



Cleft Lip & Palate Association of Ireland

Newsletter Spring 2007



This Edition

This edition covers upcoming events, the New Children's hospital, fund raising plans & successes, hospital news, reports on recent activities and our usual Waiting Room Humour. The edition also includes a new publication Eurocleft Newsletter. We hope you enjoy ...

Events

Parents Evening Spring 2007

Parent's evenings are informal occasions that allow parents of children born with cleft to meet and share experiences. It can be encouraging for parents to meet with other parents who have children of the same age or a little older. It is also good to share tips with parents who have younger children. The evening is not geared for children as such, but newborns are more than welcome – we know that getting babysitters in the early days is not always possible. We look forward to seeing you over a cup of tea! All you have to do is turn up on the night!

Date: Wednesday 9th May 2007 at 8pm
Venue: NEW BANKERS CLUB, Stephen Street Upper, Dublin 8

Bankers' Club located at the junction of Golden Lane, Longford Street and Stephen Street Upper - see website for details - nearest car park Drury Lane.

22q Conference

22q is a very rare condition that amongst other symptoms involves cleft palate. On **Saturday 26th May** a conference is being organised for people that are 'living with 22q'. It is an opportunity to meet other families, healthcare professionals and experts and admission is free. The conference is being held in Croke Park Conference Centre. Crèche facilities will be provided. Please contact Anne Lawler (01) 8338390 or email grainne.mooney@o2.ie for more details.

Family Day Update

Planning has begun for our next family day. Target dates are the **second or third weekend in June**. It would be useful for planning if we could receive expressions of interest as soon as possible. Other than that, please keep an eye on the website for the most up to date news.

Fundraising

2007 Mini Marathon

The financial mainstay of the organisation is due to take place on Bank Holiday Monday, 4th June 2007. It is of course the 2007 FLORA WOMEN'S MINI MARATHON. The Association is, as usual, looking for participants to raise funds. Sponsorship cards and t-shirts can be arranged by contacting Anne Gilsean at 087 1319803 or annegilsean@cleft.ie. In the meantime we would like to let you know that the first entry form will be in the Evening Herald on Thursday 1st March 2007 and the closing Date is Tuesday 24th April 2007 or when maximum number of entries is reached. Happy training people!

Christmas Cards

2006 was a first for the organisation when we produced our own Christmas cards but certainly won't be a last. Being the first year our sales strategy was more like 'suck it and see' than a set 'game plan'. However we are glad to report that we have not only covered costs but have made a profit and have a stock that we will be able to sell early in the season in 2007. This good fortune is in no small way down to the design of the cards - for those of you who have not seen them yet - they are bright, colourful and definitely child oriented.

One of our goals was to promote awareness of the Association so we are equally glad to report that the feedback from relations and friends has been positive on that score also. The Association would especially like to thank committee member Niall Murray for putting the pack together and of course we would like to thank the generosity of those who bought the cards and the effort of those who sold them.

Donations from Far Afield

Many thanks to Tony & Mary Kelly who organised a gate collection at their local GAA ground - many thanks to the supporters at Naomh Teagain. We would also like to thank the extended Kearney family who swapped Christmas gifts for CLAPAI donations ... what a cool idea! Thanks also to Eddie, Alice, John, Paula, Noel and the Carrig Ladies Club who all made much welcomed donations recently.

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



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New Children's Hospital

Building a new children's hospital is something that is of significant interest to families affected by cleft. In 2005 both Children's University Hospital and Our Ladies Hospital for Sick Children were well advanced in planning replacement and upgraded hospitals respectively. Plans were put on hold when the option of building a single tertiary hospital was put on the agenda. The initial recommendation came from a report the HSE commissioned from McKinsey. The Association broadly welcomed the idea and made a brief submission to the group in charge of the next part of the process. Since then, public disquiet, expressed by medical professionals and parents alike, has prompted the Association to undertake a more detailed look at the process to date using documentation available in the public domain.

