



Cleft Lip & Palate Association of Ireland

Newsletter Spring 2008



This Edition

In this edition we cover events, need for funds, news and our usual Waiting Room Humour (yes, more of those jokes!) We are particularly glad to feature the next part of Sean O' Donohue's story. Sean's story should be encouraging for anybody thinking of going back to complete treatment. We are also glad to publish our first hospital story from one of our young readers Cormac. Even though treatments differ we think that our young readers will enjoy comparing notes on hospital stays! We would like to say a big thank you to Sean & Cormac. If you have a story we can add we would most happily add it to our newsletter.

Maternity Pack Launch & Information Evening

Date: Tuesday 26th February 2008 @ 8pm

Venue: Accenture, No 1 Grand Canal Square, Dublin 2 – see website for location details

EVENTS

Maternity Pack Launch

For some time the Association has been working on a pack for new parents. The pack includes our information leaflet series, tips on feeding, before & after pictures, sample newsletter, sample screen from our website, children in hospital charter, an appointment & contact card and an all important set of pens! It is all contained in a durable folder that can be used to build up important information.

Dr Michael Robson, Master of the National Maternity Hospital will officially launch the pack. The production of the pack represents a milestone for the Association. We hope you will join us for this important occasion. Fundraising activities by parents have entirely financed this pack and its distribution to all maternity hospitals in Ireland!

Guest Speaker from Changing Faces

Following a successful talk in 2003, we have asked Changing Faces back to give us advise on how our children born with cleft can cope with difference in their school and play environments. Changing Faces is an organisation that was set up in Britain over 10 years ago and has a lot of experience in this area. The aim of Changing Faces is to enable people to tackle disfigurement with confidence. It does this by providing information, support, counselling, workshops, family days and other activities. The organisation has researched practical

ways to help deal with difficulties that may be experienced at school.

Presentation of Funds

Thanks to the effort of some of our young adults that were born with a cleft we are in a position to contribute €6,700 towards the cost of software required for the new 3D equipment that will be used by the Dublin Cleft Team. The new equipment will facilitate better pre-operation planning for work that is typically carried out on teenagers and young adults. The equipment allows the Team to get a very precise image pre-surgery; they can plan each adjustment more accurately and give the young adults a much better prediction of post surgery results. We are fortunate that the Team never stops striving for better patient care. As an Association we are very pleased to be able to help.

Family Day Update

Planning has begun for our next family day. Target dates are the second or third weekend in June. We are looking for a venue – help in this regard would be welcome – (contact editor).

For a full report on our 2007 family day see our website.



**Joining in with
the Band**

Curragh 2007

FUND RAISING

2008 Mini Marathon

This year has been a very active year for the Association in addition to the normal newsletters; information evening and annual family day we have reached a milestone with our Maternity Pack. Volunteers doing marathons finance the majority of this activity. This year more than most we need your help. The Flora Women's Mini Marathon is on Bank Holiday Monday 2nd June 2008. Sponsorship cards and t-shirts can be arranged by contacting Anne Gilsenan at 087 1319803 or annegilsenan@cleft.ie. The first entry form will be in the Evening Herald on 28th Feb and on Thursdays and Saturdays until the closing date in April (or when capacity reached). Entry will be



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available on www.womensminimarathon.ie from 29th Feb.

NEWS, REQUESTS & UPDATES

New Committee Member Needed

The committee is in need of a new member to augment the current team and bring it up to full strength. So why not be that person? The Committee meets approximately once every 5-6 weeks, less during holiday periods. Remember, your contribution, no matter how small, can go a long way! See contact details below.

Research Update



Before Christmas we caught up with Peadar Kirke from the Health Research Board to find out how the 'trans-Atlantic' research group are doing. Peadar says "I am happy to report that we have been making good progress in our research on clefts. In our study of the first group of genes which we are investigating, data analysis is continuing and should be finished in the next few months. We will then submit a research paper on our findings to a scientific journal for publication. The usual interval between submitting a paper and publication is about 6 to 12 months so you should not be holding your breath! We are also interested in investigating the role of other genes in causing clefts and we hope to pursue this over the coming months". Peadar will give us another update when the first of these papers is actually published.

New Children's Hospital

Since our last newsletter a Development Board has been appointed and RKW have issued their high level (419 page!) report.

