

22 April 2024
Brussels, Belgium

Statement on the upcoming landscape of recommendations in haemophilia care.

Over the past months, our community has been made aware that the International Society of Thrombosis and Haematology (ISTH) has engaged in drafting new 13 recommendations, which were shared publicly for review and comment in November 2023.

Since then and considering the content of these 13 recommendations which raised some concerns among healthcare providers and patients, a coalition composed of the main global patients and haematologists organisations was established to open a sincere and transparent dialogue with the ISTH. Despite our willingness to collaborate, it has become increasingly evident that these recommendations are not adequately adjusted to meet the evolving needs of our community. Outcomes are based on limited evidence and methodological orientation, raising concerns regarding their efficacy and potential to hinder patient access to optimal treatments, particularly in low-income countries.

It is imperative to acknowledge the wealth of valuable recommendations already available from esteemed organisations such as the World Federation of Hemophilia (WFH). These meticulously crafted and continuously updated recommendations have provided invaluable guidance to healthcare providers and patient advocates worldwide.

Regrettably, the development of the ISTH recommendations did not involve meaningful contributions from international organisations representing patients or healthcare professionals. Despite persistent efforts from our coalition, the ISTH has remained steadfast in their stance.

In light of these considerations, the EHC wants to express its concerns and reiterate its commitment to evidence-based practices that prioritise the well-being of patients above all else. The EHC believes that the recommendations would be a step backwards for haemophilia care, and would send a misleading message to decision-makers and payers in all countries, particularly those with limited access to treatment. It is incumbent upon the EHC and other stakeholders to foster an environment of collaboration and inclusivity, ensuring that all voices are heard and valued in developing guidelines that shape our community's future.

As we move forward, we urge all stakeholders to join us in advocating for transparent, inclusive, and evidence-driven processes that uphold the highest standards of patient care and clinical excellence.

Additionally, the EHC states that due to the abovementioned developments, it will not be present at the upcoming ISTH Congress in Bangkok on June 22-26.

