



INTERNATIONAL DATA INTEGRATION PROGRAM

A program designed to integrate data from established national registries into the World Bleeding Disorders Registry.

WORLD BLEEDING DISORDERS REGISTRY

In 2018, the World Federation of Hemophilia launched an international, multi-center, and observational World Bleeding Disorders Registry (WBDR) to support its evidence-based approach in achieving the WFH vision of Treatment for All. Today, the WBDR remains the only global registry collecting standardized clinical data on people with hemophilia (PWH) and von Willebrand disease (VWD) from all around the world.

WBDR GLOBAL REACH

13,000+
PWH enrolled

1,000+
PwVWH enrolled

119 HTC in **44** countries

2 countries participating in the
International Data Integration Program



RESEARCH

WBDR data are key in addressing research and clinical questions and evaluating patient outcomes at national, regional, and global levels.



ADVOCACY

WBDR is an unbiased tool that highlights gaps in care and accessibility to diagnosis and treatment, which can be crucial for evidence-informed advocacy initiatives.



CLINICAL MANAGEMENT

The WBDR is an electronic patient management system that helps health care providers track patient progress and quality of life.



PATIENT EMPOWERMENT

WBDR patients have exclusive access to a myWBDR mobile app to record their bleeds and treatment data and monitor their own health – thus taking an active part in their own wellbeing and bleeding disorder management.

HOW TO PARTICIPATE

- 1 A meeting between the WFH and the national registry custodian for a thorough assessment of the legal and regulatory implications, including data privacy, security and patient consent between the integrating registries is required.
- 2 The WBDR has developed a Data Exchange Protocol (DEP) to facilitate data alignment and subsequent import. Following data mapping and adequate transformation, the national registry dataset is integrated in the WBDR database.

BE PART OF THE SOLUTION

Data collection in the area of rare diseases is of crucial importance in advancing research and clinical practice for improved disease management. Ensuring patient representativeness is key to any research study. By agreeing to combine your de-identified national registry data with the global WBDR, you are giving the people with bleeding disorders (PwBDs) in your country the chance to be represented in a global dataset that aims to improve their health status and that of all PwBDs.

DATA PRIVACY AND PROTECTION

Only de-identified data is stored. The WBDR adheres to strict European patient data privacy and protection laws: CE-mark (Conformité Européenne), the U.K. standard Information Governance Statement of Compliance (IGSoC), and the General Data Protection Regulation (GDPR).



WBDR IN ACTION

CAMEROON

Funded by the WBDR Research Support Program (RSP), The Yaoundé HTC in Cameroon conducted a study entitled "Epidemiological, clinical and radiological profile of articular pathology in the Cameroonian haemophiliac." PWH were assessed using the Hemophilia Joint Health Score (HJHS), and radiological tests and joint ultrasound. Data were collected and monitored in the WBDR. 84% of the 38 participants had damaged joints. From radiographic and ultrasound findings, 67% of examined joints were pathologically affected and 45% had hemosiderin deposition. The team presented their findings at the 2023 ISTH congress, for which they have received a travel grant. This is the first study on joint disease profiles in Cameroonian PWH.

INDIA

The Ludhiana, India, HTC completed a study also sponsored by the RSP entitled "Effectiveness of myofascial therapy and conventional physiotherapy with intermittent prophylaxis on joint health haemophilic arthropathy." Sixteen people with hemophilia A with joint arthropathy were randomly divided into two groups: Group A (myofascial therapy with conventional physiotherapy) and Group B (conventional physiotherapy alone). Patients underwent four physiotherapy sessions/week for three weeks with intermittent FVIII prophylaxis twice weekly. Participant underwent joint health assessment and completed the Functional Independence Scoring for Hemophilia (FISH). Data were stored and monitored in the WBDR. The mean scores on all tools used demonstrated improvements in Group A compared to Group B. In 2023, the team submitted a manuscript to a peer-reviewed journal.

CURRENT PROGRAM COLLABORATIONS

1. In a proof-of-concept study, a de-identified minimal set of data on 770 patients from the 2018 Czech National Haemophilia Programme Registry (CNHPR) were imported into the WBDR. Thus, began an annual collaboration to update the CNHPR data. In 2023, data on people with VWD were added. Today, we have over 1000 Czech patient represented in the global registry.
2. Since 2021, the Hemostasis Registry of the Thai Society of Hematology (TSH) has been collaborating with the WBDR to integrate data on over 300 PWH.

FROM OUR COLLABORATORS

"As a result of collaboration between the Thai Society of Hematology (TSH) and the WBDR, the minimal data set of Thai patients with hemophilia from our existing registry, namely 'Hereditary Bleeding Disorder' of the TSH will be smoothly transferred to the WBDR by pressing a 'Magic Button' of 'Connect'. Consequently, an annual individual patient report concerning bleeding episode, joint bleed, utilized factor concentrate and days of hospitalization will be integrated. In 2021, data on up to 100 Thai patients with hemophilia will be transferred to the WBDR."

— Ampaiwan Chuansumrit, MD, Director,
International Hemophilia Training Center-Bangkok

"Disease-specific registers are a way to maximize the use of a limited amount of available data on rare diseases in a long-term and attainable way. Pooling and sharing data on international level is the optimal way to increase real-world evidence in this field. This gives us the chance to further improve care worldwide. This is the reason why the Czech National Haemophilia Programme Registry appreciates our cooperation with the WBDR."

— Jan Blatny, MD, PhD,
Czech National Haemophilia Programme Registry (CNHPR)



For more information, please contact WBDR@wfh.org



WBDR
WFH WORLD BLEEDING
DISORDERS REGISTRY



WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA