

INTRODUCTION

European Inhibitor Network (EIN) is a programme of the European Haemophilia Consortium that is dedicated to people with haemophilia who have inhibitors (PWI), their families and caregivers from across Europe.

As you know, haemophilia is a rare disorder, but haemophilia with an additional diagnosis of inhibitors, further places the patients and their families into living with a rare disorder within a rare disorder. The number of patients diagnosed with inhibitors in each country is, thankfully, small, nevertheless this diagnosis brings a degree of stress and isolation due to a variety of reasons, e.g. lack of information among the patients and clinicians, scarcity of sufficient treatment, as well as social barriers caused by mobility and other issues.

We can bring those patients together on the European level, in larger numbers with the help of various support systems. Through EIN they have the opportunity to connect, share experiences, and build a community and support network on a European level.

OBJECTIVES

In implementation of programme and activities of the European Inhibitor Network, EHC is working closely together with its National Member Organisations (NMOs) and the key partners in order to achieve the following objectives:

- Better understanding and prioritisation of the needs of PWI both at a community as well as at a policymaking level;
- Establish European consensus in order to harmonise and ensure that we have optimum standards for the treatment and care of PWI;
- Enable social and educational connections between PWI and between their caregivers to allow them to support and educate one another;
- Ensure that PWI themselves are also active and effective at engaging directly with payers, policymakers and other authorities to advocate for optimum therapy and care.

An **Inhibitor Working Group** was established to work towards realisation of the objectives and implementation of the various elements of the programme. This working group consists of patients, parents, clinicians and other community members, as well as a staff member of the EHC to coordinate the programme. It has been and will continue to be essential to work in a close cooperation with all the NMOs of EHC, as well as to seek partnerships with the relevant partners.

PROGRAMME ELEMENTS

There are **three main European Inhibitor Network programme elements**:

1. Establishment of European standards of treatment and care for PWI;
2. Establishment of peer-to-peer communication platforms (face-to-face and/or online);
3. Development of advocacy tools and materials specifically focused on PWI.

1: ESTABLISHMENT OF EUROPEAN STANDARDS OF TREATMENT FOR PWI

Ten complementary principles for the management of inhibitors in haemophilia have been developed and published, emphasizing the importance and benefits of a centralised, multidisciplinary, expert and holistic approach. These principles will serve as a benchmark to improve the multidisciplinary and practical management of patients with inhibitor.

Implementation and adherence to each of these principles should have a major positive impact on the management and outcomes of patients developing an inhibitor.

In addition to the article published in Orphanet Journal of Rare Diseases, a video and a poster outlining the principles, are being produced to be used as advocacy tools by PWI.

2: PEER TO PEER COMMUNICATION

EHC Inhibitor Summit

The purpose of the EHC Inhibitor Summit is to offer a special time and space for people with haemophilia who have inhibitors, their family members and caregivers to build a community, educate and empower themselves, and to help improve the quality of their lives. A very important aspect of the Summit is building the community, and finding support and understanding among people in a similar situation. Since the first Summit in 2016, more than 200 patients and their families from over 17 European countries have come together to share their experiences and learn from one another. The Summit has proved invaluable in creating a community for this isolated and rare group within the haemophilia population. The next EHC Inhibitor Summit is scheduled to take place in December 2018.

Inhibitor Ambassadors

This is a person, nominated by the EHC National Member Organisation or NMO. The main role of the Inhibitor Ambassador is to further strengthen the community of people with inhibitors and their caregivers in Europe by being the active link between the PWI in his/her country and the EIN on the European level, more actively involving the people with inhibitors within your society.

Chat Room & Ask the Expert

An online platform for people with inhibitors has been developed as a part of the EIN. It seeks to create an online community and facilitate exchange, support and education, enabling social and intellectual connections between PWI and between their respective caregivers and family members.

The online community consists of 3 main segments, which are interlinked - **understanding, learning and meeting**. Information and articles are available about inhibitors and various aspects of living with inhibitors; a Chat Room is open to enable the discussions and exchange of experiences among the PWI; experts in haemophilia treatment and care are available each month to provide educational information to patients on various nominated topics. For more information please visit inhibitor.ehc.eu

3: ADVOCACY & MATERIALS FOR PWI

To enable people with inhibitors, their caregivers and family members to engage with the relevant stakeholders to advocate for optimum therapy and care, the EHC has developed several tools.

The EIN online platform provides specific educational material for each relevant stakeholder - **patients, caregivers and NMOs** - on current management and treatment available for people with inhibitors, and other issues such as physiotherapy and psychosocial issues. Series of good practices collected from the NMOs give an insight of support systems available for implementation, and the European Principles of Inhibitor Management set a benchmark that will enable improvement and help ensure that all inhibitor patients receive optimal treatment and care, regardless the country they live in.

