



Early Intervention Group

A new initiative has begun in Our Ladies Hospital regarding Speech Language Therapy. We have a parent's report on how this new service is being delivered and how it is working for parents and children.

The initiative is one of bringing together a small group of toddlers (& parents). Experience shows that very young children can be shy with adults and are slow to talk one to one. By bringing them together they lose their inhibitions faster, talk amongst themselves and moreover give their SLT an opportunity to really engage with them. So how did it work for this parent?

The first week the children were a bit quiet but had begun to come out of themselves by the end of the session. By week 2 & 3 the children were fully engaged in SLT play. They were talking to each other and generally were more relaxed. The children were in the same room every week so they quickly got into a routine. By the end there were obvious improvements in speech for all of the children. Possibly the best part from a children's perspective though was all the fun they had and the new friends they made!

How did it work for parents? Firstly the parents went to an awful lot of trouble to attend the sessions. Nobody took the opportunity lightly. The parents job was to sit quietly and learn. (As one of our SLT speakers has said before - it is the parents who are the therapists!). Afterwards however the parents were able to talk to each other and swop stories.

The overall consensus is that this programme seems to be a good idea on a lot of levels. The next steps are to bring the group back together again in 6-8 weeks. We look forward to hearing how the group progresses. Many thanks to Karen O Reilly for reporting back to the Association.

Crumlin Co Ordinator

Many of you will know Claire Kelly, co-ordinator with Crumlin & St. James hospitals. Claire has taken up a new post in Loughlinstown returning to her role as a full time speech language therapist. Many of us will be sad to see Claire leave her role as cleft co-ordinator, a job she did excellantly. I am sure however the population around Loughlinstown will be very glad to know that someone of Claire's calibre will be joining their SLT team. We wish Claire all the best in her new job. In the meantime our readers will be assured to know that the position of co-ordinator has been advertised and is in the process of being filled.

Mini Marathon



Once again our friend the mini marathon is upon us. Ann O'Brien & the Rathangan runners are once again providing sterling support for the Association. They are ably joined by Paula Piggot, Anne Gilsean, Louise Whelan, Patricia Clifford & Bridget Jones. There is still time to join in the fundraising activities and get fit! For sponsorship cards & tee shirts please contact Ed. The Association would like to thank Uniformity in Dunlaoghaire for once again sponsoring our t-shirts. Good luck ladies!



Waiting Room Humour

What time is it when an elephant sits on the fence?
Time to fix the fence!

What's grey with red spots?
An elephant with the measles!

What's grey stands in a river when it rains and doesn't get wet?
An elephant with an umbrella!

Father: I hear you skipped school to play football
Son: No I didn't, and I have the fish to prove it!

Teacher: When was Rome built?
Pupil: At night.
Teacher: Why did you say that?
Pupil: Because my Dad always says that Rome wasn't built in a day!

Knock Knock
Who's there?
Annie!
Annie who?
Annie one you like!

Knock Knock
Who's there?
Colin!
Colin who?
Colin the doctor, I feel ill!

Knock Knock
Who's there?
Tad!
Tad who?
Tad's all folks!

Teen Walk – 23rd July 2005

Teenagers and young adults born with a cleft lip and/or palate are invited to come on a hike up Three Rock Hill in Rathfarnham. On Sat 23rd, we'll all meet at the Molly Malone statue at 10.30am. From there we'll get the number 16 out to Rathfarnham where the bus-stop is just a 5 minute walk from the starting point for the hike. The hike to the top takes just three hours and there'll be a rest at the top for some munchables and a chance to get to know each other before returning. We should be back in Dublin City centre for about four o'clock. This will be the first of a series of hikes which serve as a chance to meet others who are in the same boat ...this usually only happens in the waiting rooms of the orthodontist or during hospital stays when most of us aren't feeling at our chattiest! It could be a great chance to meet new people and make new friends who know what you've been through, as they've been through it themselves. It's also a chance to get some fresh air and have some spectacular views across Dublin city from the top of Three Rock.

You'll need 3 Euro for the bus plus a packed lunch and plenty of water. If you're interested please email fingleton@cleft.ie or phone (086 1642548) so we've an idea of numbers.

Kilimanjaro

As reported in the last edition, Laura, Joe, Niamh & Andrew made it to the summit. New to report in this edition is the fact that they raised 4,000 Euro for the Association! We hope to see Laura, Niamh, Joe & Andrew in person at our next Information Evening. In the



meantime Laura has kindly contributed her account of their big adventure!

