



WELCOME to a combined Autumn & Summer Newsletter. For a variety of reasons our Summer Newsletter did not make it to press but I can assure our readers we are back in business again with this Autumn edition.

There is a lot going on with the organisation at the moment. We welcome Laura Fingleton our first committee member who was born with a cleft. Already Laura has given us invaluable insights and direction. We have an excellent Information Evening coming up with Helen Smith from Changing Faces UK and Laura. Our AGM is on the same evening. We have had extraordinary fund raising efforts over the summer. Some good news on Speech Language Therapy places but still bad news on the ground in trying to access services. Our discussion forum has been launched on the web and is proving to be successful. We have a series of leaflets covering all aspects of cleft care drafted hopefully going into production in the next month or two. Between newsletters and web site we will keep you updated.

With all that is going on the committee have an immediate requirement for a somebody to take minutes of our meetings. It is a relatively small task but would be a great help. The committee meets every 4 to 6 weeks in Dublin city centre. Meetings usually go from 8pm to 10pm. . Please contact me, editor, for more information. With that said I hope you enjoy our newsletter and I look forward to seeing many of you on the 16th October.



MINI MARATHON WINS AGAIN!

Once again the mini marathon has delivered much-needed funds to the Association. This year Anne O'Brien from Rathangan Co. Kildare rallied a team of 20 to fund raise for the event. With a mix of participants and collectors they managed to fill over 25 cards and lodge an incredible €2,961.50.

Anne attributes their success to baby Joe, now 2. He has been the real inspiration for the team. By the way they are all looking forward to next year!

On behalf of the Association I would like to thank the Rathangan runners and Suzanne Corley from St James who raised over €120 in the same event. This is the third year that Irish Items have supplied tee shirts, done the artwork and paid for delivery of the shirts to our fundraisers. Thank you Paul & Jim.

Pictured from left to right top- Sharon Melia, Niamh Gilligan, Martina Earley, Mary Igoe ; from left to right bottom – Natasha Gilligan, Anne O'Brien and Liz Gilligan. Deirdre Carty and Gloria Reid also ran but are not in the picture

New Speech and Language Therapy courses coming on stream

Though one could say twelve months behind schedule, it is nevertheless good to see the additional course places recommended by the Bacon Report finally come on stream*. Together with the already existing 25 or so places available at Trinity College, Dublin, These additional places see the number of graduates taken in rise from 25 to nearly 100 annually. This is the beginning of a twenty-year programme to bring the total number of speech and language therapists up to what everyone agrees in an acceptable level. Note: There were 160 applicants who listed the course as their first preference

Details:

- ☺ Trinity College, Dublin - Bachelor of Science in Speech and Language Therapy. Existing four-year course. **25 students.**
- ☺ University of Limerick - Master of Science in Speech and Language Therapy. New two-year course started June 2003. **25 students.**
- ☺ University College, Cork - Bachelor of Science in Speech and Language Therapy. New four-year course beginning at end of September 2003. **25 students.**
- ☺ National University of Ireland, Galway - Bachelor of Science in Speech and Language Therapy. New four-year course beginning 15th September 2003. **25 students.**

*SEE www.cleft.ie/slt_services/index.htm for the position paper on speech and language therapy services published (May 2002) by your Association.





Discussion Forums Launched!

March 11th saw the launch of cleft.ie Discussion Forums, our exciting new service. Forums are an opportunity for you to express your feelings, your joys, your concerns and apprehensions, to share your experiences and to share in the experiences of others, in summary to discuss within a common community any cleft-related topic you so desire. In so doing you stand to benefit from the knowledge, support and friendships that can result from your participation in our Discussion Forums.

Critically, the success of the Forums is dependent upon your active and ongoing participation. Remember, as you stand to benefit from your direct participation and the contributions of others, others, correspondingly, stand to benefit from your involvement. So we would ask you to give this new service your heartfelt endorsement and support. Available at <http://www.cleft.ie/forum/>

Further Website Developments

 **Guestbook** Launched. We have recently launched a Guestbook on our website, giving you and others the opportunity to comment on the website and the service it provides. Available at www.cleft.ie/guestbook/.

 **Poll**. Complementing our Guestbook is an online poll where currently you can vote to indicate your level of satisfaction with our website. Future polls will allow you to vote on issues of direct relevance to you. So check in regularly. Poll accessible at www.cleft.ie/poll/

Stickler Syndrome Support

Stickler Syndrome is a **RARE** condition associated with Cleft particularly Pierre Robin. It affects areas of the body where there is cartilage for example joints. There are only 12 diagnosed cases in Ireland. Whilst there is a newly formed support group for Stickler Syndrome ethically they cannot be given families' names and so making contact is difficult. If you are one of those families and would like to join the group please contact Theresa Corrigan 042 9665548. See www.cleft.ie or www.stickler.org.uk for more information on Stickler Syndrome.

Information Evening & AGM

Thursday 16th October 2003

Tea and coffee will be served from 7:45pm

Ms. Helen Smith

Helen is from Changing Faces a UK organisation that aims to enable people to tackle facial disfigurement. Helen's talk will cover practical advice for people born with a cleft. 8:00pm

Ms. Laura Fingleton

Laura is a confident 20 something who was born with a cleft. Laura will share her experiences of growing up with a cleft. 8:40pm

Annual General Meeting

The AGM will follow immediately after our guest speakers. 9:10 pm
Expected close around 9:30pm

Venue

Graduate Centre, St. James Hospital.

[Red brick building also known as the graduate centre beside the James St Entrance]

This is a public information evening – Admission is Free – all are welcome – see web site, flyers or contact editor for more information.

Planning for 2004

Many teenagers will have surgery and procedures over the summer months and may miss out on usual summer activities such as summer camps. It can be a lonely and difficult time particularly if none of the usual companions are around or have had similar experiences.

The Association are considering ideas for day outing/gathering next summer aimed at children aged between 10 and 16 specifically, but it would be even better if parents came along and older people/adults also.

Maybe a barbecue or something along that line – It would be basically an opportunity for people to meet and chat in a fairly informal setting to share experiences etc.

We would very much appreciate feedback from members at this stage as to the type of event, location, timing etc. Please send suggestions and /or thoughts to fingleton@cleft.ie or the Editor.

Note: to find out how to become a member - contact Editor

Contact Editor

For more information on any of our articles, the information evening or the requirements for volunteer work please contact the editor

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Note: You can register for email copies of the newsletter on www.cleft.ie. or to get copies by post phone Editor.