



*Information Evening Spring 2003*

**Tuesday 11<sup>th</sup> March 2003 8pm**

Guest Speakers

**Mr. David Orr**

Consultant Plastic Surgeon, Our Ladies Hospital for Sick Children & St. James's Hospital

**Mr. Patrick Sheahan**

ENT Consultant, Temple St Children's Hospital & St. James's Hospital

**Venue**

William Stokes Building, St. James's Hospital.

[Red brick building also known as the graduate centre beside the James's Street Entrance]

Question & Answer, Tea & Coffee will follow speakers' session

This is a public information evening - Admission is Free - all are welcome

*Note: Changing Faces were due to join our speakers at this event, however due to circumstances beyond anybody's control they are not able to make it on this occasion. Changing Faces are planning instead to give a talk at the September Information Evening / AGM.*



*Anybody doing the women's mini marathon this year? How about fund raising for the Association? If you are interested - contact the Editor for more details.*



Welcome to the Spring issue of the CLAPA newsletter. There has been much activity within the Association in the past month, and the committee has been meeting regularly in the Banker's Club, St. Stephen's Green. We are delighted to have a new committee member Laura Fingleton, who gives us the benefit of her own unique insight and determination.

It has been clear to us for some time that there is a large deficiency in our mailing list in that many of our older members have not been contacted for some time. We are now hoping to remedy this shortfall by updating our mailing list to include all members registered with the association prior to the formation of the current committee. Many of you therefore, who receive this newsletter will be having your first contact with the association for some time. As always we are delighted to talk to any of our members and hope that you can come to our information evening the details of which are above. If you have any other queries or suggestions or indeed if you wish to join the committee, please do not hesitate to contact me at our new correspondence address at **6 The Grove, Luttrell Hall, Dunboyne, Co. Meath.**

Many thanks to all those who have been involved in fundraising, as this has enabled us to develop various projects such as the publishing of a series of information leaflets on all aspects of cleft lip & palate. It is our intention that the leaflets will be easy to access and read and be available to people in as many places as possible. We are hoping to have some of the leaflets ready for publication soon, but we will endeavour to keep all of our members up to date in as far as possible through the newsletter and through the website.

The New Parent's Evening has also been a good innovation although it started slowly. It has been of immense value to any of the parents who have attended due to its informal atmosphere, and the hard work of our committee. We would also like to take the opportunity to thank St. James's Hospital for the use of the room for the events as well as the Information Evenings.

Finally I would like to pay tribute to Georgina Wade for her consistent excellence in the production of the newsletter as sometimes we all need a little nudge in the right direction!

**Ruairí Ó Dúlaing, Chairman.**



### GREAT FUND RAISING SUCCESS

A fundraising event for the Association was held on December 18<sup>th</sup> last at Doyle's Pub, College Green, Dublin. The event was organised by Debbie McCann and Peter Brady. In all, the event raised Euro 900 for the Association. Well done to everybody concerned.

Pictured Debbie and Audrey McCann making a presentation of a cheque for Euro 900 to Tony O'Connor, the Association's Treasurer. Debbie and Audrey are no strangers to fund raising for the Association. They and their mother raised Euro 475 in last year's Women's Mini Marathon!

### New Appointment at Cleft Lip & Palate Team Our Lady's Hospital for Sick Children

Melanie Talbot, Medical Social Worker, is now working with the Multi-disciplinary Cleft Lip & Palate Team based in Our Lady's Hospital. This Social Work service has been set up to provide support to families and children attending the Cleft Lip and Palate Service.

This support includes ongoing contact, providing information, direct work with families and parents, direct work with children and young people, assessment, education and research. This service is available to all those attending the Cleft Lip and Palate Team.

Melanie Talbot can be contacted at the Social Work Department in Our Lady's Hospital or through the Cleft Lip & Palate Clinics.

*The Association would like to welcome Melanie to her new post and to wish her all the best in this new role.*

### RESEARCH

There is currently a research programme underway called 'The Irish Genetic Study of Cleft Lip and/or Palate.' The goal of the study is to understand why a person is born with a cleft lip and/or palate. It is a joint effort between the Health Research Board and Trinity College.

The team involved is looking for people of all ages born with cleft lip and/or palate to participate by

- ☺ Signing a consent form
- ☺ Filling out a questionnaire
- ☺ Taking buccal (mouth) swabs with cotton buds

This can all be done from the comfort of your own home in your own time. The team will send out a kit with an explanatory leaflet and will arrange for collection of same.

We are not sure what causes a cleft but scientists are studying how the condition might be influenced by what we inherit from our parents, that is, our genes, and how these genes, interact with nutritional and environmental factors.

DNA from genes is contained within the cells of the cheek in the mouth. Samples taken will be analysed by the research team. Many of our members have already participated. Well done. The more numbers involved the better.

The research pack can be obtained from the HRB --- freephone 1-800-201074.

### Toy Box

Thank you to the parents and children of Little Acres Montessori school, Dalkey. Toys in very good condition were donated to the Association for a toy box for the Speech Language Therapy Centre in St. James's Hospital.

Many thanks also to Michael, Marie and Jim Wade for making this happen.

### Carrickmacross

There have been a number of contacts to the Association from the Cavan, Monaghan, Louth area over the past few months. Given that it can be difficult for people to travel to Dublin for Parents' Evenings, the Association is planning to organise an evening in Carrickmacross with the help of parents in the area.

If you are interested in attending such an evening can you please contact the Editor - details below.

### Future Editions

You can register for email copies on [www.cleft.ie](http://www.cleft.ie) 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 [wade@cleft.ie](mailto:wade@cleft.ie)