



### This Edition

Welcome to our Autumn edition. Since our last newsletter we have had another successful Parents' Evening and our Chairman has attended the European Congress of Cleft Support organisations. We have been planning our AGM and Information Evening for the 22nd November. We have also met with the new Crumlin Co-Ordinator. Read On!

### Maternity Initiative

The committee have been working hard to develop a maternity for hospitals. The pack is now almost complete. The pack is based on the new leaflet series but also includes photos, feeding tips, a sample newsletter, a booklet for keeping notes and dates and a covering letter. The Association has written to all of the maternity hospitals advising them of the new pack. Packs can be made available by contacting the editor.

### Crumlin Co Ordinator

We are delighted to let our readers know that Laura Duggan has recently been appointed as Cleft Co-Ordinator succeeding from Claire Kelly. She will operate between St. James's Hospital and Our Ladies Hospital for Sick Children Crumlin, Dublin. Laura comes into the team with a General /Paediatric Nursing and a Managerial background. Having most recently worked as a Ward Manager in The Children's University Hospital, Temple Street, Laura has a considerable amount of experience in Paediatric/Family Centered Care. We wish Laura well and look forward to working with her in her new role.

### Last Parents Evening

Parents evenings are always good nights for finding out how other families are managing- none more so than our last evening held in September. We were glad to be able to especially welcome baby Phoebe and to welcome Co-Ordinators Anne McGilivarry & Laura Duggan who came direct from another

meeting skipping dinner to be with us! Feeding was a 'hot' issue on the night. Do you know that free flow cups are available in Boots? Our next evening is in Feb.

### Information Evening

The Association is delighted to be able to host an information evening on **Tuesday 22nd November** in the Graduate Centre St. James's Hospital.

Guest speakers are Mr. Eamon McKieran Consultant Orthodontist - St. James's Hospital and Ms Sally Ann Lynch National Centre for Medical Genetics - Our Lady's Hospital for Sick Children.

Mr. McKieran is responsible nationally for the orthodontal care of cleft patients and is a regular speaker at our information evenings. Mr McKieran will give an overview on **orthodontal care** including what treatments are available, who carries out the treatments and where they can be got. Ms Lynch will be giving the **first** ever talk to the Association on the subject of **genetics**. Ms Lynch will outline the function of the National Centre for Medical Genetics and will explain how the unit relates to families who have experienced cleft lip and / or palate.

Our Annual General Meeting will also take place - topics include financial report for last year, re-election of directors, appointment of auditors and AOB. Tea & coffee will follow with an expected finish of 10pm

### Next Family Day

We are targeting a weekend next June for our next family day – more details to follow. In the meantime if you are interested in coming to the event or helping with organising the event please contact us.

### Marathon Fund Raising

We want to wish Noel Conway all the best when he runs the Dublin City marathon in aid of CLAPAI. This year the marathon is expected to reach a record number of participants 10,000! Noel has been inspired



to fund raise for the Association by his baby niece Ellie. We'd like to thank Noel for his time and effort. You might say he is one in ten thousand!

### **Waiting Room Humour**

**What's a vampire's favourite sport?  
Batminton!**

**Why didn't the skeleton go to the party?  
He had no body to go with!**

**What happened at the cannibal's  
wedding party?  
They toasted the bride and groom!**

**How can you tell if a corpse is angry?  
It flips its lid!**

**What's Dracula's car called?  
A mobile blood unit!**

**What happened when the ghost asked  
for a whiskey at his local bar?  
The bartender said "Sorry sir, we don't  
serve spirits here!"**

**Why does Dracula have no friends?  
Because he's a pain in the neck!**

**What do you call a ghost's mother and  
father?  
Transparents!**

**What did the doctor say to the witch in  
hospital?  
With any luck you'll soon be well enough  
to get up for a spell!**

### **Social Research**

Reminder - Susan Lawlor is conducting research into the social experiences of adolescents born with a cleft. If you would like to assist in this research please contact Susan on her work mobile (085) 7360994 or email [susan.m.lawlor@nuim.ie](mailto:susan.m.lawlor@nuim.ie). For more details on the research, including consent

form, please see the last edition of the newsletter which can be found on our website [www.cleft.ie](http://www.cleft.ie) or contact the editor.

