



## Cleft Lip & Palate Association of Ireland

### Newsletter Summer 2006



#### This Edition

Since our last newsletter we have had our annual information meeting in November, a parents evening in February (we have another one coming up on 10<sup>th</sup> May) and now we are preparing for our family day on the 10th June! We would like to thank Eamon McKiernan & Sally Ann Lynch for their respective talks in November. We have included extracts below. We also have some hospital news, reminders & requests and some humour! The Association hopes you will be encouraged to join us at our family day. It should be lots of fun.

#### Orthodontics

Mr. McKiernan gave an excellent presentation on Orthodontics for cleft including treatments available and their associated timelines. Orthodontic treatment breaks down into five stages. Importantly, each individual will have a unique treatment. For example pre surgical orthopaedics is only suited to a small number babies. Similarly not all children will need a bone graft and of those who do not all will need work beforehand. The stages are ...

- Presurgical orthopaedics *birth - 6mths*
- Monitor Growth & Development *birth - 18 yrs*
- Maxillary Expansion prior to Grafting - *10 yrs*
- Orthodontic Alignment *13 - 14 yrs*
- Orthognathic surgery *17-18 yrs*

Routine orthodontics starts at 13 - 14 years approximately. Treatment lasts 24 - 30 months. Routine visits are held every 4 - 6 weeks. For this type of care a hub and spoke system is used to provide treatment, in other words visits to the hub, St. James Hospital, are mixed with visits to a more local orthodontist. Given the frequency of visits and the number of years involved this is important for families outside the Dublin area.

The best way to describe orthognathic surgery is that it typically involves manipulating the jaws to bring them into line. Orthodontic preparation occurs for approximately 18 - 24 mths prior to surgery. Again not all young adults will require or perhaps want this type of treatment. It is available and like other treatments for cleft there is no charge to the family.

Regardless of the treatment plan an individual might have, the common theme that affects us all is oral hygiene. Anybody who is going to wear braces must have a proven track record of looking after their teeth. Why? If food particles are caught on braces they can start to erode the enamel covering of the teeth. The result would completely take away from all the efforts to straighten teeth etc. So what can you do?

1. The usual stuff, wash teeth regularly, avoid sugary products, avoid sugary intake over prolonged periods etc
2. The recommended time to spend washing teeth is **3 minutes**. That might not seem long but try it ... yes it is very long isn't it ... so why not try to wash your teeth to your favourite music track (which happens to be about 3 minutes long). If you are little, why not get a grown-up to read you a favourite story (which happens to last 3 minutes). If you like to wash your teeth in peace & quiet, try use stop watch to keep time. Let us know how you get on!
3. If you want to check your progress you can get a special dye from the chemist, which will show you the areas that your brushing is not getting to. The dye comes as a tablet, you chew it, rinse and look at where the dye has been left i.e. it sticks to the poorly washed areas. This can be really fun because the dye is red!! Try doing this with your siblings (and definitely at Halloween). Teeth care isn't supposed to be fun but sometimes it just is!
4. On a more serious note, you should be visiting your local dentist every 6 months to make sure your teeth are healthy. If you would like advice on how best to wash your teeth organise a visit to a dental hygienist - your local dentist or the cleft team can arrange this. (Again there is no charge to the family for these consultations)

Finally, many thanks to Mr. McKiernan for his excellent presentation and his continued support of the Association.



## Cleft Lip & Palate Association of Ireland Newsletter Summer 2006



### Hospital News – Bone Graft Surgery

Traditionally children that have their first surgeries in OLHSC Crumlin move to St James for their bone grafts. From 2006, bone graft surgery will revert to Crumlin. The Association is very pleased with this move, as we believe wherever possible children should receive medical treatment in a children's medical environment.

### Hospital News – Waiting Room

Orthodontic treatment will continue in St. James hospital which is a centre of excellence in this area and has the technical equipment and skilled staff required for cleft related orthodontics. The Association however has been in correspondence with the management of St. James hospital regarding waiting facilities for children. Informally we believe our request has been positively received. Watch this space ...

### Hospital News – New Children's Hospital

The Association attended the Children in Hospital Ireland Annual Lecture for 2006. Professor Drumm was the guest speaker and his topic was Health Service Reforms: The Implications for Children. The lecture was illuminating. Professor Drumm outlined his vision for the health service and specifically how children's health care will be addressed from the perspective of the patient & family, the community and national children's health. Those present discussed the new children's hospital, its location, its function and other factors at length. The Association has made a submission to the task group assigned to decide on the hospital location. We will continue to make submissions as the process unfolds.

### Marathon Fund Raising



Mini Marathon time is upon us again and we are once again grateful to know that we have participants raising funds for CLAPAI. If you are walking, running or skipping and would like to raise funds at the same time please contact the editor.

### Genetics Counselling?

In the words of Sally Ann Lynch "genetic counselling" is a most misinterpreted concept! Way back when, counselling meant advice and it is in this context that it is still used today when describing genetic services. The service is most certainly not "touchy feely", although all concerned are very pleasant! The service is not one of telling people what to do either nor is it about finding fault. So what is the service about ...

