Cleft Lip & Palate Association of Ireland

NEWSLETTER - WINTER 2004

Dublin City Marathon

Congratulations to Ronan Ely who not only completed the Dublin City Marathon in 4 hours 30 mins, he raised 2,700 Euro for the Association. Ronan, who is studying Business Studies in Cork Institute Technology, travelled to our recent Information Evening to present the Association with a cheque for 2,400. He is pictured here with Georgina Wade (left) and his mum Mary Ely. Since November a further 300 Euro has been lodged to the Association bank account. Ronan is not only to be congratulated on a fantastic fund raising effort, in the middle of his marathon training he managed to get to the county finals in hurling and the county semi-finals in football!

Ena Lynn Moves On

Many of our readers will know Ena Lynn from her work with the Health Research Board. For those of you that don't, Ena has had the extraordinary job of collecting clinical data and samples from cleft affected families all over Ireland. When she started three years ago, there were 112 samples (collected with the help of the Association). Thankfully at the time there were enough samples to help researchers secure a fund for further work.

Ena has attended all cleft clinics in Dublin & Sligo over the past three years. In the last year she also attended all Mr McKiernan's orthodontic clinics. Almost everybody currently in treatment has contributed to the research. The total number of samples collected has reached in excess of **1000**.

We caught up with Ena in the Autumn and asked her for her thoughts. The thing she liked most about her work was meeting people. She met families before operations and saw them again afterwards. She was able to witness first hand amazing results of treatment. One of the unexpected bonuses of Ena's attendance at clinics was that she was able to spend time chatting with families and listening to their stories. The recurring theme with new parents was the gap in information etc in parts of the country where cleft co-ordinators don't reach. The other thing Ena noticed was the difficulty teenagers go through. There is no psychology help for dealing with the impact of cleft. On the plus side parents, particularly of older children, are agreed that the system overall has improved. Asked about the role of the Association, Ena could see that there is still a strong need for the Association to provide an advocacy role in dealing with issues. Also the web site is an excellent source of information.

Overall it has been a great experience and Ena has made some great friends. She will miss the families and medical staff that she has got to know over the years. We wish Ena well with her new appointment.

Report from Craniofacial Society (2004)

The theme for this year's conference was "Setting a positive agenda in cleft & craniofacial care". The conference was attended by members of cleft teams from both Temple Street & Crumlin hospitals. The first day was dedicated to Special Interest Groups such as Co-ordinators, Speech Language therapists, Nurses, Orthodontists, Psychologists & Surgeons. Day two included presentations from guest speakers and members. A synopsis has kindly been provided by Anne McGillivary and is available on www.cleft.ie. Topics included "Effect of Palate re-repairs on the airway", 'Nature of feeding Patterns in Infants with Cleft", "Breast Feeding & Breast Milk Feeding", "Behavioral Treatment of Social Anxiety in Children with Cleft", "Bullying and Appearance"and "SLT Results of 2 year Old Assessment".

Emily Lovegrove gave her talk on Bully & Appearance. Research has found that 75% of 11-13 year olds ***with no disfigurement*** cite teasing or bulling about their appearance causes them distress. 38% of them admit discomfort around disfigurement issues. Concerns were further identified as being compounded by the lack of effective coping strategies. Ms. Lovegrove spoke about intervention strategies that she has used with disfigured and non-disfigured adolescents. Research shows that offering all young people the social skills they need to cope with teasing or bulling about appearance may not just substantially reduce general bullying but may also reduce that specifically targeted as disfigured population.

The Association would like to thank Anne McGillivary for giving us her report.

Root Canal

We recently had a query from one of our parents about Root Canal Treatment. On a routine visit to the Orthodontist in St. James Hospital our parent was advised that root canal treatment might be needed for daughter Christina. The question raised was where could root canal treatment be received and would there be a cost.

Thanks to Mr. McKiernan of St. James Hospital we can tell our readers that

- Root canal treatment is regarded in the same way as fillings and regular dental hygiene treatments.
- Root canal work is not done in St. James Hospital but is carried out by the local dentist.
- If a patient needs root canal treatment, the orthodontist will write to the local dentist.
- The local dentist will then arrange treatment.
- As with other cleft treatments there is no charge to the patient for this work.

Remember – children born with a cleft are entitled to attend their local dentist from the time their first tooth appears. Regular check ups are to be encouraged to make sure that both baby and second teeth remain healthy and as strong as possible.

Of course, avoiding sugary products and brushing well regularly are essential parts of good tooth care! But we all know that … don’t we!

Kilimanjaro Update

A fuller report on the Kilimanjaro adventure will follow in our next edition. In brief - **they made it.** They got to the summit, they raised their target funds and they increased awareness of cleft and the work of the Association. Congratulations to Laura, Joe, Niamh & Andrew.

Treatment for Adults

For a variety of reasons, many children did not complete their cleft treatment in the past. From time to time the Association receives calls from these children who are now adults. The main question they have is how to go about completing their treatment and how much it might cost. One of the people who has been in touch with us is Sean. In 2004 he set about completing his treatment. He has kindly agreed to share his journey with us. His first report is enclosed.

AGM Report

The Association AGM took place on Saturday 6th November. After the formal agenda, a review of the previous year was undertaken and objectives for 2005 were discussed. A lot of discussion took place on how to strengthen and formalise ties with the Galway branch. As well as the ongoing activities of the Association such as Family Support, Fund Raising, Administration, Information Provision, Publications & support for Medical Team Support; the Association will concentrate on addressing the gaps in maternity care and providing a forum for teenagers. There was a lot of enthusiasm and exchange of ideas from those present. We hope we will have a better story to tell in the areas that have been targeted at next year's AGM. Reminder - volunteers are always needed.

Wanted

The Association is in need of a treasurer to manage our books. If you have this skill we would really appreciate your help. Contact Editor for more details

Information Evening

Some 30 people who took a very encouraging interest in the speakers' presentations attended our Information Evening. First up was David Orr, Consultant Plastic Surgeon, who spoke of his involvement in an Operation Smile project twelve months previously in Kenya. Next up was Julie Young, Speech and Language Therapist, who spoke on feeding matters. Questions from the audience indicated a concern about the quality of advice and guidance available in maternity hospitals on feeding the child with a cleft palate. The final speaker, Suvianna Hakalehto-Wainio, Chairperson of the Finnish Cleft Lip and Palate Association, speaking on the Scandinavian experience and was very well received. Being a parent of a child born with a cleft, Suvianna also brought a parent's perspective, which is one we have not had in recent years and which was most valuable for that very reason. She also had some interesting ideas in terms of future co-operation between our respective Associations.

The most pleasing aspect of the evening was the willingness of the audience to become actively involved in the evenings discussions, and also in the affairs of the Association. Initiatives aimed at supporting new parents and younger people, plus a maternity hospital initiative, were the areas receiving most support.

Parents Evenings

Parents evenings are relatively recent for the Association. They have proved beneficial for all attending. Parents gain a lot from sharing experiences with other parents. Feedback also helps the committee to know where the greatest needs are. This year we hope to continue with these forums.

The next two evenings will be on **Wednesday 2nd March** and a date in May to be arranged. The venue for the March evening is the 'Bridge Room' upstairs in the Bankers Club, St. Stephens Green. [The Bankers club is on the southside of the Green i.e. the same side as the Department of Foreign Affairs]. The evening will start at **8pm** [the doors will be open earlier. We look forward to seeing you there.

Seeking a Pen-Pal! Aged between 8 and 18 years? Read on!

Like to make a friend in another country? Why not let us put you in touch with someone of a similar age in Finland? The Cleft Lip and Palate Association of Ireland, in conjunction with the Finnish Cleft Lip and Palate Association, is offering the opportunity for children and teenagers between the ages of 8 and 18 years to become a pen-pal to someone of a similar age who, like them, was born with a cleft.

