



# Cleft Lip & Palate Association of Ireland

Welcome to our 1st 2010 newsletter. It has been a while since we have gone to print, this is mainly down to juggling the work load! Now we are in print again though we hope you will find the newsletter useful.

## Calendar of Events:

CLAPAI  
Information Evening  
Thursday 15th April

Mini Marathon  
Closing Date  
Thursday 27th April

Donegal  
Parent's Evening  
Thursday 29th April

CLAPAI/Temple St  
Focus Group  
Tuesday 18th May  
(TBC)

Women's  
Mini Marathon  
Monday 7th June

CLAPAI Family Day  
Saturday 19th June

Committee Meetings  
13th April  
11th May  
8th June

**Contact:**  
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**0871319803**  
[www.cleft.ie](http://www.cleft.ie)

**We are now listed with  
11850 & 11890  
Directory Enquiries**

## AGM & Information Evening 15th April

Our annual AGM & Information Evening will be held on Thursday 15th April 2010 at 8pm (doors open from 7:15pm)

In the Louis Fitzgerald Hotel,  
Newland's Cross,  
Naas Road, Dublin 22.

## Information Evening Theme "Speech & Hearing"

Following our successful event last year 'Dental Care All the Way', this year we are concentrating on Speech and Hearing. We will be looking at each area separately and where they overlap. We are delighted to have three excellent speakers for the event.

**Nicole Prenderville,**  
Senior Speech & Language Therapist  
Our Lady's Children's Hospital, Crumlin

**Rob Wormald**  
Senior Ear Nose & Throat Registrar  
Children's University Hospital, Temple St

**Julianne Gillen**  
Community Resource & Access Officer  
DeafHear.ie

The information evening is aimed at parents but will also be of interest to adults born with cleft or medical personnel working in this area.

Carers or close relations are also welcome. While admission is free, we would appreciate an email, text or call in advance so that we have an idea of likely numbers attending.

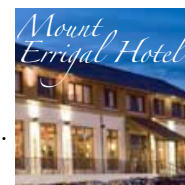
## Donegal Meeting

We are delighted to announce that we will be having our first ever Parents Evening in the Mount Errigal Hotel, Letterkenny on Thursday 29th April at 8pm.

This is an informal evening for parents where they will have the opportunity to find out more about CLAPAI and hear

other parents experience while sharing their own over a cup of tea or coffee.

While admission is free, we would appreciate an email, text or call in advance so that we have an idea of likely numbers attending.



## Family Day

Its that time of year again! Hurrah! The Family Day will take place on Saturday 19th June in Causey Farm which is located between Kells & Athboy Co. Meath. There is lots to do on the farm - hail, rain or sun! We have activities planned for junior and older children. This year we are asking families to bring a packed lunch and also a change of clothing - its all about bog jumping in case you are wondering! Registration for the family

day will commence on 16th April. Forms will be on the web site and will also be distributed with the next newsletter. So put the date in the diary and look forward to another fun day out. In the meantime, could anybody planning to travel with the Galway bus please contact the Association asap?





## Committee Update

*We want to thank Davida Diamond and Frank Conroy for answering our recent call for new committee members.*

*We always have new areas that we want to tackle as well as keeping up with our normal activities. None of this would be possible without our committee members and fund raisers.*

*As Cathaoirleach I would like to take this opportunity to thank our committee Aine, Anne, Annemarie, Donal, Niall & Sinead for their enthusiasm, dedication and for their fun attitude to getting the work done!*

*To the people throughout the country who make donations and organise fund raisers a big thank you, you know who you are!*

*Georgina Wade*

## Focus Group

Are you a parent of a child with a diagnosis of a Cleft Lip and/or Palate? If so, would you be interested in helping to inform the development of services so that they might better support both your child and yourself?

The Cleft Team at The Children's University Hospital, Temple Street, and the Cleft Lip and Palate Association of Ireland, are working together to identify the support needs of children and parents.

To this end, it is proposed to run a focus group at which parents will be given an opportunity to reflect on their experience of having a child born with a cleft lip and / or palate and, from this, to identify supports that parents and families would find useful and appropriate in dealing with the diagnosis and the ongoing condition and its impact on their child.

The Association will be inviting parents to participate in this focus group, which will be facilitated by social work staff from Temple Street.

