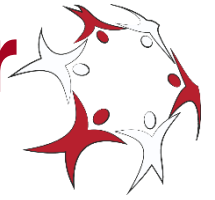


European Inhibitor Network

World Haemophilia Day
Strasbourg, 19 April 2017

What is the European Inhibitor Network?



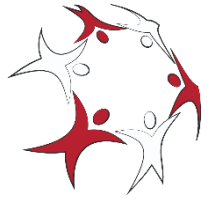
- Idea was presented at workshop on the EHC conference in Belgrade 2015
- Combat isolation of people with inhibitors (PWI)
- Collect relevant data through surveys
- Establish Inhibitor Working Group

Mission and objectives



- Better understanding and prioritising the needs of PWI both at a community as well as at a policymaking level
- Establishing European consensus in order to harmonise and ensure that we have optimum standards for the treatment and care of PWI
- Enabling social and intellectual connections between PWI and between their respective caregivers to allow them to mutually support and educate one another
- Ensuring that PWI themselves are also active and effective at engaging directly with relevant stakeholders such as payers, policymakers and other authorities to ensure that they receive optimum therapy and care

Programme elements



- Establishment of European standards of treatment and care for PWI
- Establishment of peer-to-peer communication platforms
- Development of advocacy tools and materials specifically focused on PWI

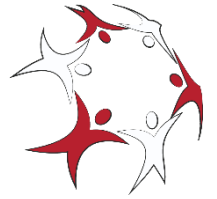
Establishment of European principles of inhibitor treatment



- Achieve standardised and optimal care
- Multidisciplinary approach for inhibitor management
- Prophylaxis as standard of care



EIN online platform



- Information about EIN, inhibitors, current and upcoming treatments, NMOs
- Information about workshops and summit
- Social network to improve communication between PWI, caregivers and doctors

Inhibitor summit



- First European inhibitor summit
- Barretstown, Dublin, Ireland
- 1.12 - 4.12.2016
- More than 100 participants, speakers and facilitators from 26 European countries

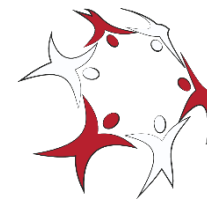


Workshop



- Finding ways for better inclusion of people with inhibitors in the life of NMO





Next steps...

- Workshop preparation for the EHC conference
- Outline programme for the next Inhibitor Summit
- Inhibitor Stories movie



Conclusion



- Creation of EIN has been welcomed and approved among all patients
- Online platform will be a place to connect with other people across Europe
- European principles are the real need so all the patient can get standardized approach in the inhibitor treatment
- Inhibitor summit will hopefully become traditional event in the EHC calendar

THANKS AND SEE YOU IN DUBLIN THIS YEAR!!!

Questions?

