



WELCOME to our Spring Newsletter for 2004. As usual the Association has been kept busy. The early part of the year has been dedicated to completing our new series of information leaflets and securing additional funding for their production. The Association were invited to speak to students at the School of Midwifery, University College Hospital Galway in February. Planning is continuing on our activity day on 19th June in Arklow and for our next information evening. Enjoy our Spring edition and don't forget to **book now** for our activity day. Ed

Leaflet Series

The Association is happy to announce that it has, this month, been awarded a grant from Lotto funds. This money in addition to the funds raised last year by Mini Marathon participants will allow us to go into production directly. The leaflets in the series are

1. About the Association
2. What is Cleft Lip & Palate
3. Questions and Answers for New Parents
4. Feeding Issues for New Parents
5. Speech and Hearing Concerns
6. The Genetics of Cleft Lip & Palate
7. Orthodontic Treatment plus Dental Health
8. Surgical Treatment
9. Social & Psychological Aspects and your child
10. Handout for Teachers & Carers

The leaflets are designed for use at relevant times throughout the treatment period. For example, while it is important initially to know that orthodontic treatment will be a factor the detail may be lost on the new parent or may be overwhelming. Using the leaflets, there should be the right level of detail for all phases.

There will be more on release and distribution in our next newsletter.

Research – A Message from the HRB

The Health Research Board wishes to sincerely thank all the CLAPAI members who have taken part in our study so far. The study has continued to expand with over 1,000 families presently involved. The more people we have in the study the more valid our research findings will be. The study aims are to find out what causes clefts and to investigate how clefts can be prevented from occurring. Without the valuable input from families, we would not be able to undertake this important research.

The research team will be recruiting up to the autumn of 2004, so it is not too late to take part. We would also like to ask people who have yet to return study materials, such as swabs, consent forms and questionnaires, to return them as soon as possible or contact the research team for replacements (**Freephone number 1 800 201074**). This will help us to get results as soon as possible.

We sincerely hope that this study will bring answers to why clefts occur and how to prevent them and we would like to thank you again for taking part.

Urgent Appeal

I would like to take this opportunity to express a special word of thanks to committee member Georgina Wade for her Trojan work in producing the newsletter... an altogether more remarkable achievement when you consider that George must combine that task with others she performs on behalf of the Association. And therein lies the reason for this appeal. The aims of the Association have been pursued by an enthusiastic and hardworking committee, which, unfortunately, has seen its number drop to a dangerously low level in recent times. Dangerous in so far as **the Association cannot survive indefinitely without new faces becoming involved at committee level.**

I would therefore earnestly appeal to you to consider giving of some of your time so that the Association, YOUR Association, can continue to fulfil its many roles effectively, not least of which is informing and supporting parents and those born with a cleft lip and/or palate. Please note some of the deliverables and involvements of recent times; a wonderful repository of information in the form of its website (www.cleft.ie), an online discussion forum, the highly successful information evenings (2-3 per annum), quarterly newsletters distributed to several hundred subscribers, and talks to trainee health professionals on CLP. Currently the committee is producing a series of information leaflets that will greatly enhance its information provision role, and is organising a special 'Activity Day' for 10-18 year olds (see below). **You can be a part of this marvellous and rewarding work - please consider this appeal and become involved at committee level.**

Please contact me at (mobile) 085 1452088 or by e-mail at byrne@cleft.ie.
Eddie Byrne
Chairperson

SUMMER ACTIVITY DAY

The date is set **Saturday 19th June 2004**. The plans are being made. A great day is expected by all! The Association's first ever day out will take place in Arklow. You may remember from our last newsletter Jimmy Meyler has been able to make the facilities of the Sea Scouts available to the Association. In addition his Scout Leaders will co-ordinate all the activities. An experienced crew – they can do this, almost, in their sleep! So what is the line up of the day ...

Arrive and register around 10am with a kick off at 10:30. The first activities will be 'ice breaker' type games. These should help people to get to know each other and settle down to enjoy the rest of the day. Then follows 'round robin' activities. For those of us not in the know on this type of thing, it means dividing in groups and taking turns at different activities. The number of activities will depend on the numbers of attending but will include items such as rowing, canoeing, other water sports and as promised for those who prefer dry land activities such as arts & crafts. Don't worry there will be a break for lunch in the middle of the activities and there are showers available afterwards.

