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 HTCs in 46 countries
7 countries where the WBDR is the national registry
2 countries participating in the International Data Integration Program
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.

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.

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.

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).
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)