



NEWSLETTER - WINTER 2003

WELCOME to our Winter Newsletter for 2003. We have had a busy period since the last issue including a very successful AGM & Information Evening on the 16th October. The topics this year were geared to the social aspects of dealing with cleft. A lot of good contacts were made during the course of the evening and the feedback from all was very positive. The AGM noted that Ruairí Ó Dulaing has stepped down as Chairman after 7 years. Many of you will know Ruairí from various events and from telephone support. I am sure those of you that were not present at the AGM will agree with the sentiments expressed on the night regarding Ruairí's excellent contribution to the work of the Association. Once again, on behalf of everybody, I would like to thank Ruairí for his time and energy. Finally a small reminder, last newsletter the committee asked for a volunteer to take notes at our meetings ... the invitation still stands. **Ed**

NEW & ADVENTUROUS FUND RAISING EFFORT

Standing at 19,340 ft (5895 m) above the African plain, Mt Kilimanjaro is the highest mountain in Africa. It has captured the imagination of writers and climbers. Situated 3° south of the Equator, the dormant volcano has an ice cap cover all year round. It is an extraordinary sight.



What has this got to do with CLAPAI you might ask? A group of dedicated young people, are undertaking to climb to the top in 2004 with funds going to CLAPAI. The group are striving for their Gaisce Gold award. What is Gaisce? It is the President's award for young people. Its purpose is to reward young people who have set and achieved a demanding challenge for themselves in four different areas of activity. Gold is the highest of three levels that can be awarded.

The programme the group have undertaken is to climb Kilimanjaro and at the same time raise funds for CLAPAI. Between fund raising and getting fit they will have their work cut out for them in the months running up to August. We will be following their progress in our 2004 newsletters.



The group are (Left to Right) Joe Lennon, Brendan Clerkin, Andrew Forde, Nelson Moody and (Front Row) Laura Fingleton & Niamh Burke. They are all students at DCU except Joe who's a primary teacher.

The Craniofacial Society of Great Britain & Ireland Annual Scientific Conference 2003 [University of Leeds]

Earlier this year CLAPAI contributed funds towards three cleft specialists attending above conference. Anne McGillivray and Julie Young have very kindly furnished us with a comprehensive report on the conference. The full report is posted on the web and is available from the Editor. A synopsis follows;

Five members of The Children's University Hospital attended the conference. Mr Michael Earley, Professor Triona Sweeney, Louise Cafferky, Julie Young and Anne McGillivray.

Day 1 was for special interest groups - Co-ordinators, Speech Language Therapy, Nurses, Orthodontists, Psychology, clinical directors and Surgeons.

Day 2 & 3 was the Scientific Programme. There were two guest lecturers Professor Roberto Brusati from Milan who spoke on 'Primary CheiloRhynoplasty in Unilateral & Bilateral Clefts and Ms. Lidia Bobock from Romania who spoke on 'Cleft care in Romania – The good and the bad'.

There were numerous other presentations; the full report contains a write up on ten including the conclusions of the presenters. Presentations from Irish representatives were Prof. Triona Sweeney's presentation on 'Nasalance scores for normal speaking Irish children' and Mr. Earley's talk on 'Incidence and natural history of middle ear disease in cleft lip, cleft palate and velopharyngeal insufficiency'.

Julie, Anne and Louise Cafferky have thanked the Association very much for its contribution. It would seem to have been a very full and informative event. The Association is glad that there is a forum for cleft teams to share their knowledge and keep up to date.

Announcements

The Speech and Language Therapy Department in the Childrens' University Hospital Temple Street are delighted to announce that Dr. Triona Sweeney has been appointed adjunct Professor in Speech and Language Therapy by the University of Limerick. This is a joint Academic/Clinical Specialist post and is the first professorship in the Allied Health Professional group to be attached to a teaching hospital. It is a great achievement for Professor Sweeney and is due in no small measure to her dedication to progressing our knowledge with her research in the assessment and treatment of children with speech and resonance disorders associated with cleft lip and palate. Her research has received great acclaim not only nationally but also internationally and is accepted for publication in America next year.

Thanks to the Management team in the Childrens University Hospital for supporting this unique development, which ensures that we have retained in the hospital the skills and knowledge of a leading expert in the assessment and treatment of speech and resonance disorders.

We would like to welcome Roberta Fleming to our team who will be doing two clinical sessions with the Cleft Team and who has many years of experience in working with children with physical and sensory disability. She also in the past worked on the Cleft team in the Royal in Belfast and is also married to Mr. Paddy Fleming, Consultant Paediatric Dentist in Our Ladys Hospital for sick Children.

Congratulations to Triona and Welcome to Roberta."

Eilis Murphy,
Speech and Language Therapist Manager,
The Childrens University Hospital,
Temple Street,

Summer Camp

It is sometimes surprising how things can happen ... At the Information Evening in October one of our members, Jimmy Meyler, approached us about the Summer Camp article in our last newsletter. It turns out Jimmy can make a facility available to us with trained volunteers to help our teenagers and young adults enjoy activities etc. We had been wondering how to start on organising an event like this and lo and behold one of our own comes to the rescue!

We are working out the logistics currently and will keep you updated on the web and with newsletters. So far we have arranged that location and provisional date – that is Arklow and 19th June. Given this is our first event like this we are keeping it to a day trip.

The camp will be geared to the 12+ age group and will include water sports, games, fireside camp and lots of fun. At the Information Evening some of the teenagers present had a few questions – here are the questions & answers

Will only people born with a cleft be going?
Yes, the event is organised to let people mix outside of hospital environments and to have a bit of fun.

Will you have to be sporty to go on the trip?
No, not if you don't want to be, there will be something for everyone

The most important step next is to get people who are interested to contact us. Please phone or email Editor.

Almost Ready, Steady, Go !

Over the past number of months, the Association has been drafting a series of leaflets covering all aspects of Cleft Lip & Palate. We have applied for and are waiting to hear from the Lotto regarding funding. We are very hopeful that we will get the green light and will have a new series of leaflets in production. We would like to thank members of the Cleft Teams who have reviewed and advised on content. A fuller report will follow in next edition.

Contact Editor

For more information on any of our articles or the requirements for volunteer work please contact the Editor

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