

Letter from the Presidents: No Brexit for EAHAD and the EHC

Last Friday, 24 June, following the referendum and the decision of a majority of citizens from the United Kingdom (UK) to leave the European Union (EU), we woke up in a different Europe that we neither expected nor hoped for. Besides the political, diplomatic, and economic consequences, the Brexit will have major implications for health care and medical research. These consequences were likely underestimated or even fully ignored by those who voted to leave the EU. This is certainly true for rare diseases such as haemophilia and it is imperative that decision makers now act responsibly to maintain the important developments that Europe has brought to the lives of patients. We would like to assure the rare bleeding disorder community including patients and healthcare professionals from across the EU and the UK that the European Association for Haemophilia and Allied Disorders (EAHAD) and the European Haemophilia Consortium (EHC) remain committed to adequately representing them, improving patients' lives, and furthering scientific and medical research.

EAHAD and the EHC were both established with an aim of utilising and synergising the knowledge and expertise of healthcare professionals and patient advocates from across Europe to improve the quality of life of people living with rare bleeding disorders. This long-standing collaboration between countries and among patients and healthcare professionals is evidenced by multiple initiatives that EAHAD and the EHC have led and participated in such as the European safety surveillance registry (EUHASS); the European Haemophilia Network (EUHANET) platform; and the establishment of the European Principles of Haemophilia Care and the Wildbad Kreuth recommendations adopted by the European Directorate for the Quality of Medicines and Healthcare (EDQM). These efforts have resulted in widespread recognition of the bleeding disorders community as one of the most well-coordinated and progressive groups in the rare disease area.

The bleeding disorders field has benefited significantly from the major, unique, and longstanding expertise in haemophilia in the UK where major scientific findings and models of multidisciplinary care and management have been successfully developed. On an organisational level, both EAHAD and the EHC have been made stronger by the dedication and leadership of our many active members from across the UK.

Despite the results of the UK referendum, our organisations remain committed to working together with our colleagues in the UK to preserve and further develop strong relations between all European countries. This is our wish as presidents of these organisations, and one that we believe is echoed by our colleagues involved in rare bleeding disorders across the diversity of our continent.



Cedric Hermans
EAHAD President



Brian O'Mahony
EHC President