Parents Evening

Our last parents evening was held on 2nd March 2005 in the Bankers Club. We were most honoured to have baby Emma & baby Monica in attendance. I am glad to report both little ladies were very well behaved & extremely cute! An amazing range of topics were discussed on the evening including 1st Operations, Feeding, Orthodontics, Speech Therapy, Starting School and Later Surgery. We ran out of time for other areas of interest - Teenage Years & Genetics. A hot topic on the evening was hearing. Some readers will remember Mr. Patrick Sheahan ENT gave an excellent talk to the Association in March 2003. Given the level of interest we may cover this topic again at our next Information Evening.

Our next parents evening is planned for **Wednesday 18th May**. For a change we are moving to suburbia, our location for the evening will be the Glenageary / Killiney National School, in Wyvern, off Killiney Road, Killiney Co. Dublin. We will have our usual start time of 8pm. Tea & coffee provided. All you need bring is yourselves. If you have any queries please contact Ed, otherwise we hope to see you there on the night. The Association would like to take this opportunity to thank the school for giving us use of their premises. We would also like to thank the staff at the Bankers Club who regularly facilitate the Association.

Habermann Teats

Habermann feeders are currently provided by Medicare in Mount Street. The feeder costs 36.00 Euro and can be bought over

the internet, by contacting the company and in some instances through a local pharmacy. Parents in the past have found that the teat has needed to be replaced before the rest of the bottle. Previously that would have meant replacing the whole bottle. Medicare now offer a service where replacement parts can be bought by contacting the company directly. The cost of a replacement teat is 12.00 Euro. Please note a delivery charges of 10 Euro applies.

Bi Lingual Thoughts

At our recent parents evening, we had a couple who had intended raising their baby with both the English and Italian languages. When their daughter was born with a cleft they were wondering if this was still a good idea particularly given that speech language therapy would be on the cards. As luck would have it, we had another couple in the group who have reared their children speaking both English & Irish. Their daughter hasn't had any difficulty. One of our committee members is from Belgium and she has raised her daughters through French. So the verdict from parents is ... bi-lingual works!

Contact Editor

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

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Diary Dates

18th May 2005 Parents Evening
23rd July 2005 Teen Walk

Kilimanjaro - The Summit

By Laura Fingleton

On the 20th of October last, myself, Niamh, Joe and Andrew set off on what was to be one of the most physically challenging experiences each of us had ever undertaken.

After a year of planning our trip, fundraising...which I feel was almost more difficult than the actual climb...and working together as a team on our fitness, it was finally here. From face-painting on all-Ireland final days, bag-packing in Tescos, numerous table quizzes, approaching businesses both large and small, articles in the print media, appearances on TV3's Ireland AM, a slot on 2FM's Newstalk, there was lots to do!

The four of us had agreed from the outset that raising awareness was equally as important as raising funds. We are very proud of the awareness we raised about cleft lip and palate as well as highlighting the fact that there is support out there for those born with a cleft and for their parents/siblings in the form of CLAPAI. Indeed, personally as someone born with a cleft – I was particularly touched when people who also had a cleft saw our t-shirts on our face-painting days/Tesco bag-packing days and came up to chat to me – many never even knew that CLAPAI existed! They were very supportive of what we were trying to do.

In the months nearing the destination date, things got very hectic indeed. Here's a snippet from my fundraising diary, which gives an idea of the preparation needed:

Tuesday 10th of September

- Emailed President of D.C.U. re. Sponsorship.
- Rang Garda Siochana - Portlaoise and got ok re. Electric Picnic Camping Fundraisig idea.
- Rang Walshe P.R. for some publicity tips - they gave me addresses and points of contacts of radio stations throughout Dublin, speaking with Mary Bodely.
- Emailed Tesco Ireland re. Bag-packing permission
- Emailed Croke Park re. Collecting on All-Ireland Final day
- Emailed TV3 Ireland AM as regards re-appearing just before climb to raise awareness about CLAPAI and what we do etc.
- Emailed P.O.D. organising Electric Picnic re. Campsite idea.
- Spoke to John re. Fancy Dress Hike at beginning of Semester.
- Emailed Martley's Bus-hire re. Organising buses for Electric Picnic Day.
- Emailed Laois Hire re. Portaloos for Electric Picnic day.



When the months of fundraising, jobs and fitness work drew to a close there was nothing left to do, but climb the mountain!

We flew from Dublin to Nairobi via London staying in Nairobi for one night. We set off the following morning on the daylong drive through Kenya to the little town of Arusha in Tanzania. That first night in Nairobi, the four of us were apprehensive – Nairobi is a dangerous city so we were a little uneasy and on edge. While we were physically prepared for the climb, I myself wondered how much we'd have to push ourselves mentally. Our training involved climbing some of the highest mountains in Ireland - Carrauntuohill and Mt. Brandon and also smaller hikes in Wicklow as well as regular jogging **but** Mt. Kilimanjaro stands at 5,895m in height (the tallest free standing mountain in the world)...Carrauntuohill is 1039 m so altitude sickness would be a real concern.

