

This Edition

As the summer draws to a close we publish another edition of our Newsletter. With the exception of the mini-marathon, the summer has been relatively quiet for the Association. You will see from this edition however that there is a lot planned for the Autumn, Winter & Spring. We look forward to seeing you at one or all of our forthcoming events. In the meantime we hope that a good number of volunteers will participate in Susan Lawlor's new research. Editor.

Events

Parents Evening

Next parents evening is planned for September - see calendar. Parent's evenings are informal occasions that allow parents to meet and share experiences. It's always good to meet parents whose children are at the same stage or a little ahead. So far parents evenings have been very useful for all. [Newborns are more than welcome - we know that getting babysitters in the early days is not always possible!]. Looking forward to seeing you over a cup of tea!

Formal Notice of AGM

This year the Association's AGM will take place on Tuesday November 22nd at 8pm. All interested parties' welcome.

The AGM is combined with an information evening. Guest speakers will be invited to talk on a number of topics. Please check for details closer to the time.

Next Family Day

Following on from the great family day we had in Arklow in 2004, we are organising another family day for May 2006 - see

calendar. We are still at an initial stage in planning. Next year we aim to go to a midlands venue. It would be very useful if we could get an estimate of numbers of families interested - so give us a ring as soon as you can.

Mini Marathon

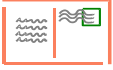


The Association is fortunate enough to have had 17 fundraisers in the mini-marathon this year. The Rathangan Runners once again provided a sprightly team under the stewardship of Anne Brien - see pic. Paula Piggot mustered a group from Dublin West including Donna McGill, Jean Mullins and Samantha McGill. Bernie Gilsean, Aoifeann McKinney & Anne Gilsean teamed up to give us a Dublin South contingent. Patricia Clifford, now a regular, drummed up lots of funds from Limerick. Bridget Jones successfully scooped Swords for cash. Finally, Louise Whelan discovered a new race to use for fund raising (& getting fit) - the Kellogg's run. The work of the Association is entirely reliant on voluntary funds. Many, many thanks to our runners for giving up time to train, to fund raise and to collect & lodge money.

L-R Tasha Gilligan, Liz Gilligan, Martina Early, Susan Igoe

L-R Anne O'Brien, Sharon Melia





Waiting Room Humour

Knock Knock

Who's there?

Amos,

Amos Who?

Amos quito

Knock Knock

Who's there?

Anna

Anna Who?

Anna 'nother mosquito

Knock Knock

Who's there?

Helen

Helen Who?

Helen other mosquito

Knock Knock

Who's there?

Notta

Notta Who?

Notta 'nother mosquito

The End

Back to school leaflet

As you know the Association recently published a new series of leaflets. Leaflet 10 - Handout for Teachers & Carers' is particularly useful at this time of year.

Anybody wishing to get copies of the leaflet should send an S.A.E. to the editor. If more than one leaflet is needed please let us know.

Social Research

It is known that adolescence is a period of special stress. Dealing with the impact of being born with a cleft may be another challenge. The problem is that there has been very little, if any, research in this country on the subject. When planning services, there is no researched evidence, to say whether the existing services for treatment of cleft need to be extended.

Susan Lawlor BA, MA has embarked on a study in this very area. Susan approached the Association at the start of the summer to see if we could help. In order to conduct the study, Susan needs to interview volunteers that were born with a cleft. The areas she will be concentrating on are the impact of cleft on the family environment and forming friendships in the neighbourhood & school. The interviews are completely confidential and governed by strict ethical guidelines.

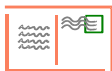
A copy of Susan's Interview Consent Form has been published in this edition along with Susan's contact details.

Contact Editor

For more information on any of our articles please contact the Editor

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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 CLAPAI mailing list. If you want to receive regular updates you need to give us your details ...



Cleft Lip & Palate Association of Ireland



NEWSLETTER - SUMMER 2005

Interview Consent Form

My name is Susan Lawlor. I am currently pursuing the Ph.D. degree with the Department of Sociology at the National University of Ireland, Maynooth.

I would like you to take part in my research. It is an investigation into the social experiences of adolescence born with congenital anomalies and how their peers and medical discourse construct these experiences. I would be very grateful if you would assist me as the research will provide an in- depth revelation of the ways in which facially impaired adolescents live with a facial “difference” and adjust to their appearance in different social environments. It will make a helpful contribution to providing people with an insight into how facial impairment for adolescents is conceptualised in Ireland and also into the views of impaired young people themselves.

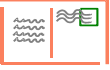
If you agree to participate I will come to interview you at your convenience in your home/ clinic or my office. Our conversation will take between one and two hours and I will tape record our conversation. The questions I will be asking will be about your daily life experiences as an adolescent.

The benefit to you is that you will have access to my research when it is finished and may use it to understand the social experiences of other adolescents born with or without a congenital anomaly. Participation in this study does not constitute any form of advice/ counseling. If you request that you would like to speak to a specialist in this field I will refer you to the multi-disciplinary medical team who are taking care of you in the clinic you are attending.

All the information that I obtain will be kept confidential. I will store the tape of our conversation in a locked file cabinet in a secure location on campus. Your identity will be kept confidential and then I will use a code number on your tape and will keep your name and code number in a separate place.

After this research I may use the tapes and notes for future research, but the same confidentiality guarantees will apply. You may access your individual interview tapes at any time. Furthermore, you are free to withdraw your data from the study up until the work is published. Your participation is voluntary. You are free to refuse to take part, and you may refuse to answer and questions.

If you have any questions about the research, you may call me Susan Lawlor on my work mobile at (085) 7360994 or email <susan.m.lawlor@nuim.ie>



Calendar of Events

Parents Evening

8pm Wednesday 28th September 2005
Bankers Club, Stephens Green, Dublin

Information Evening & AGM

8pm Tuesday 22nd November 2005
Graduate Centre, St. James Hospital, Dublin

Parents Evening

8pm Wednesday 22nd February 2006
Bankers Club, Stephens Green, Dublin
Please check closer to date

Family Day

Weekend of 20th May 2006
Please check closer to date

