

## EHC NOW!



# European inhibitor patients gather in Barretstown for the 3<sup>rd</sup> EHC Inhibitor Summit

*By Laura Savini, EHC Public Policy Officer*

*From 6 to 9 December close to 150 people gathered in Barretstown, located an hour outside of Dublin in the beautiful Irish countryside. Their meeting: the European Inhibitor Summit, a yearly event organised by the European Haemophilia Consortium (EHC) for people affected by inhibitors in rare bleeding disorders. The Summit was also the last EHC event of the year and the culmination point of European Inhibitor Network (EIN) activities led by the EHC Inhibitor Working Group (IWG).*

### **What's the EIN, anyway?**

In 2015, the EHC started the [EIN](#) to support an often under-served and marginalised part of the European bleeding disorders community: people with rare bleeding disorders and inhibitors.

Haemophilia and other rare bleeding disorders are in and of themselves rare diseases, which means that they only affect a very small number of people in each country. Even rarer are those affected by inhibitors. These are patients that often would not have met anyone else like them in their lifetime just because of the rarity of their condition and this singularity will contribute to the feeling of isolation and disempowerment. Furthermore, until recently people with inhibitors were faced with very limited and costly treatment options, which meant that unlike their non-inhibitors counterparts, their health, and in particular their joint health, would be severely damaged leaving them disabled. This in turn had a negative impact on their own and their family's mental and general health as well as social and economic life. The idea of the EIN was to build a network to provide a peer support system where people affected by inhibitors can meet, exchange and seek support from each other, as well as empower and train them to become strong and active advocates in their own right.



Chief amongst the EHC's current objectives for the EIN is to identify an Inhibitor Ambassador in each country that could be a liaison or contact person for all other people affected by inhibitors in that country, and that would be able to provide support and information on inhibitors and in turn liaise with other patients in Europe.

### **The Times They Are a-Changin'**

Besides building a community, the objective of the EIN is also to provide information to patients about novel treatments. Regular readers of this newsletter will know that [this is a very exciting time for haemophilia because so many novel and innovative treatments are being developed](#) and are starting to appear in European countries. Some of these treatments will also be effective in people with inhibitors and can be used prophylactically. This will give our patients with inhibitors a real alternative and provide much-needed options for their treatment and quality of life.

However, care in rare bleeding disorders is not only limited to treatment and also includes other comprehensive care services such as physiotherapy and dental care. This is why the EHC runs a [monthly exchange with healthcare professionals](#) specialised in the care of people with inhibitors where

participants can ask them questions from the comfort of their homes. The video conference is open to all those with an interest in inhibitors and runs every last Thursday of the month.

Another early EIN objective was to provide consensus recommendations and guidance on managing inhibitors in order to establish common standards across Europe. To achieve this, the EHC partnered with clinicians to develop the [European Principles on Inhibitor Management](#), which were published earlier this year. The EHC is currently working on the production of multiple advocacy tools, including posters and an animated video, based on these Principles with which to reach various stakeholder groups across Europe and promote their implementation.

Finally, the EIN wished to raise awareness of the reality of life with an inhibitor. As we all know that *'an image speaks a thousand words,'* the EHC produced 20 minutes of moving images through its documentary ['Inhibitor Stories'](#) filmed in 2017 and launched last year. It is a short and compelling movie that captures patient, parent and healthcare provider stories from across Europe.

### **Third time's a charm**

So: back to our Summit. It is meant to be the culminating point for the European inhibitor community. It is an opportunity to meet in person with peers who are facing similar situations but also to get information from experts on the management of inhibitors, as well as the latest medical and scientific updates in that management.

For the third year running, the event was held in [Barretstown](#), a not-for-profit camp designed for children who are suffering from severe illnesses and disabilities, so that everything is designed to accommodate people with reduced mobility and special needs. Barretstown was funded by actor Paul Newman and is part of the SerioüsFun Children's Network of camps across the world.

The EHC was very proud to see that this year numbers of participants (compared to the first year) almost doubled! The atmosphere was one of a family reunion! We were thrilled to see so many familiar faces of returning participants and to witness their personal progress on their inhibitor journey. We were equally delighted to see many new faces and how they were immediately welcomed and taken under the wings of the 'returning attendees.' For our part, the initial objective of the Summit, to create a community and peer-support system, seems to be going in the right direction. The event was a mix of lectures on scientific, medical and care topics (such as for example stress management). The programme also featured several peer-to-peer sessions, enabling participants to have their own private space to freely discuss and exchange on issues of concern or day-to-day challenges. Children and teens had parallel programs around the camp that include a mix of adapted sports, arts and crafts activities as well as lectures on how to manage their inhibitors, for example via good dental hygiene that is adapted to people with inhibitors.

The camp is attended by lots of families, therefore during the day, there is free time built into the programme for families to spend some quality time together and do some activities that they wouldn't normally get to do, such as rock climbing, zip lining or horse-back riding under supervision and guaranteed safety. At the end of each day, participants are welcomed into smaller home groups, designed to allow participants to digest the day's learnings and events, and address any questions, concerns or other matters in a smaller and more intimate setting.

All of this is made possible thanks to a wonderful team of volunteers and staff from Barretstown but also thanks to the volunteers of the Irish Haemophilia Society (IHS) who have massively contributed in bringing participants to the camp, entertaining the children and helped to ensure that everything went as smoothly as possible.

We also wish to give our heartfelt thanks to all of the speakers and moderators that attended the meeting, giving generously of their free time over the entire weekend. We were really delighted to welcome amongst them representatives from the Canadian Haemophilia Society and also the US National Haemophilia Foundation. Since the beginning of the EIN, it was really important for the EHC to learn from, and exchange with, other Societies on inhibitor programmes, and we are delighted that our colleagues from across the pond have been so enthusiastic about taking part in our Summit and welcoming the EHC to theirs. This ensures that our collective work on inhibitors is coherent and we can all learn from each other and share best practices.

A special thanks also goes out to our corporate partners Roche, Sanofi-Genzyme and founding partner Shire for their financial support of the entire European Inhibitor Network.

Finally, our biggest thanks go to all of the participants, who make this event truly special! We leave you with some quotes from this year's Summit and hope that this will encourage many more to attend next year!

#### **What our participants said about this year's summit:**

*"It is exceptional achievement, just wish we had heard of you years ago. Feel as though we have struggled alone for such a long time."*

*"Thank you for an amazing couple days! Attending the summit has been life-changing. There are so many uniquely different "experiences" of living with an inhibitor, but also so many similarities. It is really quite powerful to see how families in other countries cope with life with an inhibitor. Will take what I have learnt here and implement into our programming in the US inhibitor programme."*

*"Excellent summit and helping people mix together was much better. I love that all the summits have been fantastic and EHC take on the feedback and suggestions each year to improve when I already think it was good. Well done!"*

*"I am meeting the most wonderful people every year and it is amazing :)  
Thank you!"*

#### **References**

- [The EHC European Inhibitor Network](#)
- [Ask the expert](#)
- [EHC Newsletter on novel treatments in haemophilia](#)
- [EHC Inhibitor Stories](#) (a short movie about people affected by inhibitors in Europe)
- [The European principles of inhibitor management](#)
- Pictures from the event will be published in the coming days on the [EHC Facebook page](#)
- Want more? [www.ehc.eu](http://www.ehc.eu)
- For more information about the EHC Inhibitor Programme you can get in touch with Kristine Jansone (Kristine.jansone[at]ehc.eu), EHC Programme officer