The information gathered through the focus group will be used to assist the development and piloting of support services for parents and children attending Temple Street. Participants will be kept informed about the outcomes from the focus group and any subsequent developments through the newsletter.

The Association will be inviting parents to participate in this focus group in the coming weeks as part of a random selection. Date, time and location will be included in the invitation.

## Maternity Matters



CLAPAI has been working for the past two years to improve the information available to families in a maternity ward setting.

To date we have distributed over 600 maternity packs to hospitals throughout the country. We are in the process of collating our next 300.

As part of that exercise we have carried out a review of our leaflet series. With the help of funds from the Lotto the series has been reprinted and will be included in the pack and made available generally.

We are aware that there still can be difficulties with both access to information and specialised feeding bottles. We would like to get feedback from parents, including positive feedback, so we can target our resources on the problem areas.

The next maternity project we are considering centres around bottles & teats - sourcing and distributing. Your input would be invaluable. Feedback can be given by phone or email and will be treated as confidential.

***Don't leave it to someone else - We want your feedback!***

## Preparing for School

Are you preparing your child for pre-school or primary school?

If so you might like to bring a copy of the leaflet 'Handout for Teachers & Carers' to the school for the school principal and for the class teacher.

As there is no 'class teacher' for teenagers starting secondary education, it might be beneficial to meet with the principal.

It is probably best to meet before the summer break and give him/her copies of the leaflet which they can then use as best they see fit.

Copies available by emailing/phoning/texting the Association with number of copies required (no limit) and postal address.

## SLT Resource Pack

**Note to Parents: If your child is receiving speech language therapy, please bring this article to the attention of your local therapist.**

The "Cleft Lip and Palate and Palatal Anomalies SIG" are a Special Interest Group that have recently produced a resource pack for Speech and Language Therapists working with children with Cleft Lip and Palate in different clinical settings.

This resource contains very specific information ranging from the care pathway to therapy that can be conducted with children from earliest stage of babble stimulation right through to specific techniques to articulation therapy as well as instrumental assessment techniques that are available.

It was launched at the IASLT (Irish Association of Speech and Language Therapists) conference on 22 and 23 October 2009. The final resource which is available on CD, is part funded by CLAPAI and the resource is available on request to Speech Language Therapists.

Parents can advise their local Speech Language Therapists that the pack is available and can be requested by emailing [cleftsig@gmail.com](mailto:cleftsig@gmail.com) or by contacting one of the below directly. Please note that this is only available to professional SLTs. It is not designed for any other use.

The Association would like to thank the dedicated members of the SIG that have taken this initiative. It will no doubt assist local professionals and in turn the families that they are working with.

Thank you also to our fund raisers who make it possible for us to contribute to this type of innovation. Well done all!

### CONTACT DETAILS

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## Report on 11th International Congress for Cleft Lip and Palate & Related Craniofacial Anomalies

Held in Brazil this year, it provided a forum for each discipline involved in the Cleft lip/palate care to relay current research, thus paving the way for advances in each centre's development of treatment plans for their patients.

Ireland was represented by three members of the Dublin Cleft Centre. The representatives were from Children's University Hospital Temple Street, **Dr Triona Sweeney** (Clinical Specialist Speech & Language Therapist), **Tanya Gilroy** (Senior Speech & Language Therapist); and from Our Lady's Children's Hospital, Crumlin, **Nicole Prendeville** (Senior Speech & Language Therapist).

The scientific program consisted of Keynote Speakers presentations, Symposia discussions, Oral presentations, Junior Investigation and Poster Sessions in interdisciplinary areas such as: Plastic Surgery, Craniofacial Surgery, Oral & Maxillofacial Surgery, Orthodontics & Dentistry, Speech and Hearing Physiology and Pathology, Psychology and Social Work, Genetics and Basic Research.

Dr Sweeney presented two papers entitled 'Inter-rater reliability, acceptability and clinical utility of the Temple Street Scale of Nasality and Nasal Airflow Errors (Sweeney 2000)' and 'Inter-rater reliability of an adapted version of the universal parameters system in the rating of (Ethiopian) oromo cleft palate speech.' Both were very well received and provoked discussion around varying methods of capturing speech data in Cleft Centres.

