**ATTENDEES**

**1. Name of person with CdLS** \_\_\_\_\_ Age \_\_\_\_\_

Is s/he attending? \_\_\_\_\_ Does s/he require catering by hotel? \_\_\_\_\_

**2. Other members of your family / group.** (Names as you wish them to appear on name tags).

**ADULTS attending the Conference**

Family name	First name	Relationship to person with CdLS
_____	_____	_____
_____	_____	_____
_____	_____	_____

**CHILDREN attending the Conference**

Family name	First name	Relationship to Person with CdLS	Age
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

**SPECIAL REQUESTS**

Do you require a highchair? \_\_\_\_\_

Does anyone in your family have special dietary requirements or allergies?



**SIBLINGS OUTINGS**

To help plan transport and carers, please indicate your interest in attending the outings.

Children attending: \_\_\_\_\_ Person with CdLS + carer: \_\_\_\_\_



**PLEASE READ AND SIGN THIS RELEASE FORM**

**Liability, Information and Photo Release**

**All adults attending the 2012 CdLS Conference must sign their consent to the following:**

I release CdLS Association (Australasia) Inc., committee members, officers, and any other person acting on behalf of or acting or purporting to act as agent of CdLS Association (Australasia) Inc. including volunteers, from any liability whatsoever arising from any conduct including any alleged negligence by act or omission of CdLS Association (Australasia) Inc. and of any other person acting on behalf of or acting or purporting to act as agent of CdLS Association (Australasia) Inc. in connection with my attendance, and the attendance of any member of my family, at the 2012 Conference.

I give permission to CdLS Association (Australasia) Inc. to release my name to professionals participating in the 2012 Conference.

I give permission to CdLS Association (Australasia) Inc. to use my name and image (photographs and/or video) as well as that of family members at the 2012 Conference in any CdLS Association or Federation publication.

**Requires the dated signatures of each attending adult below:**

Name \_\_\_\_\_ Signed \_\_\_\_\_ Date \_\_\_\_\_

Name \_\_\_\_\_ Signed \_\_\_\_\_ Date \_\_\_\_\_

Name \_\_\_\_\_ Signed \_\_\_\_\_ Date \_\_\_\_\_

# CONFERENCE PAYMENT FORM

## MEMBERS

Annual Membership of CdLS Association (if unpaid)     \$25                             =         \$\_\_\_\_\_

### Attendees

### Number

Free Adults (13+ yrs)                     \_\_\_\_\_ x             (max. 2)                     =         \$ \_0\_

Free Children (6-12 yrs)                     \_\_\_\_\_ x             (max. 2A+2C or 1A+3C)                     =         \$ \_0\_

Free Children (0-5 yrs)                     \_\_\_\_\_ x             Free                             =         \$ \_0\_

Person with CdLS                             \_\_\_\_\_ x             Free                             =         \$ \_0\_

Extra Adults (13+ yrs)    FRIDAY                     \_\_\_\_\_ x             \$65                             =         \$\_\_\_\_\_

Extra Adults (13+ yrs)    SATURDAY                     \_\_\_\_\_ x             \$65                             =         \$\_\_\_\_\_

Extra Children (6-12 yrs) FRIDAY                     \_\_\_\_\_ x             \$35                             =         \$\_\_\_\_\_

Extra Children (6-12 yrs) SATURDAY                     \_\_\_\_\_ x             \$35                             =         \$\_\_\_\_\_

Payment Total             \$\_\_\_\_\_

## NON MEMBERS

Adults (13+ yrs)                     FRIDAY                     \_\_\_\_\_ x             \$65                             =         \$\_\_\_\_\_

Adults (13+ yrs)                     SATURDAY                     \_\_\_\_\_ x             \$65                             =         \$\_\_\_\_\_

Children (6-12 yrs)                     FRIDAY                     \_\_\_\_\_ x             \$35                             =         \$\_\_\_\_\_

Children (6-12 yrs)                     SATURDAY                     \_\_\_\_\_ x             \$35                             =         \$\_\_\_\_\_

Free Children (0-5 yrs)                     \_\_\_\_\_ x             Free                             =         \$ \_0\_

Person with CdLS                             \_\_\_\_\_ x             Free                             =         \$ \_0\_

Payment Total             \$\_\_\_\_\_

Select payment method:

\_\_\_\_\_ Cheque enclosed (made payable to CdLS Association (Australasia) Inc.)

\_\_\_\_\_ Please charge my    \_\_ Visa    \_\_ Mastercard    account     \$\_\_\_\_\_

Card number             \_\_\_\_\_             Expiry date             \_\_\_\_\_

Name on Card: \_\_\_\_\_             Signature             \_\_\_\_\_

# Membership Form

CdLS Association (Australasia) Inc.

Date: \_\_\_\_\_

Enclosed is a Donation of \_\_\_\_\_

\_\_\_\_\_ I wish to become a Financial Member/renew membership (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 and sent to The Secretary, P.O. Box 20 Putney, NSW, 2112, AUSTRALIA.

### Credit Card:

Mastercard \_\_\_\_\_ Visa \_\_\_\_\_ (Please tick)

Card Number \_\_\_\_\_

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

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

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

*Thank you for your financial support.*

**Cornelia de Lange Syndrome Association (Australasia) Inc**

**Nomination Form For Position of Office Bearer or Ordinary Committee Member  
in the Above Mentioned Association**

I, \_\_\_\_\_

Of (address) \_\_\_\_\_

\_\_\_\_\_ STATE: \_\_\_\_\_ P/CODE \_\_\_\_\_

and being a current financial member in good standing of the above mentioned

Association, do nominate \_\_\_\_\_ for the position of:

\_\_\_\_\_

signed: \_\_\_\_\_ Dated: \_\_\_\_\_

I, \_\_\_\_\_

Of (address): \_\_\_\_\_

\_\_\_\_\_ STATE: \_\_\_\_\_ P/CODE: \_\_\_\_\_

do hereby second the nomination by \_\_\_\_\_ for

\_\_\_\_\_ to hold the position of \_\_\_\_\_

signed: \_\_\_\_\_ Dated: \_\_\_\_\_

I, \_\_\_\_\_

Of the above address: Accept nomination for the position of

\_\_\_\_\_

signed: \_\_\_\_\_ Dated: \_\_\_\_\_

## CONFERENCE CHECKLIST

- Complete Registration Form
- Read and sign Release Form
- Complete Payment Form
- Include cheque (if applicable)
- Complete Membership Form (if joining or renewing now)
- Complete Nomination form if you would like to be on the CdLSA Committee.

- Post it all to:

CdLS Conference Registration  
PO Box 20  
PUTNEY, NSW, 2112

*Thank you. See you there!*

### **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.