The day's proceedings finish with a barbeque for everybody, parents, helpers, children and organisers! Time around the camp fire will allow everybody to catch up on the day and maybe even compare notes on cleft and what it means.

So what next

If you want to come along, please phone the editor, fill out the attached application form and get ready to enjoy the day – the target age group is 10 – 18

If you are a young adult and would like to help organise activities and add to the general fun of the day please phone the editor

If you are a parent, you are more than welcome to stay for the day; help will be needed particularly with the 'food' end of things. Siblings are welcome but let us know in advance, we won't necessarily have facilities for some age groups. If transport is an issue please contact us we may be able to help.

Looking forward to seeing you in Arklow – 19th June. **Remember to book now!**

Mt Kilimanjaro – Team Update

The expedition date is now set for October 04. The team are in the middle of training and have initiated the process of approaching businesses about sponsorship but with three of the team in final year exams it is proving difficult. Roll on the summer when thesis, exams and all of that is over. The team are certainly proving their metal working for their Gaisce Gold!



Women's Mini Marathon

Over the past number of years the Women's Mini Marathon has been a great source of funds for the Association. I am glad to say the Rathangan Runners are back in action this year albeit their numbers are down due to some expectant mums!

The Association would very much appreciate any fund raising activities. If readers are participating in the marathon and would be happy to do some fundraising at the same time, please contact the Editor. Sponsorship Cards and Tee Shirts [courtesy of Irish Items] are available.

Recent Publicity

Cleft treatment has got an amount of publicity recently. There were two articles in the Irish Times Health Supplement on the 23rd March. The main article dealt with the current crisis in Speech Language Therapy services with contributions from several voluntary organisations including CLAPI. The second article was specifically about Cleft treatment & early SLT intervention. Again CLAPI made a contribution to this article.

Listeners to the Marian Finucane's radio show would have been pleasantly surprised to hear Mr. Orr talking about his recent work with Operation Smile. This organisation does incredible work in developing countries with medical volunteers and international fund raising. Between May – Oct 2003 1402 people were treated. Currently Mr. Earley is in Russia. We hope to hear more about Operation Smile and the Irish connection at our next information Evening.

Contact Editor

To register for the Activity Day or for more information on any of our articles please contact the Editor

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

You can register for email copies of the newsletter on www.cleft.ie or to get copies by post just phone the Editor. Please note patients attending clinics cannot be automatically added to the CLAPI mailing list. If you want to receive regular updates you need to give us your details ...

Cleft Lip & Palate Association of Ireland



Arklow activity application form 2004

KEEP

The Arklow Activity Day has been planned for cleft children and their families to meet in an informal setting. The idea is mainly to have fun but also to let children know that they are not alone as they go through treatment, school etc. Under the able direction of Scout Leaders a full day of activities are planned. There will be a break for lunch around 12:30 and there will be a barbeque to finish from around 4pm to 5

VENUE – ARKLOW SEA SCOUTS

DATE – 19TH JUNE 2004

START & FINISH TIME – 10 am to 5:30 pm

BRING – Togs and some old clothes to wear for the activities. A change of clothes, towel, shampoo etc for afterwards. Some good jokes from around the camp fire!

Note: There is no charge for coming to the Activity day. All involved are giving up their time free of charge and direct costs are being paid from CLAPAI funds.



SEND

. Firstly

- Phone 01 2848227 to book your place.
- Volunteers run the Association and this is a home number.
- Leave a message clearly stating your name and number.
- You will be phoned back within 24 hours.
- Please phone again if for any reason you do not get a call back

Secondly

- Fill out the form below
- Send to Georgina Wade, 4 Wolverton Glen, Dalkey, Co. Dublin

Child's Full Name –	
Age –	
Address	
Contact Phone Numbers Home, Mobiles etc.	
Parents / Guardian's Name	
Please outline any special needs or special dietary needs your child may have	