# Cleft Lip & Palate Association of Ireland



## **NEWSLETTER - WINTER 2002**



## WHATS IN A STARE?

I recently attended the AGM of CLAPA UK. It was my first visit although CLAPAI are represented most years. There was a packed agenda that was full of interesting topics. Jane Frances from Changing Faces gave the first talk. I cannot give a report on all of Jane's talk suffice to say it was most enlightening. The following are my own notes on the section of the talk that dealt with staring.

Sometimes a child will tell a parent that other children are 'staring' at them. We might be tempted to shrug it off or say that it's only in the child's imagination. The reality is that it is probably true. If we think about a stare as being an unasked question then maybe it will help us to cope better. If we accept that children born with cleft can look different then we will realise that children are bound to stare particularly at a first meeting. They are staring because they probably have not seen the condition before. How to cope?

Firstly, validate what your child says. Yes children do stare. Its because they have not seen anybody with your condition before. Next develop some coping mechanisms that your child can use. Having a standard response to the ready can make all the difference. Try in the standard response to answer the unasked question and then engage the person in conversation. Examples of some standard responses are below. The trick is to engage in conversation by asking a question, maybe changing the subject as you go.

- © It's called a cleft lip, have you not seen it before?
- © Its called a cleft lip, I had an operation when I was young, have you ever had an operation?
- My nose is weird, its cool to be weird, what's your weird thing?
- © I had an operation when I was young but I still play football and everything else. Do you play football? [or ballet etc] If you are an adult that notices one child staring at another then don't be afraid to answer the unasked question.

There was a lot more to what Jane had to say and this short piece will not do the information she presented justice. Changing Faces do not have an organisation in Dublin but the good news is that they will be coming over to give a talk at our March Information Evening. Dates to be confirmed. Details in next newsletter.



# CHRISTMAS GIFT IDEA



With the Christmas season fast approaching you may want to consider the gift of an electric toothbrush but what do the experts say? Talking to Paddy Fleming, Paediatric Dentist with Our Ladies Hospital for Sick Children, he says electric toothbrushes are just as good as regular ones. You can get the same result. If however the novelty of an electric toothbrush stimulates more brushing than that's a plus.

The key factor to brushing is parental supervision. Here are some of the things parents should know.

- © It is important that children do not swallow toothpaste small children in particular need to be carefully watched.
- Make sure that gums are taken care of, gums should be gently brushed. Again small children need to be watched they can get carried away and can be a bit rough on their gums.
- $\odot$  2  $\frac{1}{2}$  to 3 minutes is about right for brushing as long as the right areas are being covered.

One of our parents has had good results from using an egg timer to check brushing. The novelty factor makes sure that children (and grown-ups) put enough time into the job.

Bernie Owens, Dental Hygienist with Crumlin, says that 70% to 80% of Irish people have gum disease. She points out that the area between gum and tooth needs to be brushed to help prevent gum disease.

Keeping teeth healthy is crucial for children born with a cleft. A fact you may not know is that local dental health clinics will carry out 6-month checks from the appearance of first teeth. This is a measure of how important dental health is for children with cleft. There is no charge by the way for the check up.

So what's the best gift to give your child's teeth this Christmas? It's got to be parental supervision. After that I don't think the novelty factor of an electric toothbrush will go too far wrong.

Thanks to Paddy Fleming and Bernie Owens for their input.

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## REPORT ON INFORMATION EVENING & AGM

The Annual General Meeting of the Cleft Lip and Palate Association of Ireland was held on Tuesday, 24th September 2002 at 7:30 pm in the William Stokes Building, St. James' Hospital, Dublin 8.. Ruairí Ó Dúlaing was re-elected Chairman.

In addition to the AGM two talks were given. Our guest speakers covered topics concerning treatments of children at different ages. Ms. Julie Young, Speech Language Therapist Lecture spoke on "Speech Language Therapy in Cleft Treatment". Mr. Frank Brady Oral and Maxillofacial Surgeon Lecture spoke on "The role of the maxillofacial surgeon in cleft lip and palate".

Ms. Julie Young is a Speech and Language Therapist [SLT] attached to Temple Street Children's Hospital. The role of the SLT is vital for a successful outcome to cleft treatment. Ms. Young concentrated on speech and language therapy but also addressed feeding issues, highlighting the role in this respect of the SLT. Mr. Brady is one of the country's leading maxillofacial surgeons involved in the treatment of cleft. His work starts with children age 10+ through to adulthood. The evening was a notable success with questions being put to both speakers from the floor and delight being expressed at the contributions of both speakers

We would like to thank both speakers and all that attended for making the night an informative and enjoyable experience. Note: The presentation by Julie Young on speech and language therapy in cleft treatment is now available at <a href="https://www.cleft.ie">www.cleft.ie</a>.

#### NEXT PARENTS EVENING

## Tuesday 21st January 2003 at 8pm

The Association regularly hosts informal evenings to facilitate parents. The evenings are aimed at helping parents to learn from each other. Open discussion is encouraged on all topics that affect children and their families. Parents, grandparents and guardians are all welcome. We hope that everyone will benefit. Free Admission.

Venue is - William Stokes Building, St. James Hospital [The modern redbrick building right beside the James Street entrance. The following buses serve the hospital:

- The 123(Imp) passes through the hospital grounds.
- Numbers 78 and 78A pass by the James's Street gate.
- Numbers 19 and 19A pass the Rialto gate of the hospital.
- Number 17 serves Rialto, a five minute walk from the Rialto entrance to the hospital.

## NEXT INFORMATION EVENING

Week commencing 10<sup>th</sup> March - date to be confirmed.

The next information evening will be held in March in the same venue. Please watch out for our next newsletter for information and finalised date. Newsletter available by post or on the web <a href="https://www.cleft.ie">www.cleft.ie</a>

# **Mentec**

# Fundraising Event Raises Euro 930.00

Mentec's social committee recently organised a table quiz fundraiser for the Association. By coincidence Triona Sweeney from the Children's Hospital Temple Street sent us a request for funds to help train Speech Language Therapists in the use of new techniques / equipment. With this in mind the folks in Mentec pulled out all the stops and organised an excellent raffle in addition to the table quiz.

Prizes for the raffle were donated by - Irish Items (2 lovely golf bags), Discover Scuba, Panache Dry Cleaners, and Maguire Sports. In addition T. Bourke & company donated a cheque to the fund.

Many thanks to everybody involved for organising sponsoring and participating in such a successful event.



## **Future Editions**

You can register for email copies on <a href="www.cleft.ie">www.cleft.ie</a> The Association brings out four newsletters per annum. If you would like to submit an article for any of our future publications please contact Georgina Wade, 4 Wolverton Glen, Dalkey, Co. Dublin. Phone 01 2848227 Email <a href="www.wade@cleft.ie">www.cleft.ie</a> The Association brings out four newsletters per annum. If you would like to submit an article for any of our future publications please contact. Georgina Wade, 4 Wolverton Glen, Dalkey, Co. Dublin. Phone 01 2848227 Email <a href="www.wade@cleft.ie">www.cleft.ie</a> The Association brings out four newsletters per annum. If you would like to submit an article for any of our future publications please contact.