As part of their research RKW has had 250 meetings (CLAPAI included in 3). This is the level of consultation that is to be welcomed.

RKW had seven items to consider in their report. The result is a framework for

1. How a national services network will operate
2. How the hospital will work
3. Where & how the emergency units for Greater Dublin will fit in (Tallaght in advance of the new hospital build, Blanchardstown later depending on the Tallaght experience and possibly long term Loughlinstown)
4. What services will be provided & for how many patients
5. What standards are to be set for space

6. What the size of the hospital might be which varies from 'all in' 113,600m² to the minimum size 75,620m². Decisions on what services to share with other hospitals and what services to have off campus will influence the size. These decisions and building design will be dealt with at the next stage.
7. How the hospital might lie within the Mater site. A number of possibilities are outlined – the main influencing factor seems to be interaction with neonatal care in the maternity hospital.

Note: location of the main hospital was not part of RKW's brief.

Operation Smile Ireland – Largest Ever Effort

In November 23 medical Irish volunteers went to Ethiopia Kenya & Morocco. Between them they treated 250 patients in a two-week period. Co-ordinator Anne McGillivray was based in Jimma Ethiopia along with Mr. David Orr and Triona Sweeney. The conditions in Jimma were particularly challenging but the team managed to screen 157 patients and perform 127 surgeries. Patients' ages ranged from 3 mths to 68 years!

Web site – Did You Know

A key feature of the new website is the inclusion of RSS which stands for Really Simple Syndication). It is an easy way to receive automatic updates from a website. The feature allows busy parents to keep in touch without having to 'go look' for information. It is simple to use... just click on the type of information you want to track.

Subscribe

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[\[What is RSS?\]](#)

This brings you to a page where you can pick the mechanism for receiving notices e.g. your browser, Google Reader, email. Then let the information come to you! Why not try it!



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For CLAPAI's Winter 04 newsletter [available on web] Sean wrote an article describing how he had returned to start completion of the work on a bilateral cleft lip and palate. The next part of the story follows.

Treatment from November 2004 to October 07

After my consultation with the cleft team in November 2004 the next stage/s for the treatment were to begin with the Orthodontics once my palate had healed. This started in January/February 05 with the measurements for the fitting of orthodontic wiring to begin the re- alignment of my teeth to bring them to a stage so that Orthognathic surgery could take place.

For almost the next two years I would attend the maxillo facial clinic in James on average once a month to every six weeks. This meant each attendance I took a full day out of my working life and travelled from Limerick to Dublin. I have being lucky in the respect that the firm I work for allows me this time, and also that I can still continue to complete work whilst out on these days thanks to modern technology.

In between the orthodontic treatment I would have seen the cleft team a few times to evaluate my process with the Orthodontics. In September 2006 it was decided I had arrived at that Orthognathic surgery could take place.

The surgery took place on the 29th of November 2006 in St Francis Hospital Mullingar. I spent about five days in hospital. I will not lie here and say the surgery was easy; it can be described as just about tolerable. I had the bone harvested from my hip to graft the space in my jaw when the bone structure was moved forward. I was wired up with a split holding my jaws in position to allow the graft to heal. The worst part of all this was the diet. For a person who likes different tastes in food the liquid diet for the few weeks until the end of January 07 was not the most enjoyable of times. The average time for the wiring to remain in place is around 6 weeks it was however the first week in February before the splits were finally removed. I must also say at this on the 29th November 2006 there was attempt to close a remaining fissure in my palate, as there was still a fissure after the August 2004 graft.

I got back eating in February but with care, and my weight began very slowly increasing, once again as an active person I was never over weight and more often than not find it hard to keep it on. I think the weight loss got to me more than anything over these

few months. Just before I had planned return to work in March 07 I underwent a pre medical, which threw up some issues with my blood specs. The iron levels in my body were extremely low; this resulted in an investigation to establish why this was taking place. It was April before the actual cause of the low iron levels was established the reason being I was COELIAC. Within weeks of eliminating gluten from my diet my weight had recovered to its normal level – it had stabilised for the first time since my teens!