Tanya Gilroy who works exclusively in the areas of cleft and feeding, found two particular resources which were presented at the conference, to be extremely useful and relevant to her clinical practise.

Nina Lindberg, RN from the Norwegian Resource Centre for Breastfeeding, Oslo, Norway presented an informative Breastfeeding DVD, about successful breastfeeding of babies with cleft lip and palate. According to Lindberg, 120 children are born every year with cleft lip and palate, 85% are breastfeeding at 4 months and 80% continue breastfeeding at 6 months.

The Cleft Palate Foundation has produced a CD called 'Feeding your baby', with sections on using the Mead Johnson bottle and the Haberman Feeder. As a result of the conference Temple Street have incorporated the 'Feeding Your Baby' CD into initial clinic consultations and preliminary verbal feedback from parents has been positive. Note: The Cleft Palate Foundation have made Feeding Your Baby videos available on the internet - see [www.cleftline.org](http://www.cleftline.org)

Asked for their reflections on the conference, this is what Tanya & Nicole had to say.

*"Being exposed to such insights from colleagues in different fields has not only contributed to my knowledge of the multiple needs of a child with cleft lip/palate that evolve and undergo a shift in priority over the course of their childhood/adolescence, but also has embellished therapeutic plans specific to my own field of Speech and Language Therapy"* Nicole Prendeville.

*"Attendance at this scientific conference assisted me in staying informed of ongoing research developments and changes to best practice within the field. This in turn, allows me as a clinician on the Cleft Team to continue to offer a patient-centred service founded on evidence-based practice, worthy of a centre of excellence."*

*"Personally, I have also been inspired to implement a new long term research project which aims to explore the interrelationship between speech impairment arising from cleft palate and Quality of Life (QOL), as measured by examination of Activity limitations and Participation restrictions, using the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) and ICF-version for Children and Youth (ICF-CY)".* Tanya Gilroy

CLAPAI is glad to be in a position to part fund attendance at conferences such as this.

They help our specialists to examine patient's care both holistically as a service and also on an individual basis, fuelling an ongoing desire and need to further advance treatment, while maintaining contact with healthcare professionals from around the world and thus seeing advances that may be adapted for use in Ireland

We are also very proud that Ireland's Dr. Sweeney presented not one but two papers at the conference.



Can you work out the phrases below?

HEAD LOHEELSVE

ECNALG

GIVE GET  
GIVE GET  
GIVE GET  
GIVE GET

CYCLE  
CYCLE  
CYCLE

MILONELION

CCCCCCC

(C) 12

(B) 68

(A) 21

Conundrums

The 7 seas

One in a million

Tricycle

Forgive & forget

Backward glance

Head over heels in love.

ANSWERS

Please send us your stories, Jokes & quizzes

## CHILDREN'S SECTION

W E A K I N G R O O M W U M M O U R

### ELEPHANT JOKES

What did Tarzan say when he saw the elephants coming over the hill?

*Oh look, here come the elephants?*

So, what did Tarzan say when he saw the elephants coming over the hill wearing dark glasses?

*Nothing, he didn't recognise them!*

What is it that looks like an elephant and flies?

*A flying elephant.*



What is it that looks like an elephant and flies and is very dangerous?

*A flying elephant who's suffering from the a tummy complaint!*

What did the nearsighted elephant say when the Volkswagen ran into it?

*How many times have I told you kids not to play in the street!*

What did the nearsighted elephant say when he saw the tank?

*Hi Dad!*

### Cleft Lip

*I have got a cleft lip, who cares  
I can still go up the stairs,  
I have arms and legs  
And can hang clothes with pegs.*

*There is nothing mentally wrong  
I'm still big and strong.  
I can read big books  
And can fish with hooks.  
I have friends all over the place  
I can even tie my lace.*

*There's nothing wrong inside  
And also glad I'm alive  
So that proves my point  
I got cleft, who cares.*

*By: Ciaran M. Kearney  
(Age 11)*



### Countdown Conundrums

(A) Seven men arrive at a meeting and each one shakes hands with all of the others. How many handshakes does that make?

(B) Which number, written in figures, increases in value by 21 when turned upside down? Clue between 60 and 70.

(C) When asked how old she was, Rosie replied, "In 2 years I will be twice as old as I was 5 years ago". How old is she?