

## ARCHIVES – INTERNATIONAL CONFERENCES

### 2003 INTERNATIONAL CONFERENCE - SYDNEY, AUSTRALIA



#### BRIDGING THE CONTINENTS – WHAT A SUCCESS!!

The first **International CdLS Conference** held in Australia, in fact, the first for the southern hemisphere! Keep checking the Conference Page for new and updated information.

Our conference logo of a stylised Sydney Harbour Bridge was designed by *Marcia Kennedy*, Mum to Clare (8 yrs, CdLS). It, with the theme "Bridging The Continents", depicts the links between CdLS families around the world. (June 2003)

From 3 – 6 July 2003, Sydney Australia was home to 44 people with CdLS, their families and carers, and professionals who are experts in this rare genetic condition. In fact over 300 people from 10 countries attended the 2003 CdLS International Conference and during those four days, new medical information was presented, friendships were forged, support was shared and hope for the future revived.

#### Wednesday, 2 July 2003

A joint meeting of SAC and Federation Council members was held and their report is now available below the conference report on this page.

#### Thursday, 3 July 2003 – Professionals Day

This was a one-day medical conference, a first for any CdLS gathering in the world. It gave doctors, therapists and educators an opportunity to hear what the experts had to say, have their questions answered, and share their own experiences of their CdLS clients.

The day began with sessions from members of the CdLS Scientific Advisory Committee (SAC) who gave an overview of the CdL Phenotype in the Young Adult Patient, Dysmorphology Changes, Clinical Presentation and Problems followed by Medical Guidelines for Clinical Follow-ups.

**Prof. Chris Oliver** presented his latest research findings on Self-Injurious Behaviours and **Dr Angelo Selicorni** also presented a detailed research report on Kidney Problems in Patients with CdLS.

After lunch was dedicated to Workshops on the topics of Teaching Strategies and Assessment of Children with Multiple Disabilities; Gastro-oesophageal Reflux and other GI Problems in the New Medicine Age; Behaviour – Understanding and Managing Problems; Communication – Language delays and potential for computer aided communication and Feeding Difficulties.

#### Friday, 4 July 2003

The Family Conference was officially opened by **Her Excellency, Professor Marie Bashir AC, Governor of NSW**, who also joined the families for a typical Aussie BBQ lunch. Following a welcome from the CdLSA Vice-President and a local Aboriginal Elder, the Conference was underway with presentations from members of the SAC and Australasian medical specialists.

Families were given an update on Genetic Research and General Health Issues for Adults with Disabilities.

**“Ask the Doctor”** Panel was very popular and extremely successful. Parents and caregivers were able to pose their questions to experts in the field of Ophthalmology, Dentistry and Growth and Development.

#### Saturday, 5 July 2003

The morning began with **Dr Bryce Meads** presenting his research results on Hand Differences in People with CdLS. **Dr Mary Morse** gave an interesting talk on educational issues and showed hands-on examples by way of video of a delightful young lady with CdLS, with a mischievous sense of humour. **Dr Marjorie Goodban** gave some practical and useful tools in assisting our children with developing speech and language. **Prof Chris Oliver** finished the morning session with a comprehensive report on his research into Self-Injurious Behaviours in CdLS.

After a lunch of Italian fare, the afternoon was devoted to Workshops which were well-attended and very informative.

Nutritional, Metabolic & Environmental Influences on Children's Health was presented by **Dr Robyn Cosford** – an expert in this field. A précis of her report is on the [MEDICAL PAGE](#)

For 1½ hours, parents and caregivers were able to empathise with their children's needs during the excellent presentation of the hands-on workshop of the Impact of Sensory Deficits on Children with Severe Communication Impairment.

**Jo Moss** and **Jenny Sloneem** reported on their findings of Behaviour Management as a result of their research into self injurious behaviour.

The Dads' Meeting was an excellent opportunity for fathers to connect, share ideas and concerns. The Nature of Grief provided parents with a safe and supported environment where they could express their emotions and feelings of grief.

#### Banquet and Bush Dance

The Banquet was a great opportunity for all to unwind, meet new friends, catch up with old ones and have fun. And did we have fun!!!!!! Guests dined on a feast of hot and cold dishes which included Australian lamb and seafood, followed by a sumptuous selection of desserts with the Aussie Pavlova taking pride of place. Tables were decked out with bags of Australian lollies (candy) and individual souvenir "cling-on" koalas. The Bush Dance was a very popular choice and everyone joined into a dance or two at some stage during the night.

I'm not telling any secrets BUT – Who was the National Leader who overdid the dosey-doeing and was limping the next day? Name the professional that did a great “rocking chair” during “Home Amongst the Gum Trees”!! Which UK visitor put on an unconvincing performance of disliking Aussie beer??

#### Sunday, 6 July 2003

No one seemed the worse for wear after Saturday Night's party and it was down to business early with workshops on Recreation Options, Siblings Issues for Parents and Looking to the Future. **Drs Lynette Gillis** and **Cheri Carrico** gave very informative and helpful sessions on Gastroenterology, Reflux and Feeding Issues.

The final General Session was opened by **Dr Alex Levin** who gave an overview of the SAC's anticipated role in the future. Alan Peaford was introduced as the newly elected Federation Chairperson. **Ulla Mulger** gave an interesting overview of the Italian Association

for CdLS and presented a very tantalising view of Italy and all it has to offer as the venue for the next International Conference in 2005.

Following the official closure of the Conference, delegates enjoyed another lunch of international cuisine before venturing out to the Blue Mountains.

#### Children's Activities

In house care was provided by the **Bogota New Jersey Girl Scouts** headed by **Kathy and Gene Van Buren**. There was great rapport between the children and the Scouts who entertained them with games and videos whilst their parents attended sessions.

Students from the **Nepean College of TAFE Childcare Course** provided 1:1 care for people with CdLS who accompanied their siblings on the many outings organised by the Australian Committee. The outings included a trip to Featherdale Wildlife Park, home to some of the unique animals found in Australia. On Saturday the kids went to a movie followed by lunch at McDonalds and finished off the afternoon with Ten Pin Bowling. Sunday was another busy day with time spent at Panthers' Kaos Games Room followed by Aqua Golf.

Congratulations to **Phyl Crawford** and her team for the organisation involved in achieving the smooth running of the successful child care program.

It wasn't all fun and games though; a Siblings' Workshop was held for children over 5 years of age. This session was an excellent opportunity for siblings, both children and adults, to express their feelings, anxieties and fears for the future. Whilst it was an emotional session, the kids came away with a sense of "not being alone".

Many new friendships were formed during the three days of the Conference. Kids who had not previously known each other were seen "hanging out" as best friends by Sunday afternoon and many tears were shed when it was time to say farewell. Email addresses were exchanged with promises of staying in touch.

Congratulations to **Jenny Rollo** and her dedicated team of helpers for the successful hosting of the 2003 CdLS International Conference!!!

### **GOVERNOR'S SPEECH**

We were honoured to have the family portion of the Conference officially opened by **Her Excellency, Professor Marie Bashir AC, Governor of NSW**. Her Excellency has kindly given permission for her speech to be published [HERE](#).

### **FEDERATION COUNCIL MEETING**

The Federation Council met on 4 July 2003 during the International Conference at Penrith. Countries represented were Australia, Canada, Denmark, Italy, Portugal, United Kingdom and the United States. We received apologies from France, Japan and the Netherlands.

**Alan Peaford** (the English leader) was elected the new Chair of the Council. We also set up a three person executive, consisting of the Chair, a representative of the country which is hosting the next Conference and the immediate past Chair. So the three people are: Alan as Chair, the representative from Italy, **Ulla Mugler**, and **Peter Crawford** as the immediate past Chair.

The Council had fruitful discussions with the International Scientific Advisory Council. During their meeting, they re-organised elements of their international structure which will enhance its ability to work with the Federation in every country.

They propose that each country will appoint a professional director (not necessarily a 'medical' director) who will thereby become a SAC board member. When each country has appointed its own professional director the International SAC will look at which areas of expertise are covered by those directors and appoint other experts to fill in the gaps. (The idea is that **Alex Levin**, the new Chairman of the International SAC, will help each country, if they want to ask his help, to choose their professional director -who will be an SAC member. When all the countries have chosen their professional directors, Alex will see what fields of expertise they cover and will then add to the SAC by inviting other experts so that there will be at least one if not two experts covering every field.) In addition, to assist liaison, the Chair of the International SAC will sit on our Council and our Chair will sit on theirs.



The Federation Council decided to adopt in principle three wide ranging functions for the Federation:

1. to liaise with and 'manage' the International SAC (in the context of their insistence that they work for us)
2. to be a forum of best practice in serving our CdLS families (exchange ideas and information)
3. to act as a resource base for the wider family of people affected by CdLS throughout the world for both research and for families moving from one country to another.

With regard to the '**Ask the Doctor Online**' facility, the Federation Council decided that each country should develop its own "Ask the Doctor Online" for its own website but that the answers would still be all stored in the one database. This Data base of responses to previously asked questions is to be shifted from the US website to the HUB. The United Kingdom (England) will administer the HUB.

The Federation Council decided to establish an annual levy of \$US3 per CdLS person in each country not only to help fund the development and maintenance of the HUB but especially to establish a fund to ensure that an adequate representation of SAC members comes to each International Conference. Each country will be responsible for funding its own professional director to each International Conference and the general fund will be used to cover any other fields thought necessary for that conference.

The Federation Council also decided that **Canada** will host the 2007 Conference.

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## 2005 INTERNATIONAL CONFERENCE – GROSSETO, ITALY

### VIVA ITALIA!!

We extend our many thanks to **Ulla Mugler**, **Dr Angelo Selicorni**, and the Italian committee, for organising such a spectacular conference. International CdLS conferences have been brought to a new level of excellence with the addition of simultaneous translation in three languages – a 'must' for Europe.

The two-day professionals' conference was extremely well attended. The meeting room was packed with doctors, therapists, carers, and other related professionals – speaking a variety of languages, and all learning more about CdLS. There was an emphasis on the genetic research, as well as speakers covering the whole range of medical problems people with CdLS face. This can only lead to better informed treatments for our children.

Thank you, Italy, for making us so welcome!

## **SCIENTIFIC ADVISORY COUNCIL AND FEDERATION COUNCIL MEETINGS**

by *Peter Crawford*, President, CdLSA

At Grosseto, the **International Scientific Advisory Council** met, as did the Council of the Federation of National CdLS Support Groups.

**Dr Levin**, Chair of the SAC, reported that he had nearly filled all the positions on the SAC. The idea is that the SAC have as members at least two international experts in about 18 areas of expertise relevant to CdLS. For example, not only geneticists and reflux experts, but also educationists and behavioural experts – as well, the professional director of each national body is a member of the SAC.

He also reported that all the members were now linked electronically so that each can communicate with all the others.

The SAC is constantly faced with the problem of bringing individual families into contact with appropriate experts in their own countries. This is even harder when the family lives in a country that does not have a national organisation. He urged those of us who have national organisations to establish our own panel of experts so that they could be at least an initial contact point for the SAC.

**Dr Levin** reiterated the willingness of SAC members to carry out what they see as their basic purpose: to be of use to all families with a CdLS member.

**The Federation Council**, in its discussions, identified two major issues – language and the database of answers to ask the doctor.

Although the database of answers has been set up on the **CdLSWORLD** website, making it available in languages other than English is of high priority. Further, the Council became aware that the databases of answers maintained separately by the US Foundation and the CdLS world website were diverging. Ways and means to prevent this need to be found.

**Dr Levin** assured Australia (on behalf of The Philippines) and Portugal (on behalf of Brazil), that he would identify doctors who would be willing and able to support local families in those countries. Increasing numbers of families seeking support from established groups due to geographical location (the Philippines) and language (Brazil) necessitate increasing knowledge of local services. This in turn will help establish local CdLS chapters in the future.

On matters financial, the Council accepted the financial statements, adopted a working budget for the next two years and determined the amount of the Federation's contribution to the Italian Association towards the costs of the Grosseto conference.

The Council received a draft constitution/by-laws for the Federation that had been prepared by Sara Pinto and passed it to the executive to progress.

Canada announced that the themes of the 2007 International conference in Niagara Falls would centre around behavioural issues and siblings

The Council unanimously welcomed the proposal that the 2009 conference be held in the UK.

**Ulla Mugler** was elected as the new Chair. **Alan Peaford** stays on the executive as the immediate past Chair. **Bernadette Dallingwater** was nominated by Canada to the position on the executive reserved for the next host country. The Council decided to create a further executive position of Treasurer and elected **Peter Crawford** as Treasurer.

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## 2007 INTERNATIONAL CONFERENCE – NIAGARA FALLS, CANADA



It has been a long journey to get here but we are overjoyed to be hosting the 4th world conference of CdLS organizations, medical professionals, care-givers and families.

"Canada" is a Native American word that means "the meeting place" and with this in mind we have chosen the famous Niagara Falls (one of the Seven Wonders of the World) as the backdrop for the 2007 world conference. Niagara Falls is the perfect place for all types of gatherings and family vacations.

This conference will be a family oriented affair with a focus on your family's CdLS journey and the issues that occur in your day-to-day lives. Along with the CdLS conference there will be a Siblings Conference running alongside with family issues also as the focus. The doctors from the World SAC (Scientific Advisory Council) will be joining us and there will be workshops, presentations, consultations, Q & A sessions, not to mention all the wonderful and numerous festivities that are planned. What fun we have when we gather together!

Please consider joining us for: "The Journey of a Lifetime!"  
~ Bernadette Dalingwater, President CdLS Canada

 [www.cdlsCanada.ca/](http://www.cdlsCanada.ca/)

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## 2009 INTERNATIONAL CONFERENCE – BRIGHTON, UNITED KINGDOM



After nearly three years in the planning, CdLS UK hosted the World Federation CdLS Conference at Brighton. More than 500 people took part with families and professionals coming from every continent other than Antarctica.

As well as the family conference, the World Federation held its biennial leaders meeting and the meeting of the Scientific Advisory Council. The SAC also had a research day where researchers presented their latest work.

Read more at the [UK Website](#)