Professor Alicja Chybicka
Chairperson of the Parliamentary Group for Rare Diseases
The Sejm of the Republic of Poland
Wiejska 4/6/8,
00-902 Warsaw, Poland

February 23, 2024

Subject: Representation of the rights of people living with hemophilia and other bleeding disorders in Poland

Dear Prof. Chybicka,

Firstly, we would like to take the opportunity to express our appreciation for the ongoing collaboration of many years with the World Federation of Hemophilia (WFH) and the European Hemophilia Consortium (EHC). We highly value Poland's unwavering commitment to continuously enhance the access to care and treatment for people living with hemophilia and other bleeding disorders. During the visit to Poland of the WFH representative Ms. Kocharyan in 2023, we were delighted to learn that the National Hemophilia Program 2024-2028 had been signed ensuring uninterrupted access to treatment for the patients, as well as commitment to maintain the centralized tender system, which ensures equitable and affordable access to treatment throughout the country.

Drawing from the framework of our shared productive collaboration, we find it important to hereby reaffirm and emphasize the significance the WFH and the EHC attribute to engagement of the patient organizations in national program development and decision-making processes at national level. Further, the WFH and EHC adhere to the principle of 'one country – one patient organization', recognizing it as a best practice. In the case of Poland, the National Member Organization of both WFH and EHC, representing the community of patients with bleeding disorders, is the Polish Hemophilia Society (Polskie Stowarzyszenie Chorych na Hemofilię) since 1969. Since then, the organization has been carrying out a highly successful and constructive work for the bleeding disorders community in the country, widely acknowledged by the WFH and the EHC.

Furthermore, we deeply acknowledge the longstanding collaboration between the Polish Hemophilia Society and the various levels of legislative and executive governance, including the Parliamentary Group for Rare Diseases, the Ministry of Health, the Blood Centre, and other key stakeholders. Hereby we express our strong hope that this practice will be maintained further by continuing to include the Polish Hemophilia Society in all multistakeholder discussions pertaining bleeding disorders from the onset. Early and active engagement of the internationally recognized patient organizations, fosters a more comprehensive understanding of the challenges faced by the patients facilitating informed decision-making processes and ultimately development and enactment of policies and initiatives that address the needs of the community at the best possible level.

The WFH and the EHC remain dedicated to the wellbeing of every patient in a given country and actively contribute to develop their member organizations enabling them to effectively advocate for the collective interests of the community while ensuring inclusion of opinions, so that the rights of each individual patient are respected and upheld.

Please do not hesitate to contact us if you have any questions or if you wish to exchange views on best practices of national hemophilia care organization.

Sincerely,

Cesar Garrido
President of the WFH

Miguel Crato
President of the EHC

C.c.:

Izabela Leszczyna, Minister of Health
Maciej Miłkowski, Deputy Minister of Health
Damian Kuraś , Ministry of Health Spokesperson
Malgorzata Lorek, Director of the National Blood Center
Dorota Zielinska-Bak, aa; Sejm Office
Bogdan Gajewski, Polish Hemophilia Society