

For immediate release

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The European Haemophilia Consortium highlights Wildbad Kreuth recommendations on optimal treatment of haemophilia in Europe

In light of World Haemophilia Day, the European Haemophilia Consortium (EHC) took the opportunity to highlight an important set of 12 new consensus recommendations directed at improving haemophilia care and treatment throughout Europe. Over 50 patients, healthcare professionals, regulators and pharmaceutical industry representatives attended the event, organised by the EHC and, hosted by the European Directorate for the Quality of Medicines and Healthcare (EDQM), part of the Council of Europe, in Strasbourg, France.

The recommendations are the result of the latest European symposium 'Wildbad Kreuth IV' Initiative on the optimal use of clotting factors and platelets, held in May 2016 and organised by the University of Munich, the Paul-Ehrlich-Institute and the EDQM. During these series of meetings, experts from 36 countries issued consensus recommendations on how to address current challenges in haemophilia treatment and care.

The 12 recommendations cover pressing issues in the haemophilia community and include:

- European haemophilia treatment centres should seek formal certification as either European Haemophilia Treatment Centres or European Haemophilia Comprehensive Care Centres as per the guidelines developed by the European Haemophilia Network (EUHANET) project,
- Countries should develop and adopt national treatment protocols or guidelines for the management of the ageing population with haemophilia,
- Countries should strive to achieve the minimum consumption of 4 international units per capita of coagulation factor VIII and 0.5 international units per capita of coagulation factor IX,
- Treatment for hepatitis C with direct-acting antiviral agents should be provided to all people with haemophilia on a priority basis, and
- People with inhibitors should have access to immune tolerance.

See here the full list of recommendations of the 'Wildbad Kreuth IV' Initiative:
<http://www.ehc.eu/kreuth-iv-consensus-recommendations/>

Brian O'Mahony, EHC President:

"We believe these recommendations address current challenges faced by both patients and clinicians in Europe. People often think of Europe as a wealthy and homogenous region but in fact, differences in access to treatment and care are sometimes staggering.

The EHC is thankful for the work carried out by the EDQM and the other parties involved in the Wildbad Kreuth initiative. We believe these recommendations will improve the lives of those living with haemophilia and other rare and congenital bleeding disorders in Europe. We are hopeful that the Committee of Ministers of the Council of Europe will once more endorse these recommendations (as it did for the 2013 recommendations) to recognise the needs of those living with these conditions in Europe."



In support of the recommendations, the EHC also unveiled a new project aimed at improving access to treatment for people with bleeding disorders in Europe. The Procurement of Affordable Replacement Therapies – Network of European Relevant Stakeholders (PARTNERS) project seeks to ensure sustainable access to treatment in selected European countries that do not meet the minimum standards of haemophilia care, as outlined by the 2016 consensus recommendations. These countries, where level of factor VIII and IX consumption is below 4IU/capita and .5IU/capita, respectively, provide little or no prophylactic treatment for children and adults with severe haemophilia. By taking part in this project, the selected countries, together with other partners, such as healthcare professionals, patient organisations and product manufacturers, agree to the following:

- To use national-level tender or procurement processes for coagulation factor concentrates,
- To formally include clinicians and EHC NMO representatives on a long-term basis in the tender/procurement system;
- To award contracts to the winning bid(s) of at least a three-year duration; and
- To increase factor purchase without decreasing the national haemophilia budget and to agree in principle to at least double the current national purchased amount of factor replacement therapies over the duration of contracts awarded or until the minimum IU/per capita set by the Kreuth IV consensus recommendations is met.

One of the most important aspects, without which this programme would not be possible, is the involvement of pharmaceutical companies. During the World Haemophilia Day event, three pharmaceutical companies – Kedrion Biopharma, Pfizer and Sobi – signed a Consensus Agreement to confirm their intent to support the development of the PARTNERS programme.

Brian O’Mahony, EHC president:

“Today in Europe we still see countries where people affected by haemophilia have the same level of joint damage and poor quality of life as we saw in patients before the advent of modern coagulation factor concentrates and this is unacceptable.

We believe that haemophilia budgets can be put to better use and that increased quantities of treatment can be purchased through better tender systems. This ambitious project aims to provide an increased access to treatment but also to include patients and healthcare professionals in the decision-making process of the organisation of haemophilia care in any given countries.

Background

The EHC is an umbrella organisation gathering 45 national patient organisations in the field of rare bleeding disorders including haemophilia, von Willebrand Disease and other rare bleeding disorders. The EHC represents approximately 90.000 patients in Europe who are affected by these life-threatening and congenital disorders. The EHC is both a member of the European Organisation for Rare Diseases (EURORDIS) and the European Patients’ Forum (EPF).

Amongst other activities, the EHC organises three to four ‘Round Table of Stakeholders’ discussions every year, a platform where patient representatives, the medical community, policymakers and the industry come together to discuss current issues for the haemophilia community while bridging the gap between

European health policy, the state of medical and scientific research and the state of haemophilia care in Europe.

Additional Information

For more information on the PARTNERS project, please click here:

<http://www.ehc.eu/partners/>

Photos from the event:

<https://www.facebook.com/EuropeanHaemophiliaConsortium/>

To learn more about haemophilia and other congenital bleeding disorders, visit

<http://www.ehc.eu/>

For further information, please contact:

Amanda Bok

amanda.bok@ehc.eu

+32 2 893 24 70