



**Declaration of Panama City  
on Integrated Care for the Quality of Life of the  
People with Hemophilia and Other Inherited Bleeding Disorders (PWHIBD)**

We, the National Member Organizations (NMOs) of the Coalition of the Americas (CoA) and the World Federation of Hemophilia (WFH), gathered at the Summit of the Americas on Hemophilia and Other Inherited Bleeding Disorders held October 24-26, 2019 in Panama City:

We express unrestricted support for the declaration of Heads of State and Government meeting at United Nations headquarters on September 23, 2019, in which they state that efforts must be accelerated to achieve Universal Health Coverage, both in financial protection and in services by the year 2030. This aspiration is of special relevance for Latin America and the Caribbean, given the foreseeable increase in the number of PWHIBD and the economic restrictions that have been predicted for the coming years.

We reaffirm our commitment to the vision of the WFH and its strategic principles: a) to improve the identification and diagnosis of people with inherited coagulation disorders; b) to increase access to adequate and affordable care; and c) to increase sustainable access to safe therapies.

We hope that all PWHIBD, including the carriers of these deficiencies, will be diagnosed in a timely manner, comprehensively cared for, and that they will achieve the highest quality of life, preventing disability in children, young people and adults.

We urge public policy makers in our region to undertake together the actions required for States and Governments to achieve the objectives in the following pillars:

**Regarding the role of national public bodies and institutional alliances**

- Guarantee that all PWHIBD have access to preventive treatment, continuous, sufficient and in accordance with international standards of safety and quality.
- Guarantee the inclusion of all PWHIBD in the education system and the labor market in order to promote their full development.
- Guarantee and carry out, in a regular and periodic manner, the acquisition of the required therapeutic modalities, taking into account the recommendations of the WFH in these aspects, and with consultation mechanisms with specialists and NMOs.
- Establish and consolidate the decision-making bodies in which the NMOs participate for the follow-up and improvement of the services to the PWHIBD.
- Establish formal alliances with national and international organizations to access professional training, optimize the use of resources and foster cooperation.



### **Regarding the national registries of PWHIBD**

- Consolidate in each country an accurate and updated National Registry of PWHIBD with the participation of NMOs, specialist's advice, and with the implementation of regular national campaigns to increase diagnosis, and improve efficiency and monitoring of treatments.
- Link national registries to the WFH's World Bleeding Disorders Registry and Annual Global Survey.

### **Regarding the Integrated Care for PWHIBD**

- Guarantee personalized treatment, both preventive and corrective, appropriate to the conditions of each PWHIBD (severity, frequency of administration and proximity to care centers), permanently updated to include the new therapeutic modalities that are available, and based on the protocols recommended in the WFH Guidelines.
- Establish prophylaxis as a therapeutic priority for both children and adults with severe or moderate hemophilia with a factor deficiency of less than or equal to 2UI/dl, and with the respective indication of the treating physician.
- Guarantee personalized treatment for patients with inhibitors prioritizing those appropriate to the conditions of each patient.
- Establish in each country the Integrated Care Centers (ICC) required to facilitate the articulated work of different health professionals and their respective areas.
- Implement national systems for monitoring care of PWHIBD based on indicators, including periodic measurement with specific scales for quality of life, and assessment of joints, disability, pain, access to prophylaxis and bleeding rate.

### **Regarding education and research**

- Promote the participation of ICC in clinical studies and other research areas.
- Assign priority and sufficient resources for clinical research and health services management projects that contribute to improving the quality of care for PWHIBD.
- Promote the development of a Latin American Observatory on Inherited Bleeding Disorders, which includes among its objectives to monitor the fulfillment of the goals for the year 2023.



## Targets for 2023

We propose to public policy makers the adoption of the following targets to improve the care of PWHIBD in each country of the region in the year 2023, as has been established as a reference in the United Nations General Assembly in 2019:

- By 2023, at least 75% of PWHIBD should be diagnosed.
- By 2023, at least 80% of PWHIBD must have an adequate Quality of Life Index obtained from the national system for monitoring care.
- By 2023, 100% of diagnosed PWHIBD must have access to integrated care of quality.
- In 2023, 100% of severe or moderate PWH with a factor deficiency of less than or equal to 2 IU/dL, and with the respective indication of the treating physician, must have continuous access to prophylaxis.
- In 2023, 100% of people with inhibitors to replacement factors should have access to the most effective treatments to eliminate them, or avoid bleeding, even if they persist.



**Signed by the following NMOs:**

Fundación de la Hemofilia (Argentina)  
The Bahamas Hemophilia Foundation  
Barbados Hemophilia Association & Charity  
Belize Bleeding Disorders Foundation  
Fundación Nacional de Hemofilia de Bolivia  
Federação Brasileira de Hemofilia  
Sociedad Chilena de Hemofilia  
Liga Colombiana de Hemofílicos y otras deficiencias sanguíneas  
Asociación Costarricense de Hemofilia  
Sociedad Cubana de Hemofilia  
Fundación Hemofílica Ecuatoriana  
Fundación Salvadoreña de Hemofilia  
Asociación Guatemalteca de Hemofilia  
Sociedad Hondureña de Hemofilia  
Haemophilia Society of Jamaica  
Federación de Hemofilia de la República Mexicana  
Asociación Nicaragüense de Hemofilia  
Fundación Panameña de Hemofilia  
Fundación de Ayuda al Hemofílico (Paraguay)  
Asociación Peruana de Hemofilia  
Fundación Apoyo al Hemofílico (República Dominicana)  
Surinamese Society for Hemophilia Patients  
Society for Inherited & Severe Blood Disorders (Trinidad y Tobago)  
Asociación de Hemofílicos del Uruguay  
Asociación Venezolana para la Hemofilia