Interested? Then forward your details to include the following;
Name, age, sex, postal address (not e-mail), phone number, leisure interests.

Please also state;
(a) If you wish to have one or more than one pen-pal,
(b) Preferences if any in terms of person(s) you wish to correspond with (male, female, no preference).
(c) Your preferred means of correspondance (letter post, e-mail, no preference).

The Association requests that your application be signed by a parent or guardian. A contact phone number must be included for verification purposes only.

We will then match you with a suitable pen-pal in beautiful snowy Finland, the land of lakes and forests! The only details we will forward to your prospective pen-pal will be your name, age, sex and postal address. You will receive the same information in return.

Please forward your details in writing to;

The Cleft Lip and Palate Association of Ireland
'Pen-Pal Club'
c/o 34 Sycamore View,
Carpenterstown,
Castleknock,
Dublin 15

So jump on board and grab this chance to make a friend for life!

Leaflet Launch

The Association's new series of leaflets were launched at the Information Evening. To give an idea of the quality and content of the series a copy of leaflet number 1 has been enclosed with this newsletter. For copies of other leaflets please should send a Stamped Addressed Envelope to the editor with a completed Mailing List - Subscription Form.

p.s. For full set of leaflets 98c stamp will be required.

International Conference

On September 14th 2004 the first international conference of European Cleft Lip & Palate Support groups took place. CLAPA Uk hosted the event, which was held in London. It was a tremendous success thanks to all the speakers and delegates who made it such an interesting day. CLAPAI chairman Eddie Byrne made a presentation outlining how cleft is treated in Ireland and how the Association operates here. Valuable contacts have been made particularly with Associations that are similar in size. It is planned to hold another conference next year.

News flash

Extended committee meeting to take place 24th Jan. Stop. Tony O Connor steps down from the committee after 25 years. Stop the Lights!

Contact Editor

For more information on any of our articles please contact the Editor

Georgina Wade, 4 Wolverton Glen, Dalkey, Co. Dublin. Phone 01 2848227 Email wade@cleft.ie

You can register for email copies of the newsletter on www.cleft.ie. or to get copies by post just phone the Editor. Please note patients attending clinics cannot be automatically added to the CLAPAI mailing list. If you want to receive regular updates you need to give us your details …

Waiting Room Humour!

Doctor, Doctor, I can't get to sleep.
Sit on the edge of the bed and you'll soon drop off.

Doctor, Doctor, you've got to help me - I just can't stop my hands shaking.
Do you drink a lot?
Not really - I spill most of it!

Doctor, Doctor, I think I'm a bridge.
What's come over you?
Oh, two cars, a large truck and a coach.

Knock Knock.
Who's there?
Abbott!
Abbott who?
Abbott time you answered the door!

Knock Knock.
Who's there?
Isabelle!
Isabelle who?
Isabelle necessary on a bicycle?

Knock Knock.
Who's there?
Major!
Major who?
Major answer didn't I!

Knock Knock.
Who's there?
Philip!
Philip who?
Philip my glass will you please!

Why not send your jokes to editor for our next edition!

Treatment Available for Adults born with Cleft Lip and / or Palate

Brief History Pre 2004

Firstly I will introduce myself. My name is Sean O Donoghue I was born with a bilateral cleft of the lip and palate in 1972. I was treated for the cleft under a consultant at the former Dr Steevens Hospital up until 1988 where I then received a bone graft to close the bilateral opening in the alveolar (part of jaw which has teeth). There still remained a fistula (hole) that was covered **``temporarily``** by a false denture.

After Dr Steevens hospital closed (around 88-89) I was moved to St James Hospital for further consultation. However I fell out the system after this either through lack of interest or more like exhaustion on my behalf and also at the time there was major upheaval in the health service, which did not help.

I continued to maintain my upper teeth over the years as much as possible but it become much more difficult as I got older. It was always in my conscious to complete out what had begun in 1972 and stopped without completion in 1988.

