

ERIN Manifest

We are people affected by haemophilia A with inhibitors, haemophilia B with inhibitors and extremely rare bleeding disorders, such as clotting factor V, VII and X deficiency, who gathered at European Rare and Inhibitor Network (ERIN) Summit in Ireland from 1-4 December 2022. During the Summit we had an opportunity to come together in numbers that we cannot meet in our local context due to the rarity of our condition. We learned from multidisciplinary care experts, and most importantly – from one another. Together, we outlined needs that we have as a community affected by haemophilia with inhibitors and extremely rare bleeding disorders, the challenges we face in having those needs met and support that we require to have those needs met on European and national levels.

Extremely Rare Bleeding Disorders

We are overlooked as patients and neglected by healthcare professionals, healthcare systems and government. Due to our bleeding disorders, we face challenges in our personal and professional lives that urgently need to be addressed.

Our most urgent unmet needs are access to better treatment, accurate diagnosis, and well-informed, dedicated doctors that focus specifically on extremely rare bleeding disorders. We need to enhance the solidarity for people affected by extremely rare bleeding disorders within and outside the bleeding disorders community.

To be able to achieve this we need to be empowered and independent, feel included, gain knowledge and have access to appropriate information. We need the support from our direct social network – family, friends and colleagues as well as our National Member Organisations and the EHC, as well politicians and industry and other relevant stakeholders.

Haemophilia B with Inhibitors

We are people and families with haemophilia B and inhibitors who face the expected and more importantly – the unexpected every single day. We live with the pain and damage that has been done to our bodies due to the lack of adequate treatment, we live with missed education and job opportunities.

Our most urgent unmet need is access to new prophylactic treatment, as well as adequate multidisciplinary care, especially tailored physiotherapy. We need systematically more time with our doctors, as well as more doctors that focus specifically on rare bleeding disorders. We need more awareness and education about bleeding disorders outside our community – in kindergartens, schools, universities.

To be able to achieve this we need support from our direct social network – family and friends, we need our children to be our guides. We need nurses and doctors to treat with the best options available and to be educated on the latest scientific developments in bleeding disorders treatment, as well as to work in close cooperation among all healthcare specialists – haematologists, physiotherapists, dentists, surgeons, psychosocial experts, nurses etc.

Haemophilia A with Inhibitors

We are a strong community of people affected by haemophilia A with inhibitors that have needed considerable resilience in our path. We have been very isolated and underserved for a long time and lived with limitations in our wishes and desires. Even though significant progress has been made in terms of the treatment that we have, there are many challenges that remain and work needs to be done to maintain the progress and the improved quality of life that has been recently achieved.

We need to ensure that everyone affected by haemophilia A and inhibitors is living a pain-free life and that there is accessible personalised care for everyone, as well as holistic view on haemophilia treatment and access to multidisciplinary care, regardless of where you live. We need a tool to better assess the effects of treatments and interventions.

To be able to achieve this we need a mindset of solidarity and thinking beyond oneself, as well as the ability to transmit the knowledge gained to our local communities. We also need health care providers that are dedicated to acquiring all available knowledge and sharing it with the patients as equal partners. We need standardised policies on bleeding disorders around Europe, as well as high level of advocacy and collaboration between the stakeholders.

We ask that the EHC, our National Member Organisations and the ERIN Committee who will start work on the European Rare and Inhibitor Network in 2023 take this document into account when planning their work.

We ask that in order to improve the treatment and care for all of us, multi-centre research is carried out and new approaches to data collection and treatment development are found.

We ourselves commit to being actively involved in the process of meeting our needs and the needs of those affected by the rare bleeding disorders in our countries, especially those who find themselves outside the bleeding disorders community and the future generations to follow, so that no one is left behind.

[Handwritten signatures and names]
Joseph Ap...
Eduard...
Lynn...
Mark...
Jim O'Leary...
Alex...
Cristina Bugnoso...
D. Prascovic...
Suava...
Pórey...
Birta Alexanderdóttir...
SUCIU PAULA...
K. PRASČEVIĆ...
ANDRA - Marie H.S...
GABOR EAVARA - Gabor...
Catin...
nathan chagan...
Jora...
Diana...
Artur Brantner...
Stina Alexandersson...
Lynne...
Alex...
Jim O'Leary...
Cristina Bugnoso...
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