

Members discussing issues at the Open Forum on Saturday afternoon

When I started working at the Irish Haemophilia Society, the office was in a state of AGM fever. It was five and a half weeks away and there was so much to do.

Being completely honest, I was a bit like a duck out of water, to begin with. Everyone had lists as long as their arms. I don't like being idol and while I wanted to get stuck in, I had to be rained back in and firstly become more equipped with everything haemophilia. There was a lot of reading, which has given me a solid foundation for my new role. In the led up to the AGM, the girls shared their stories of past AGM's. It gave me a good sense of what to expect when March 3rd finally crept up.

In my head, I expected the office to be mental (and I'm talking about the abundance of coffee, lack of sleep, having the shakes type of mental!). It was super busy but everything and everyone was cool, calm and collected. I feel this speaks volumes for the

abilities of this fantastic team I find myself part of.

The day arrived, we were all packed and ready to go. As we neared the Slieve Russell, I started to get so nervous. It sort of felt like I was going on a first date. What would I say? What would I wear? Would everyone like me? It is quite overwhelming being the newbie, the one no one knows. On Friday evening as I sat at the youth group registration desk, the minutes were ticking by, my mouth was getting dry, my palms were sweaty, as we waited for people to start arriving. I have no idea why I was so terrified! It was so lovely to put faces to those I had spoken to on the phone and to meet everyone else. Everyone was so welcoming and friendly. I appreciated that more than you could know. It made the whole weekend less daunting.

Throughout the weekend I spent the majority of my time in the Cranaghan Suite at the various talks and sessions. I'm not



The Annual General Meeting on Saturday morning







Dr. Michelle Lavin and Professor James O'Donnell following their presentation on the iPATH project.



Dr. Barry Harrington, Dr. Barry White, Ms. Ruth Hunter Nolan and Ms. Evelyn Singleton during the Open Forum on Saturday afternoon.



Members asking questions during the Annual General Meeting.

going to lie, I'm a complete nerd, so having the opportunity to sit in on all the talks was fantastic. I found the history session on Friday evening extremely insightful and a really nice way to start the weekend. I enjoyed getting to go to see two of the children's groups during the weekend. It was evident how much the children enjoy themselves, how much they get from taking part and the friendships they have formed. I firmly believe these friendships will be the biggest asset to them in dealing with their haemophilia or bleeding disorder, or their sibling's haemophilia or bleeding disorder. I was completely blown away by all the developments in haemophilia care. My



The Chairperson addressing the membership on Saturday morning

background is Public Health. During my masters, it was part of the core curriculum to study different diseases, one of those being haemophilia. From learning about it in a lecture hall in UCD, I would never have imaged the vast advancements made in haemophilia treatment and care, in such a short space of time. It's incredible. I was particularly enthralled in the iPath research, it's absolutely fascinating. I also thoroughly enjoyed the inhibitors session. Inhibitors are something I am aware of but I didn't know a lot about, so it made for a great learning opportunity. Another particular interest of mine is international health. I have always been the person who wants



Our fantastic volunteers.

to go to developing countries. I was amazed to hear from Dr. Nam from Vietnam on how far haemophilia care in Vietnam has come since the twinning programme commenced with the Irish Haemophilia Society. It goes to show how a partnership built on a solid foundation of friendship, support and understanding can improve the lives of those with haemophilia.

Something that really struck me, over the course of the weekend, was the level of interaction from members. I have been to more conferences than I can count over the years, when the floor is open to questions and comments and you can see the fear people have asking questions. It was so refreshing to see so many people voice concerns and ask questions. This especially stood out to me at both the AGM and Open Forum. Seeing members take both ownership of decisions regarding their bleeding disorder was inspiring. You might not know it, but you all were great teachers over the AGM weekend.

As the main part of my role will be interacting and being the point of contact for members on a daily basis, my favourite part of the weekend for me was the mingling and chatting with everyone. I could have spent the entire weekend sitting down with copious amounts of tea having the chats. I am such a talker! For those of you who I had the pleasure of talking to, I hope it was as beneficial for you as it was for me. For those I didn't get the opportunity to talk to, I'm always at the end of the phone if you need anything at all. I hope going forward

that I either get to meet you all for a chat at some point, be it a hospital or home visit, or at least have a natter on the phone.

Overall, I really enjoyed my first ever Irish Haemophilia Society event. It was extraordinary to see the comradery, support and sense of community between each and every one of you. I am so delighted I get to be a part of that.

Lyndsey Connolly, Outreach Co-ordinator.



Members discussing items during the Open Forum.





AGM 2017 Gallery







Fun and games at the crèche and cubs clubs



Treasurer Ger O'Reilly presenting the Margaret King Educational Award to Barbara Wynne



Chairperson Traci Marshall Dowling presenting the Margaret & Jack Downey Award to Daniel Hanney's dad Michael Hanney



Chief Executive Brian O'Mahony presenting Dr. Beatrice Nolan with the Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland



Dr. Beatrice Nolan and Dr. Alison Dougall during the Open Forum



Chief Executive Brian O'Mahony presenting Dr. Nam from Vietnam with a gift



The Youth Group at the gym