The service is about providing as much information as is possible about the type of cleft a family may have encountered. The process is reasonably simple – a family tree is taken and a quick history of a child's well being is noted. The genetic consultant will then do a physical check on the child. This is really all the information that is needed. The consultant should then be in a position to advise the family based on current research. [Remember there are a lot of gaps in our knowledge regarding the cause of cleft].

There are a few things to remember about the service offered

- The service is free
- Waiting lists are small 2-3 months
- Referrals must go through a cleft team
- There is no strict policy on automatic referral, although this is something that is being considered by cleft teams.

So what do you do if you get an appointment for a genetic consultation through the post?

- Keep the appointment. More information can only help. [& there are no needles!].
- If your family are not ready yet, contact the clinic so that another family can use the time slot.
- If you haven't had a consultation but think it would be of benefit to your family contact your cleft team.
- Finally, there is no time limit on seeking a genetic consultation!

The Association would like to thank Sally Ann Lynch for her comprehensive presentation. It is the first such talk we have had on genetics - we hope we may enjoy many more!



## Cleft Lip & Palate Association of Ireland

### Newsletter Summer 2006



#### Waiting Room Humour

Why did the man put his money in the freezer?

A. He wanted cold hard cash!

Q. What did the porcupine say to the cactus?

A. "Is that you mommy?"

Q. What do you get when you cross a snowman with a vampire?

A. Frostbite.

Q. What do you get from a pampered cow?

A. Spoiled milk.

Q. Where do polar bears vote?

A. The North Poll

Q. What did Geronimo say when he jumped out of the airplane?

A. ME!!!

Q. Where do snowmen keep their money?

A. In snow banks.

Q. What's brown and sticky?

A. A stick.

Q. Why do sea-gulls fly over the sea?

A. Because if they flew over the bay they would be bagels!

Q. What dog keeps the best time?

A. A watch dog.

Q. What did the grape do when it got stepped on?

A. It let out a little wine!

Q. Where do bees go to the bathroom?

A. At the BP station!

Q. What did the judge say when the skunk walked in the court room?

A. Odor in the court.

Q. What did the water say to the boat?

A. Nothing, it just waved.

Q. What did the fish say when he swam into the wall?

A. Dam!

#### Reminder

Susan Lawlor is conducting research into the social experiences of adolescents born with a cleft. If you can 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)

#### TV Series

Mint Productions is researching for a proposed television series about people with facial differences who have had medical treatment and/or surgery. As part of this research, Mint Productions would very much like to speak with people born with a cleft about their own experiences. This would be purely for research purposes and all conversations would remain confidential. If you feel you could help us, please contact Paula on 01 4913333 or email her on: [paula@mint.ie](mailto:paula@mint.ie)

#### Parents Evening – Wed 10th May

Parent's evenings are informal occasions that allow parents of children born with cleft to meet and share experiences. Our next parents evening is on above date at 8pm in the Bankers Club Stephens Green – contact editor for directions. This is our last parents evening at this location as the Bankers Club are soon to move to Stephens Street. The Association would like to thank Alan and all the staff who have facilitated the Association for many years.

#### Contact Editor

For more information on any of our articles please contact the Editor. Similarly to be added or removed from our mailing list please contact editor.

*Georgina Wade, 4 Wolverton Glen, Dalkey, Co. Dublin. Phone 01 2848227 Email [wade@cleft.ie](mailto:wade@cleft.ie)*

# FAMILY ACTIVITY DAY



**Saturday 10<sup>th</sup> June 2006 at 10am to 4pm**

**Defence Forces Training Centre, Curragh Camp, Co. Kildare**

Following our inaugural family activity day with the Arklow Sea Scouts in 2004, the Association is holding a family day in June thanks to the Defence Forces.

Not only are the army making their facilities available they are cooking up a giant barbeque, laying an obstacle course for adults and children, organising a military exhibit and setting up tents for loads of cups of tea. In between all that activity there will be games for children, face painting and lots of fun.

The family day is for anybody that has been affected by cleft lip and / or palate and their families. It's an opportunity to meet, swap stories and mostly have fun. If you want to come along complete the booking form below and send to the Association. For more details please phone **087 1319803** .... By the way there is a swimming pool too ...



## BOOKING FORM

Please complete the attached booking form and post to Georgina Wade, 4 Wolverton Glen Dalkey, Co. Dublin or complete a softcopy (available on web site [www.cleft.ie](http://www.cleft.ie)) and send to [wade@cleft.ie](mailto:wade@cleft.ie). To help us organise please contact us before the 3<sup>rd</sup> June. The Association will acknowledge your booking on the evening it has been received. If for any reason you do not hear from us please contact us by phone.

Family Name		Family Address		Contact Numbers
Name	Adult /Child	Child's Age		
Special Needs		Transport Help?		

If you are travelling by rail, please enter your expected time of arrival at Kildare station. If you wish to share the journey with other travelling from your area please let us know. Please also let us know if you are having difficulties attending due to transport problems. **This day is funded by the Association.**