Return for completion of treatment in 2004

Early in 2004 I finally decided it was time that I have the fistula closed in my palate. By now I was wearing the same retainer since 1988, which had done damage over a period of time to my upper teeth and gums. I attribute some serious attacks of mouth ulcers in recent years to the opening in the palate. These and others factors finally encouraged me to seek further treatment.

It was early March 2004 that I started investigating how I would re-enter the system (Health System). My first contact began with a search of the internet that led into the CLAPI home page from here I made several contacts and by end of March 2004 with the result of a few e-mails and telephone calls I was given an appointment for the Cleft clinic on the second Wednesday of June 2004 at St James Hospital Dublin.

Like any one I had many questions and fears. The fact of being an adult in my early 30`s I wondered was it now too late to complete. These were soon resolved on having met the Cleft Clinic Team. I was put at ease and from then on knew I was in the care of very efficient, committed and highly skilled medical professionals.

Its now almost November and much has happened since my first appointment in June at the Cleft Lip Clinic. The procedure to repair the fistula was completed on the 27 August 2004. With almost a four-night stay in St James Hospital I had the fistula closed in my palate and the **temporary** denture is now no more (strange feeling really after years of having to remove the denture each night before going to bed.). A bone graft into the palate and tissue realignment achieved this.

The bone was taken from the top of the hip compared to the graft that I had carried out in 1988 (bone harvested from the hip also) it's totally different. From 88 I have a scar running about 6 inches down the left side of my hip and it took days to get my leg back in motion and months to walk properly again without a limp. The 2004 graft (taken from my right hip) resulted in a scar only about one and a half inches long that will fade away fairly quickly over the next year and I was out of the bed the following morning and had no limp after a few days. This shows how much medicine has changed in only about 15 years.

I finally returned to work on the 11 October, I must point out here that after 3 weeks I could have returned but delayed due to the nature of my job (I work in the pharmaceutical industry as a Technologist and the risk of exposure to chemicals is much higher). As I carry out much training and presentations as part of my work, the company I work with requested me to take more time to allow myself sufficient time to heal and for my speech to recover.

I return to the Cleft Clinic in November for a check up to establish how the fistula closure has worked (at the time of writing this article everything feels fine and I feel it has being a success). The closure of the fistula is only the beginning of series of procedures and orthodontics that will take place over the coming few years to finally complete a course treatments that began over 33 years ago. It will be well worth it and my own commitment over the coming months and years is crucial to a successful outcome.

Very important lessons I have learned since March 2004

- The approach today is so much different from the 70`s and 80`s, looking back to then its maybe the fact that not knowing what was next in treatment was the worst and the lack of explanation. To be fair this was the common approach then to many procedures.

- There is much information out there on cleft palates - these exist in both web and printed form. People need to know how to access these sources. It's important to remember that the indications of treatments available and examples given may not necessarily be suitable for one's own case - everyone will differ. Individual treatment plans will be established from a few visits to the clinic. Time lines of treatments differ as well.

- The cost of receiving treatment in Ireland is covered under public health. As I have health insurance this covered my bed stay, whether I had health insurance or not does not matter as the state is covering the treatment so far. I have found this to be always the case even during the 70`s and 80`s. **Strangely I have heard of cases over the years where people never completed treatments due to excess bills? This needs to be investigated to establish exactly what is the situation.**

- Treatments for cleft are accessible under the public health system even as Adult. And as an adult with uncompleted treatment from the 70`s and 80`s, it is possible to receive further treatment depending on consultants opinions.

- My speech was naturally affected by the cleft palate, but it's important to point out that I have much improved since August, even before the procedure in August it was fairly good. Here lies a valuable lesson, considering the nature of my work involving having to give presentations on a routine basis the very essence of self confidence does affect ones speech.

Hopefully this article will give courage to someone in the course, seeking or considering returning for treatment for cleft lip or palate.

Sean O'Donoghue
29 October 2004