



# 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) from all around the world.

## WBDR GLOBAL REACH

**9000+**  
PWH enrolled

**97** HTC's  
in **46** countries

**7** countries where the WBDR is the national registry

**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 hemophilia 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 PWH in your country the chance to be represented in a global dataset that aims to improve their health status and that of all PWH.

## 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 UK standard Information Governance Statement of Compliance (IGSoC), and the General Data Protection Regulation (GDPR).



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





## WBDR IN ACTION

Through the WBDR Research Support Program, the Lagos University Teaching Hospital HTC in **Nigeria** was able to hold weekly clinics for patients, provide accurate diagnoses to PWH through factor level testing, administer inhibitor testing, and compile complete clinical and bio-demographic data with the use of the WBDR database. Having a system like the WBDR is crucial in Nigeria because the country does not have a national registry.

Their efforts had immediate results: in 2018, there were 12 PWH registered in the WBDR in Lagos. This figure increased to 77 PWH in 2020. Additionally, 59 PWH

were able to get an accurate diagnosis, 68 PWH were tested for inhibitors and 33 new PWH were identified.

In **Senegal**, data on bleeds and treatments were inconsistent and of a low volume, making it hard for researchers to get a good grasp of the bleeding disorders situation in the country. Once the WBDR was implemented at the Centre National de Transfusion Sanguine, in Dakar, data collection was significantly improved, and patient care was enhanced. In 2019, only 6 patients were enrolled in the WBDR. A year later, this number has increased to nearly 200.

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## CURRENT PROGRAM COLLABORATIONS

1. The Czech National Haemophilia Programme Registry (CNHPR) collects national data from eight pediatric and eight adult hemophilia treatment centres in the Czech Republic. As part of a proof-of-concept study, a de-identified minimal set of data from the 2018 CNHPR data were imported into the WBDR. Starting in 2019, and following the success of the first import, data on genetic testing, the Hemophilia Joint Health Score (HJHS), comorbidities, and hospitalizations were added to the imported dataset. Data from CNHPR continue to be annually updated in the WBDR.
2. In 2021, the Hemostasis Registry of the Thai Society of Hematology (TSH) is collaborating with the WBDR to integrate their 2020 and 2021 data.

## 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)



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For more information, please contact [WBDR@wfh.org](mailto:WBDR@wfh.org)