

## Federation Council

Meetings of the national leaders were held over two days at the Brighton conference. During this time:

- We welcomed South Korea, Chile and Central America as full members of the CdLS Federation Council. The aim of the federation council and the SAC is to share information about CdLS, support families and to ensure people with CdLS have access to medical support.
- The “Ask the Doctor” database’s translation into many languages is progressing well. Geritjan Koekkoek from the Netherlands, ably supported by a moderator from each of the member countries, has been working on this project since the Canadian conference in 2007. There are many hurdles to overcome still – distance, time for the volunteers and doctors, and legal matters.
- **The next International CdLS Conference will be hosted by DENMARK in 2011.** Details as they come to hand.
- The federation council executive team was elected: Chair Ulla Mugler (Italy), Vice Chair Julie Mairano (USA), Treasurer Peter Crawford (Australia), Next Host Country’s leader Henrik Hasselstrom (Denmark)
- Leaders discussed in detail the workings, aims and future plans of their nation’s support groups. There were very many similarities in the problems we all encounter and worries we have for the future. The raising of funds to keep the associations and foundations afloat is felt in every country whether they are fully volunteer organisations or if they have one or many paid staff. Succession is of particular concern. Most of the present leaders are the people who started and have run the groups from the beginning – and we are all getting older. All of the groups are finding it difficult to recruit younger parents to take up the baton.



CdLS Federation Council was represented by leaders from Holland, Poland, Italy, Spain, Spanish speaking nations, France, Germany, Denmark, Canada, UK & Ireland, Australia, USA and observers from Uganda.



Federation Executive members: Julie Mairano (USA), Peter Crawford (Aus), Ulla Mugler (Italy), Henrik Hasselstrom (Denmark), and SAC Chair Angelo Selicorni (Italy)

**AGM notice: 2.30pm Sat 31<sup>st</sup> October at 135 Princes Street Putney in Sydney OR by telephone link.**

**BY PHONE:** booking of the telephone conference call needs to be confirmed 48 hours before the meeting. Please indicate your intention to attend as soon as possible to the secretary. You will need to have a landline number we can contact.

**IN PERSON:** Please indicate your intention to attend as soon as possible.

Afternoon tea will be served after the meeting. This is a good opportunity to meet other families and to catch up with “old” friends. People fear attending AGMs but be assured that in CdLS nobody will be coerced to serve on the committee!

The AGM usually takes about 30 minutes. Nominations for positions on the management committee are being accepted up to and during the AGM. Only financial members of the CdLS Association are able to nominate and vote. Membership fees are \$25 per family per year, due at the beginning of July each year. All nominations must have the permission of the nominee and be seconded by another financial member. You can nominate yourself.

## International Rare Disease Day

Rare diseases affect 1.5 million Australians compromising 300,000 children.

International Rare Disease Day  
was held on 28<sup>th</sup> February at AGSA, 66 Albion St, Surry Hills NSW 2010

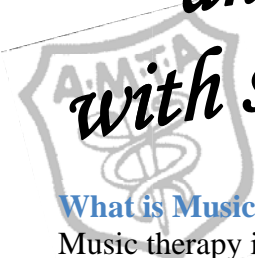
Guest speakers were:

Jerome Parisse-Brassens: International Perspective - EURORDIS  
Mary Eastman: Personal Story – Fibrodysplasia Ossificans Progressiva  
Julie Cini: Personal Story – Spinal Muscular Atrophy  
Dianne Petrie: Director, AGSA  
Karen Gair: CEO, SMILE Foundation

At this meeting we decided to form a Planning Committee for Rare Disease Day 2010 - If you are interested in being a part of this committee please contact AGSA.

## EURORDIS AND THE RARE DISEASE PATIENT MOVEMENT IN EUROPE

Eurordis was founded in 1997, on the initiative of the French Muscular Dystrophy Association (AFM), French Cystic Fibrosis Association, French National Cancer League (LNCC) and the French National Aids Federation, on the model of the North American NORD (National Organization for Rare Disorders) to advocate for the adoption of the EU Orphan Drug Regulation and for EU Rare Disease Public Health and Biomedical Research policies.



# *Music Therapy and people with special needs*

### **What is Music Therapy?**

Music therapy is a professional discipline that uses music to achieve therapeutic aims. Music therapy in special education is the functional use of music to achieve and enhance special education goals, while offering an alternative to traditional teaching methods.

### **Who is a registered music therapist (RMT)?**

Registered music therapists (RMT) are skilled and qualified musicians and therapists who assess, design and implement programs to meet the needs of individual students/adults with special needs.

### **What makes music therapy different?**

The overall aims of music education and music therapy are, in fact, complementary. They both aim to facilitate the growth and development of the student. The difference lies within the specific goals targeted by each discipline. Music educators specialize in students' acquisition of musical knowledge, skills, and appreciation while music therapists use music primarily to achieve non-music goals (Daverson & Edwards, 1998).

### **The Music Therapy Process**

Specific music therapy goals are determined by the RMT through initial music therapy assessment and ongoing review of the client. In the case of special education, music therapy goals can be an integral component of progress toward attainment of educational goals as identified by the clients' Individual Education Plan (IEP) team and parents. In the case of adults with special needs, music therapy goals can support long term goals suggested by other members of the therapy team, such as physiotherapists, occupational therapists, as well as by the client. Music therapy can therefore contribute to the quality of life of people with special needs and their families.

## Music Therapy Goals

As all music therapy programs are specifically designed for the individual, the exact goals cannot be determined until after the assessment. Some examples of goals of music therapy for children and adults with special needs are:

- ♪ To increase opportunities for cognitive, physical and sensory stimulation
- ♪ To develop motor skills (strengthening of muscles, increasing range of motion, training of movement coordination, etc.)
- ♪ To develop orientation and mobility (ie. spatial awareness, confidence to move, gait, direction, and gross & fine motor skills)
- ♪ To promote social skills and interpersonal communication
- ♪ To develop appropriate emotional expression
- ♪ To enhance self-confidence
- ♪ To increase awareness of one's immediate environment and of others
- ♪ To develop complexity and completeness of sentences, and appropriate use of vocabulary

## Music Therapy Techniques

After assessment, the RMT selects and applies a range of techniques in order to achieve the program goals. Some examples of techniques adopted by music therapists in addressing the client's needs include:

- ♪ Song writing to facilitate self-expression
- ♪ Movement to music
- ♪ Singing and chanting
- ♪ Educational/instructional songs
- ♪ Involvement in a group
- ♪ Improvisation
- ♪ Instrumental playing
- ♪ Music listening

## Results

A range of empirical literature supports the effectiveness of music therapy in increasing the skills and abilities of people with special needs in the areas of (1) social and emotional behaviour, (2) motor skills, (3) communication skills, (4) language and vocal production, and (5) pre-academic and academic skills. The efficacy of these outcomes is enhanced by the power of music to arouse emotions that can be used to motivate and engage clients toward achievement of their therapeutic goals.

## Access to music therapy programs

The cost of music therapy services is covered generally by the following school/institutional bodies:

- ♪ School funds
- ♪ Parents & Citizens (P&C) committees
- ♪ Non-profit organisations/associations
- ♪ Parents and/or clients

### **♪ SERVICE FOR QUEENSLAND FAMILIES in the Brisbane area**

Vanessa Solomon is a Registered Music Therapist (BMus, hons, RMT) facilitating community music therapy programs (with a special interest in people with special needs) throughout Brisbane and surrounding areas. She has a private practice travelling to the client's homes offering individual music therapy sessions.

"I have a particular interest in people with CdL Syndrome and really feel that people (particularly those between 15 – 35) would benefit from music therapy."

The community music therapy programs are disability non-specific (and therefore receive no funding) and are aimed at creating new social networks for those with a disability. The programs are therapeutic and are designed to assist each client achieve their therapeutic goals. Some of these may be:

- Communication skills (expressive language, non-verbal etc.)
- Social skills
- Developmental milestones
- Motor skills (gross & fine)
- Self confidence and self-esteem

All of these skills are achieved through music therapy and the other creative arts – evidence based ways that have shown to be useful with working with people with a disability.

Vanessa Solomon  
Clinical Nutritionist & Registered Music Therapist  
0405 715 709

## **QUEENSLAND CHRISTMAS PARTY IN THE PARK**

**Please join us**

**Date:** 22/11/09

**Time:** 11.00am

**Place:** Orleigh Park, Hill End Terrace, West End, BRISBANE

**Directions:** Come down Montague Road, West End and turn right into Hill End Terrace. Look for the CdLS Banner

**Bring:** chairs, rugs & extended family

**Attractions:** Sausage sizzle, face painting, Santa. Every child receives a gift. LUNCH PROVIDED

**RSVP:** 1<sup>st</sup> November 2009 to Rose Humphrey 3353 3470 or email [rose.humphrey@optusnet.com.au](mailto:rose.humphrey@optusnet.com.au)

ALL WELCOME

## **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.