It is the opinion of the Association that the McKinsey report is, in itself, a good report and the recommendations remain broadly welcomed. However the Association is critical that the terms of reference for McKinsey did not include consulting with "experts and practitioners in Ireland" nor did the terms of reference include having "access to detailed hospital specific data on the nature and quality of care" in Ireland. A review of the report produced by the Task Group that was in charge of the next phase of the process gave rise to grave concern. It appears there was a real failure to engage with paediatric professionals in this country amongst others. In November 2006, the Association gladly accepted an invitation from Children in Hospital Ireland to attend a meeting of interested voluntary groups regarding the new hospital. The outcome of that meeting was that several organisations have agreed to work together with Children in Hospital Ireland in order to make our voice heard.

Since that time, CIHI have managed to arrange a meeting with representatives of the HSE and RKW (the professionals engaged to complete the next phase of the project). At the meeting, organisations present were invited to make a submission regarding the requirements of their particular groups. This Association's submission is drafted and ready to submit.

What can you do? The process to build the new hospital is moving quickly. It is difficult for voluntary bodies such as ours to keep pace. Therefore we would encourage everybody to keep informed. If you have issues or concerns raise them with your local TD. Keep us informed; let us

know what the issues are for you as a family. We will push them through whatever channels we can. Let us not forget that the new children's hospital is a golden opportunity to get what is best for our children. The fact that all of us have direct children's hospital experience gives everyone of us the right to express an opinion, forward a suggestion, and voice a criticism. Let's make our input count!

Hospital News

Special Fund Raising Effort

In our last edition we mentioned a fund raising drive that has been launched to get new equipment for planning treatment. The piece we are fundraising for is a new computerised 3 Dimensional Capture systems. The current system uses a conventional 2 dimensional X Ray image and a superimposed digital photograph. The new 3Dcapture system allows interactive surgical simulation and evaluation due to growth, aging and intervention in 3 dimensions. It will also facilitate storage of all necessary cleft records for audit and research purposes. In the words of Mr McKiernan, it will "provide an invaluable tool for planning orthodontic and surgical treatment for children and adults with clefts". The account for making donations specifically for this purpose is below.

EQUIPMENT BANK ACCOUNT DETAILS
Bank of Ireland, St Stephen's Green, Dublin 2
Sort Code: 90-00-84 A/C No. 56191109

Radio Broadcast

Congratulations to the team and families at Temple Street. Valerie Cox did a Radio1 report on Consultant Plastic Surgeon Michael Earley and the work of the team. They also interviewed families who were able to give their perspective. Many thanks to Anne McGillivray who made sure that the website for the Association was given on air. The Temple Street team are also involved in a TV production ... watch this space for news!



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Reports

Report on Nursing Programme

Donal Garvey recently gave the Association's annual lecture to the school of Paediatric Nursing now based in its new UCD centre. The class were very enthusiastic and were very anxious to understand parents' perspective. The Association would like to wish the class well on their 18-month programme.

Report on Info Evening 2006

First to speak was **Mr. Patrick Sheahan**, Ear Nose & Throat Consultant with a special interest in Cleft, Children's University Hospital, Temple Street & St. James's Hospital. His topic was middle ear disease in cleft lip and palate. He covered the different types of middle ear disease and the different treatment options available. He spoke of the factors relating to cleft and the results of various studies of the incidence of middle ear disease amongst children born with a cleft palate. He stated how 'glue ear', i.e. fluid in the middle ear (OME), is very common amongst all children, not just those with a cleft. He covered the advantages and disadvantages of grommets, which he stated do not correct the underlying problem.

Next up was **Ms Anne McGillivray**, Cleft Co-Coordinator for the Children's University Hospital, Temple Street. Anne's topic was the management of cleft lip and palate: a personal and professional perspective. Ann's son was born with a cleft lip and palate and is now in his late 'teens'.

Anne gave an overview of the Cleft Service and the Dublin Treatment Centre, which covers three hospitals; St. James's, Crumlin and Temple Street. She discussed the various specialists involved in the multidisciplinary core team and others specialists, which can be called upon as, need arises. She outlined the role of the Cleft Coordinator and developments nationally and internationally. She spoke of 'integrated care pathways' and record management. She covered the various questions on the minds of new parents.

Anne also discussed at some length her and her son's personal experiences - the various surgeries, the pleasant surprises as well as the worries, and the amazing attitude of her son in dealing with the fact of his cleft, yet living a very full and rewarding life. Anne's personal account

was invaluable and the attention from the floor was palpable.

