



What would be your wish for NMOs who undertake a project for people with inhibitors ?

To enable as many people as possible who are affected by inhibitors to attend or take part in the project. People with inhibitors are the rarest of groups within the haemophilia community. That is why it is so valuable for them to be able to participate. It helps reduce the isolation many of them experience if they can meet with each other and share similar experiences and stories. Also, learning about the new treatments that are nearly here now is extremely important as it gives these people and their families and caregivers much-needed hope for the future.

The European Inhibitor Network is a programme of the European Haemophilia Consortium (EHC).

It seeks to understand and address the personal and systemic challenges people who have haemophilia with inhibitors face and aims to build a European community of people with inhibitors and their families and caregivers – because the numbers nationally are too small.

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UK Haemophilia Society Newly Diagnosed Families Weekend

EHC

Good practice publication series



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“One of the most important things we can do as NMOs is to share good practices. There are three reasons for this: To learn from each other and create services that might not yet exist in our respective countries, or adapt existing ones in order to improve them. To share expertise and resources that might not be available to everyone. And finally, through these collaborations, to strengthen our relationships with each other and increase the power we have collectively, rather than as individual NMOs, in advocating for and better supporting our communities.”

Introduction to the project

Finding out that one's child has a bleeding disorder can be an overwhelming experience. With the Newly Diagnosed Families Weekends, the Haemophilia Society aims to provide practical and emotional support for the whole family, offer time and space to meet and learn from medical experts and each other. These weekends for newly diagnosed families offer information, sessions with physiotherapists, paediatricians and specialist nurses, as well as time to exchange stories and make new friends.

When the UK Haemophilia Society started organising the Newly Diagnosed Families Weekends, it was not clear how much this service was needed by the community. Since 2015, the number of weekends organised has increased from one per year to four per year in 2017. And yet, there are waiting lists for each weekend. It has become apparent that providing support for this cohort is essential, particularly given how nervous the new parents are at the prospect of caring for their child. By supporting these families in the very early days of their child's diagnosis means that the Society can hopefully accompany each family on their journey with a bleeding disorder through every stage of their lives.

How was the project conceived ? What triggered it ?

It was realised that newly diagnosed families needed to be brought together in a welcoming environment and provided with tools that help build their confidence and make them better future advocates for their children. This is why we created the current format for Newly Diagnosed Families Weekends, which keeps developing and growing.

What have been the outcomes / changes so far ?

How do the people benefit from the project ?

The project started with one pilot weekend but we have now increased this, due to demand, to four per year, with ten families at each. One excellent outcome is that Haemophilia Centres, having heard about the benefits of these weekends from their patients, often now directly refer families to the Society. From sessions that range in topics, such as “What my bleeding disorder means to me” to demonstrations of treatment, families make friends and are able to discuss worries with each other. Parents are encouraged to stay in touch with each other after the week-end, thus creating an essential peer-support group.

What are/ have been the biggest challenges for the project ?

How do you overcome them ?

Obviously, getting funding, as these weekends are expensive to organise. Thankfully, our Board of Trustees agrees that they are an essential service and have approved each year for us to run more. One useful exercise we have carried out recently is to create an impact report that we can show to the Board, to healthcare professionals and also to potential sponsors so that they can appreciate the value of the week-end and its long-term benefits for the newly diagnosed cohort. Another challenge is finding volunteers but we have been very fortunate that many of the volunteers return time and again. We always ensure we have at least one nurse and one physiotherapist throughout the week-end in case of any medical problems. We also always notify the nearest Haemophilia Centre of our presence.

How is the project implemented ?

We publicise the weekend through the Haemophilia Centres, through advertising and through social media etc. The sessions are very interactive and attendees are given an opportunity to talk about issues that concern them, to share tips and advice. A crèche is provided, which not only enables parents to concentrate on the sessions, but also it might be the first time a Mum has left her child with a stranger. This is a big step prior to that child going to nursery and school.

The weekends are aimed at newly diagnosed families, including their other children who might not be affected. Over the last three years the format has changed with the realisation that not every parent has a partner. We always ensure that a single parent can bring someone with them - usually a close friend or family member who has involvement in care of the child. Depending on the family's circumstances, we will also include grandparents in the weekend. This is particularly helpful when there is no history of bleeding disorders in the family. For a grandparent who has no knowledge whatsoever it can be a daunting prospect to care for a grandchild, and attending the weekend gives them coping tools and information that will enable them to be additional back-up to the parents.

It is essential to have great volunteers: nurses, physiotherapists, consultants, social workers, who are happy to run sessions and be on hand throughout the weekend to answer any questions. We also have at least one of our Youth Ambassadors present. This is very reassuring for parents because they come to realise that their child, in so many cases, will grow up like these young people - go to university, be able to travel and be able to have the career they would like.

It was established that parents of newly diagnosed children are a particularly vulnerable group. If a child, for instance, has been born with a bleeding disorder as a result of a genetic mutation in the womb with no history of that bleeding disorder in the family, many of these parents are often suspected of child abuse. In addition, mothers who are carriers frequently experience guilt that they have passed the disorder on to their child. These situations can affect the mother's and father's mental wellbeing and change the dynamic within the relationship and within the family, affecting not only the child with the bleeding disorder but their siblings as well.

If resources allow, we would recommend holding a Newly Diagnosed Families Weekend four times a year to enable as many families as possible to attend. We try to limit each weekend to ten families because otherwise it is not possible to give them enough individual attention.

We vary the location between North and South so that families from across the country have access to the weekends. We always book a venue that has accommodation for families i.e. CenterParcs. It is essential that no matter what venue is used, it has a conference centre or certainly a very large room that becomes the hub for all activities. Meals are usually eaten in this room as well.

We have looked into using hotels but this would not work as they would not have enough family rooms for ten families, plus all the volunteers. Somewhere that provides individual lodges is ideal but which also has conference facilities for the sessions. It is also important for everyone to have their meals together so that they have an opportunity to bond and make friends.