

EUROPEAN INHIBITOR NETWORK inhibitor.ehc.eu

INTRODUCTION



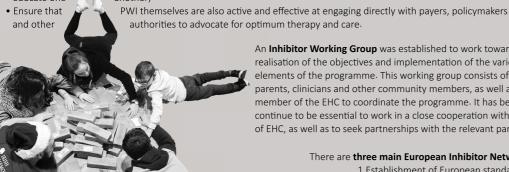
European Inhibitor Network (EIN) is a programme of the European Haemophilia Consortium that is dedicated to people with haemophilia who have inhibitors (PWI), their families and caregivers from across Europe.

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.

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



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

1: ESTABLISHMENT OF EUROPEAN STANDARDS OF TREATMENT FOR PWI





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.

2: PEER TO PEER COMMUNICATION

EHC Inhibitor Summit

special time and space for people with haemophilia who

Inhibitor Ambassadors

This is a person, nominated by the EHC National Member Organisation or NMO. The main role of the

Chat Room & Ask the Expert

which are interlinked - understanding, learning and meeting. Information and articles are available about inhibitors and various aspects of living with inhibitors; please visit inhibitor.ehc.eu

3: ADVOCACY & MATERIALS FOR PWI

material for each relevant stakeholder - patients, caregivers and NMOs - on current management and