

# Parents' Conference Review

The 2012 I.H.S. Parents' weekend took place in the Sheraton Hotel, Athlone on the weekend of May 11th to 13th. Myself, my husband and our three young children were in attendance. Yet again it proved to be a well-organised and extremely enjoyable weekend! A huge thank you to the Irish Haemophilia Society!

After a long journey from Belfast to Athlone (where we took the wrong decision to go via Mullingar!), we arrived at the beautiful Sheraton Hotel in Athlone. I was delighted to discover that it was part of a shopping centre complex, not that I would be able to avail of this wonderful facility given that our three kids are all under the age of five! After checking in we enjoyed some delicious bar food and retired for the night.

After leaving our kids at the Crèche and Cub groups on Saturday morning, we attended the first talk on developments in Factor VIII and IX. It seems the trials for a long acting factor IX are going extremely well and, in the not-too-distant future, this is a very real possibility for Haemophilia B patients. Fantastic news!

start considering joining the 'vein train'.

The latest advice suggests they should remain in site for around five years. This came as a surprise but also as a motivation for Conall and I to get to grips with injecting James through veins. A workshop followed with practice 'arms' and needles. Myself and Conall took this opportunity to join the Kidlink programme upstairs, where Haemophilia Nurse Specialist, Mary Kavanagh taught the boys how to mix factor, draw it up and find veins. Timothy kindly volunteered to show the younger boys how to self infuse. I found this workshop extremely helpful and came out feeling very positive. For the first time the notion of sticking a needle in my son was not so unrealistic!



Dr. Beatrice Nolan spoke at the conference on *Clinical Trials and the Effects of the Economy on Haemophilia Services.*

Dr. Nolan went on to explain the technicalities of how scientists are able to attach antibodies onto the Factor VIII molecule. This is the reason why factor VIII remains in the body for longer. The clinical trials have now reached a point where they are looking for children to participate as soon as this summer! After some discussion Brian O'Mahony explained how with a longer half life, a single dose will keep you above the minimal level for longer. This may be good news for a more inactive child who does not require the "peaks" that come with regular prophylaxis. However, many parents voiced a concern that they may not be covered for a physical activity 3 or 4 days after treatment, when levels are beginning to drop.

This subject naturally led on to the dreaded conversation of how long ports could last and when should parents



Mary Kavanagh, Haemophilia Nurse Specialist, led workshops on self infusion for both adults and children.

The action packed morning was followed by yet another delicious Sheraton meal! Afterwards the subject turned to bullying which provided a forum for some interesting and shocking conversations. The main point we took out of this discussion was that, if a serious bullying incident ever occurred we should request a copy of the school's bullying policy and put our concerns in writing.

After a quick dip in the pool it was time to don our glad rags, or in Emily's case a pair of heels, a wand and a crown, and attend the Gala dinner. The highlight of the

evening had to be Silly Billy who was on the lookout for some 'Professional Bubble Catchers'! The joyous giggles of the kids could be heard in Mullingar! We enjoyed little Adam's break dancing, Harry's natural conjuring skills and Emily and Priya's magical mending! Silly Billy was also expertly helped by Jennifer and Brandon!



*After a day full of activities the children were treated to a magic show on Saturday night by Silly Billy the Magician.*

The next morning brought a very humbling experience when Dr. Mai outlined the situation of people with haemophilia in Vietnam. We couldn't help but feel very privileged after watching the moving slide show. Some of the images will haunt me forever. Dr. Mai is doing truly amazing work with an extremely small budget and few resources. Brian remarked on the dedication and utmost care with which the medical staff treated their patients, often visiting homes, not only for treatment, but also for diagnosis purposes. The situation is worsened in Vietnam because patients have to pay 20 percent of the cost of the treatment and 5 percent if extremely poor.

The Mother's circle was the most valuable experience of the whole weekend for me. The open forum was in no way intimidating and I felt at ease to discuss worries and concerns. The Vietnamese mum chatted about Vietnam, mainly about the stigma attached to Haemophilia there.

It was reminiscent of the 1940s, 50s and 60s in Ireland, when the condition was often not talked about and left undisclosed. It saddened me to hear of fathers leaving their families after their son was diagnosed. The prospects of getting married are not good for carrier females, not only because of the stigma attached to the condition, but also because of the cost associated with the illness. As Brian said that morning, a family he met in Vietnam were forced to sell some of their furniture because their son had a bleed.



*The highlight for many who attended the Parents Conference was the Mothers and Fathers Workshops.*

The weekend wound up with a scrumptious lunch. After profiting from one last plunge in the pool, we bid our farewell to Athlone and another fantastic weekend. Poor James was reluctant to go and even shed a few tears when strapping on his seatbelt. We will be back in October, Factor Turtle!

Thank you again!

**Orlagh McGleenan**

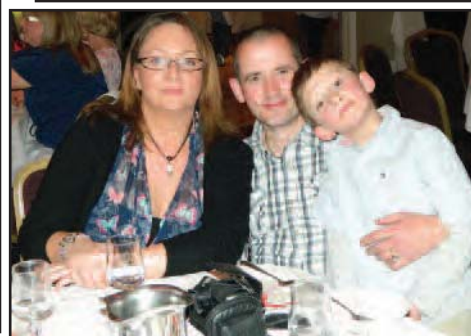


*Our son James was sad to leave the conference, but he, like the rest of us, is already looking forward to the Members Conference in October.*





**A huge thank you to all the volunteers who helped out at the Parents Conference.**



**The Parents Conference was jam packed with workshops, presentations, technology, magic and fun.**

**From these photos it looks like everyone had a great weekend.**