### **Pen Pals**

Like to make a friend in another country? The Association, 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!



**Cleft Lip & Palate Association of Ireland**

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### European Co-operation

*European Congress of the European Network of Cleft Support Organisations  
Bruges, Belgium, 7-8 October 2005*

I was delighted to represent our Association at this year's European Congress of the European Network of Cleft Support Organisations held in Bruges, Belgium, from 7-8 October. Representatives were also present from the UK, the Netherlands, Norway, Sweden, Finland, Germany, and of course our hosts, Belgium. This is the Association's second year attending the European Congress. Friday was given over to a symposium on cleft rhinoplasty where a number of surgeons enlightened the audience on different surgical approaches. Saturday's programme focused directly on the role of the various European support organisations and how we could work together to better the medical care and support available throughout the whole of Europe. It is well for us to remember that the very good level of care and support available here and in a number of our European neighbours is not replicated in all European countries, not to mention further afield. So with an equal measure of goodwill and effort our Association may be able to improve, in co-operation with other European cleft organisations, the lot of those less fortunate throughout the wider continent. With this in mind, it was agreed that a number of areas where our joint efforts could be of benefit would be identified and agreement reached on a strategy for delivering on an agreed plan of action. I would therefore hope that in twelve months time I can report in our newsletter some developments and indeed progress in this area.

The Congress was also addressed by Dr. Nichola Rumsey from the University of Bristol on the topic of psychological adjustment amongst affected teenagers of facial disfigurement. The Associations have also agreed to make available to each other articles for publication in our respective newsletters informing and enlightening our various readerships of the matter of cleft care in the various European countries.

### *Finnish Ties*

Following last year's Congress in London, you will also be pleased to know that this Association formed close links with the Finnish support group SUHUPO ry, and has explored ways of forging close ties between our respective organisations. One of the ideas to develop out of our close association with the Finnish support group was a 'pen-pal' system. See the article on our **pen-pal scheme** in this current Issue.

I also had the pleasure of visiting Helsinki in May as the guest of the Finnish Association. This was a return visit; the Finnish Chairperson was our guest at our October'04 Information Evening. There she spoke on cleft treatment in Scandinavia and on her experience as a parent of a little boy born with a cleft. She also visited the cleft treatment centre in the Children's University Hospital, Temple Street. On my visit I was able to visit the Helsinki Treatment Centre where I got an insight into treatment in Finland. The most interesting observation I have to make is that cleft treatment in Finland is delivered in one hospital in Helsinki right from birth through the teenage years until treatment is completed. So there is no switch from a 'children's' hospital to an 'adult' hospital at any point, there is continuity of care in the one centre.

It is always great to meet our European colleagues and compare notes. Our Association has long had regular contact with CLAPA UK, and it is wonderful now to see this contact being extended to our other European neighbours. May it long continue.

Eddie Byrne



## Calendar of Events

### Information Evening & AGM

8pm Tuesday 22nd November 2005

Graduate Centre \*, St. James's Hospital, Dublin

### Parents Evening

8pm Wednesday 22nd February 2006

Bankers Club, Stephens Green, Dublin

*Please check closer to date*

### Family Day

Weekend of 10th or 17th June

*Date & venue to be confirmed*

*\*Directions to the Graduate Centre – Enter the hospital via James's Street entrance, pass by the security hut, on your right hand side you will see a red brick building. This is the Graduate Centre. If travelling by car, continue following the road until you see the signs for the carpark. Retrace your steps to get back to the Graduate Centre. Any problems on the night phone 087 8047540. The Association would like to St. James's Hospital for the use of the facilities in the William Stokes Postgraduate Centre.*