Many thanks to both speakers for giving of their time and imparting some valuable insights and knowledge to a most appreciative audience.
[Please see website for full report]

Research Update



Some of you will know that there currently is in an extensive study of the causes of cleft and how clefts can be prevented from occurring. The HRB are one of a number of organisations involved in this 'trans-Atlantic' research. Many of you will remember the two-year drive that the HRB conducted to collect samples from Ireland. Over 1,000 families participated by filling in questionnaires and providing 'buccal' samples. The HRB have been in touch recently to let us know how the next phase of the study is going but first they wanted once again to thank all of the families that have taken part. Following the physical collection phase the next task was to "anonymise" the data and then carry out a high level analysis. Both of these tasks are complete and now the study team is zoning in to pursue a small number of genes. Realistically this will take quite some time. At the end the genes in question will either be 'eliminated' from enquiries or they will lead to further study. The HRB have committed to come back to us when the research findings are published which will probably be at the end of this year or early next year. We wish everybody involved success and look forward to the next progress report.

New Director & Cathaoirleach

Georgina Wade has succeeded Eddie Byrne as Cathaoirleach of the Association. Eddie was appointed Chairperson in October 2003 when he succeeded Ruairi Ó Dúlaing. Anybody who reads our newsletters regularly will know the amount of work that has happened under Eddie's stewardship. In addition to chairing the Association, Eddie is also our Webmaster. On behalf of everybody, we would like to express our many thanks to Eddie for his role over the past three years and thank him also for agreeing to remain onboard as our advisor and Webmaster.



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The Cleft Lip and Palate Association is a limited company, which means all the usual company posts must be filled. We are glad to announce that newly appointed director Donal Garvey has taken on the role of company secretary. It is perhaps opportune to thank our other dedicated committee members Aine, Anne and Niall. Not forgetting our constant guide Tony without whom we would be lost ...

Waiting Room Humour

- Q. What do you call an elephant that flies?
A. A jumbo jet!
- Q. What does an angry kangaroo do?
A. Gets hopping mad!
- Q. What do you get if you cross a cow with a camel?
A. Lumpy milkshakes!
- Q. What is the definition of a goose?
A. An animal that grows down as it grows up!
- Q. Why did Bo Peep lose her sheep?
A. She had a crook with her!
- Q. What animal always goes to bed with its shoes on?
A. A horse!

Puzzle

Imagine you are in a room with 3 switches. In the room next door there are three bulbs (all off), each switch in the first room belongs to a bulb in the second room. It is impossible to see from one room to the other. How can you find out which switch belongs to which bulb - you may enter the room with the bulbs only once.

Solution

Keep the first bulb switched on for a few minutes.
It gets warm.
Switch it off & switch another one on.
Walk into the room with bulbs, touch them.
The first one is the warm one, the second one is getting warm and the third one is still cold .. Got it?

If there is something you would like in the New Children's Hospital please ask your folks to let us know!

Tom & Molly Review...

A few weeks ago we asked Tom (9) and Molly (9) to review an unusual type of toothbrush. Here they are in interview ...

- Q. Can you describe the toothbrush for other children?
M. Pretty much looks like a normal toothbrush except it's a dancing girl in it - or a leprechaun - and it lights up.
- Q. Tell me about the light
T. You press the button on the bottom of the toothbrush and a light flashes in the handle
- Q. What's the trick with the new toothbrush?
M. It flashes for one minute at a time
- Q. Did you know how long you brushed your teeth with your old toothbrush?
T&M. NO
- Q. Do you know how long you should brush your teeth?
T&M. Don't know, maybe three minutes?



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Q. How many minutes do you brush for now?
M. Sometimes two minutes
T. One minute, I don't want to take too long!

Q. Which toothbrush do you prefer?
M. The regular one is much easier to handle & when you put it away it doesn't start flashing if you bump it against something.

Q. What would you say to other children, is it worth it?
M - it is even though it flashes when you don't want it to
T - no, it takes longer to brush your teeth
Mums say - flashing toothbrush is worth it!

If you have any ideas for making tooth brushing more entertaining please let us know!