Commitment to the treatment

The last few years have being a busy time for me with the ongoing treatment and trying to balance my work life with this. I must say that I had to slow my career advancement due to the commitment to treatment and time taken out to recover from each of the procedures. It is not easy to go through Orthognathic surgery but the end result is well worth it. It is also a huge benefit to have the necessary supports while in recovery from this type surgery. The physical recovery will come with time and due care but the psychological recovery is just as important as well. It's important to have the support of friends and family to encourage one through the whole recovery process.

The next stages

Presently the Orthodontics treatments continues and I will be moving towards the implant stages in early 2008. To be conservative I expect the overall treatment to continue at least into the later stages of 2009. It's nice to be able to say that every step is in the right direction. I am very pleased with how the last few years have progressed and I am at this stage glad to be over the Orthognathic surgery.

I must highlight the excellent support and dedication of the whole Cleft Team /Support staff of St James Hospital / St Francis Hospital Mullingar and would like to say thank you. The same goes to my family and friends for putting up with me (not the best patient at times) for the few months at the end of 2006 beginning 2007. With the current atmosphere and criticism that's surrounding the health service let us not lose sight of the fact that there are excellent highly skilled people running the service who are giving above and beyond the call of duty.

(John Michael) Sean O Donoghue [Autumn 2007]
[Please see website for full report]



Waiting Room Humour

Q. What does an electric rabbit say?

A. Watts up Doc!

Q. Why did the man run around his bed?

A. To catch up on his sleep!

Q. What time is it when an elephant stands on your foot?

A. Time to call the doctor!

Puzzle

Write down the answers to these questions as quickly as you can – then check your answers.

Q1 You are participating in a race. You overtake the second person. What position are you in?

Q2 If you overtake the last person, then you are...?

Q3 This must be done in your head only. Do NOT use paper and pencil or a calculator. Try it. Take 1000 and add 40 to it. Now add another 1000. Now add 30. Add another 1000. Now add 20. Now add another 1000. Now add 10. What is the total? Go quickly now ...

Q4 Mary's father has five daughters: 1. Nana, 2. Nene, 3. Nini, 4. Nono. What is the name of the fifth daughter?

Answers

Q1 - If you answer that you are first, then you are absolutely wrong! If you overtake the second person and you take his place, you are second!
Q2 - If you answered that you are second to last, then you are wrong again. Tell me, how can you overtake the LAST person? Q3 - Did you get 5000? The correct answer is actually 4100. Don't believe it? Check with your calculator!
Q4 Nunu? NO! Of course not! Her name is Mary. Read the question again!

Grown up ... make sure they answer quickly!

WHEN I WAS IN HOSPITAL

By Cormac (Age 9)

A True story

I went to Limerick Hospital to get a piece of bone taken from my hip and put into my gum. I got my third and last splint in.

We left at six o'clock in the morning and arrived at eight o'clock in the morning. When I arrived it wasn't so bad because I could do most of the stuff I usually do like watch my favourite T.V. programme. A doctor took some blood out of my arm. They put a gown on me and put me on a bed with some wheels at the bottom. They brought me into the theatre and put me asleep with some minty gas.

When I woke up I had a new splint in my mouth, a plaster on my face, bandages on both of my hands and two tubes out of my left hip. They took me to my room and put me in the bed. They took my temperature, blood pressure and pulse every few hours. I was on a drip as I could not eat or drink. I also had to lean on cold wet things to bring down the swelling. On Friday I was allowed clear fluids. I had my first walk and it hurt a little bit.

Early on Saturday morning they took off the two tubes in my left hip and it didn't hurt a bit and put a new plaster on it. Later that day my brother, sister and Dad came to visit me and my mum. While they were visiting a nurse took the bandage and needle (cannula) off my right hand.

Sunday morning I got sick and after that I had a sleep. After that I was allowed yougurts and milkshakes again. Later that day I took the bandage off my face myself. That night I drew a picture in my sketch book and had a chocolate Milkshake. I also drew a picture for my doctor Mr. Kearns and for the nurses but they put it on the wall in my room.

On Monday I was allowed actimels and yops. I gave the picture from my room to the playroom. I got the bandage and the needle (cannula) off my left hand on Monday as well. After I packed up, I gave the picture to Mr. Kearns, I gave the thank you card my Mum made and the box of sweets my mum bought to the nurses and went to get my nose cleaned (because there was dry blood in it) I went home.

Home sweet home!

The End