We spent the next six days on the mountain. It took four days to ascend and two to descend. We were careful to take it at a nice slow pace as our guides advised that "pole pole" (slowly slowly) would give us more chance of making it to the summit - your body copes better with the change in altitude if you give it time to adjust. The first day's hike took only four hours and was mostly through rain forest, it was very scenic although we did encounter a particularly nasty "long-drop" in the middle of the rainforest, swarming with flies and not exactly smelling of roses. We arrived at base-camp and found our tents had already been set-up by our guides as well as our dinner having been pre-prepared – this was a pattern that continued throughout the climb which was great!

During the following days, the scenery changed dramatically – rainforest to scrub to rubble and finally to the desert between the two peaks of Kili. After the tough and thirsty scrambling during the day, we'd reward ourselves with charades and singsongs by candlelight as we looked out over the plains of Kenya from our great height. We didn't encounter too much wide-life, bar the odd huge crow...although the rat-infested caves were definitely not the nicest when munching sandwiches during pit stops. By the third day, most of us were feeling the affects of altitude sickness – the headaches being the worst. Then came the final stretch.

We awoke at five on the fourth day for our summit attempt from Kibo Hut to Uhuru Peak. We all felt pretty exhausted at this stage and both Niamh and I were feeling particularly rough suffering from all the symptoms of acute altitude sickness. Trying to climb while feeling like this was a real challenge and about an hour into it, I personally thought I would have to turn back. But we'd put too much of ourselves into preparation for this thing that we couldn't just turn back.



NEWSLETTER - SPRING 2005

Close to Gilman's Point, the summit – 200m from the top – I felt very ill. Our head-guide – Reginald, a lovely local Tanzanian, felt I should start descending as he was concerned that I was putting my body under too much strain. Serious symptoms of altitude sickness are high altitude pulmonary edema (HAPE) or high altitude cerebral edema (HACE), which can be fatal. Our watchful guide asked me how bad I felt, and if I thought I had it in me to continue. I had a real think – I felt pretty awful but was unsure – things that ran through my head at that time – were a) the amount of work it took to get to here (for us, our friends & our families!) b) the four of us had pledged to reach the top for CLAPAI c) maybe everyone else was feeling as bad as I was but I just wasn't coping aswell...I decided to continue.

Without Reginald's continuous words of encouragement and giving out, when I requested just another 5 minutes during our frequent pit-stops, I don't think I could have made it to Gilman's Point...every time I sat down to rest, my eyelids refused to stay open – my stomach was churning and I just felt like curling up in a ball and sleeping for a week. But, when I waned – the others muttered words of encouragement in between their own gasps for more air and when I thought they needed a boost – I returned the favour.

Without totally being aware of it, we suddenly found ourselves at Gilman's Point – the summit! We were thrilled but absolutely wrecked! The three guides with us encouraged us to drink water and eat some biscuits before the attempt to go another 200m across the ice-glaciers to Uhuru Peak. I looked at the others, and admitted I was feeling very unwell, and thought it might be best if I turn back and they continue. Andrew was also feeling particularly bad – suffering from an acute headache, exhaustion and dizziness. Niamh and Joe felt ok to continue. Andrew and I started our descent to Kibo hut with one of the guides...Saying goodbye to other two was very hard – Andrew and I desperately wanted to continue - the four of us were a team. We wished Niamh and Joe the best of luck and began our descent to Kibo hut, which took about two hours – it had taken about seven to ascend!

On the way down, we were still very ill which in a way was reassuring as it proved continuing to gain altitude would have been a real risk. We fell through the door of our tents and conked out – still rigged out in our many layers of clothing. We both fell asleep mid-conversation about how worried we were about Niamh and Joe. About four hours later, Niamh and Joe peaked into the door of the tent – they'd made it to the top and we were truly delighted for them...they spoke animatedly about the ice-cliffs they'd seen...we all shared a well-earned meal together and then had to pack up to descend to the next base-camp as the guides felt we all needed to get to a lower altitude – it was very difficult as the temptation to stay and sleep was hard to fight. Once we got moving – we were ok and noticed our condition dramatically improved during our descent.



NEWSLETTER - SPRING 2005

The following day we spent hiking down to the bottom...and at the last camp we felt a real sense of achievement but also great sadness at leaving this great mountain. It was an amazing experience and one the four of us will never forget.

We like to say a huge thank you to all those who supported us.

Congratulations Laura, Niamh, Joe & Andrew