



WELCOME to our combined Summer / Autumn newsletter for 2004. This edition's news covers the Arklow Activity day, News update from the West, New Leaflet Launch, Recent Publicity, Fund raising & Awareness, Details of AGM and Next Information Evening. Due to space constraints on this edition, Anne McGillivray's report on this year's Craniofacial Conference will be published in our Winter newsletter. Ed



Arklow Activity Day

The Association set out at the end of last year to hold an event that would bring teenagers together doing some kind of activity. Almost directly Jimmy Meyler stepped up and offered the Sea Scout facilities in Arklow for a day out. The wheels were set in motion ... Once we got to the part where we were taking bookings it became apparent that the logistics of moving young teens was not going to work – quickly the event became a family day and a great success.

The relaxed, homely setting that Jimmy & Majella provided allowed everybody of all ages to mix and get to know each other. I don't think anybody under 21 spent any time talking about cleft, they were too busy playing pirate games, running around, kicking football and generally having fun. The highlight though had to be the water activities provided by the Scouts. So many different floating crafts and everybody got a go! The Sea Scouts are to be commended for their excellent water safety skills, which they have combined with a real sense of fun.

The day finished off with a monster barbeque, photos and tired but happy good byes. The general consensus leaving Arklow was that there had to be a Next Year! Hopefully even more families will enjoy another great fun day out!

News from The West

The Association has been talking to Mr. Mc Cann about new developments in the West. We are happy to report that recruitment is under way to get a full time Speech and Language Therapist along with a Counsellor and hopefully a Cleft Coordinator.

Currently a Speech Language Therapist, Orthodontist, Ear Nose and Throat Surgeon, Plastic Surgeon and a Maxillofacial Surgeon attend the Combined Team monthly clinics in Galway.

Galway has recently made an Association with Cork to provide a Cleft Service that will be known as the South Western Cleft Group. The 2 Units will combine their numbers for audit and will meet on 3 monthly basis as well as hopefully holding clinics in Limerick. The national database will be updated using the same protocols as already being used in the Dublin Centre.

We would like to thank Mr. Mc Cann for his update and look forward to hearing more from the West

AGM Notice

This year the Association's AGM will take place on **Saturday November 6th at 2pm** in the Graduate Centre, St. James' Hospital. The time has been changed to a weekend afternoon to enable people to travel from outside the Dublin area.

The AGM also affords people an opportunity to discuss and review the workings of the Association. All are welcome.

November 17th Information Evening

The next Association Information Evening is on the **Wednesday 17th November**. As has been the custom in recent times the event will be held in the Graduate Centre in St. James Hospital.

- 7:30 – 8:00 Tea & Coffee
- 8:00 Official Launch of the new Leaflet Series
- 8:20 Operation Smile from an Irish perspective ... Speaker: Mr. Orr, Consultant Plastic Surgeon
- 8:50 Feeding & Cleft ... Speaker To Be Confirmed.
- 9:20 Chairman's update
- 9:30 Expected Close

This is a public information evening – Admission is Free – all are welcome – we look forward to seeing you!



Mt Kilimanjaro The Deadline Looms



Departure date is the 21st October 2004. The team have been very busy fund raising in the last few months. With an ambitious fundraising target it's been more than just a high mountain to climb.

So far their activities have included events such as offering camping facilities at this summer's Electric picnic, doing face painting on Grafton Street and at the All Ireland Football final, doing bag packing in Tesco's of Prussia St. and holding a table quiz in Doyle's pub. Between now and departure, the team are planning to hold another pub quiz in Doyle's. They are also planning to have a night of traditional music on the 15th Oct in O'Brien's pub in Nurney.

Besides the money collected at these fund raising events there has been a big plus for the Association in terms of awareness. The team have been amazed by the number of people who have wanted to know more about the condition and the work of the Association.

The team have got recent publicity with an article in the Leinster Leader. They are also due to be on Newsbeat 2FM and hope to be on TV3 either before or after the expedition.

If fundraising and training are not enough, the team are also readying themselves for their 'shots' and working their way through the visa paper trail!

For more information, see the team's web site. In the meantime we wish Laura, Niamh, Joe and Andrew all the best. They sure are earning their Gaisce Gold!

www.dcucleftclimb.com

Marathon Fund Raising



Yet again the mini marathon has come up trumps for the Association, or should I say all those brave souls who participated and got sponsorship for CLAPAI came up trumps. The Rathangan Runners were out in force again. Many thanks to Liz Gilligan, Tasha Gilligan, Martina Earley, Mary Igoe, Deirdre Carty, Gloria Reid and of course organiser extraordinaire Anne O'Brien.

The Rathangan Runners weren't the only ones to take to the field. Connie Conway, Patricia Clifford, Amalia Murray and Linda Moore all crossed the line with healthy sponsorship cards! The Association relies every year on fund raising. Many thanks to all of you for making the effort and keeping the Association going.

Not to be out done by the ladies, Ronan Ely is taking to the Dublin City Marathon. Aply supported by the Ely family, neighbours and friends from Thurles; Ronan is raising funds for the Association. We wish you good luck with your training Ronan & hope you enjoy the race on the day.

Please contact Ed if you can run a fundraising event in your area.

Leaflet Launch

After a lot of hard work on the part of the Chairman and Treasurer, the leaflets have now gone to print and are ready for distribution. Readers will be delighted with the content and presentation of this new and valuable Information series. The series has been part funded by the National Lottery.

The official launch takes place on the **17th November.**

Ongoing Publicity

As fundraising efforts have shown, there is a gap in public awareness of cleft lip & palate. In recent times however there has been more national publicity, which is to be welcomed. In July, Laura was on TV3 with Mr. Earley. The topic under discussion was the real value of plastic surgery versus cosmetic surgery. Both participants came across well. The result was the profile of cleft was raised at a national level.

In August the Irish Star ran a centre page article on cleft featuring Laura Fingleton & Molly Wade. The spoke to Laura on her reflections as an adult born with cleft & they spoke to Georgina Wade as Molly's mother. Some lovely pictures accompanied the piece. That was followed by radio interviews given by G. Wade with Highland Radio and Northwest Radio. Hopefully this type of publicity will help connect people who may not previously have known or heard from anybody else who has been affected by the condition.

Contact Editor

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

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