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The WFH World Bleeding Disorders Registry – 16-month update

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Abstract

Objective: The World Federation of Hemophilia (WFH) World Bleeding Disorders Registry (WBDR) is the only global registry collecting standardized clinical data on a large population of people with hemophilia (PWH). By collecting real-world data, which can be used to address important clinical questions and support advocacy initiatives, the WBDR aims to improve the quality of care for PWH around the world. The goals of the WBDR are to enroll at least 10,000 PWH from more than 50 countries, aiming for representation of patients from around the world. **Methods:** The WBDR is a prospective, longitudinal, observational registry of patients diagnosed with hemophilia A and B. HTC participation steps include: 1) registration with the WBDR; 2) approval from their Institutional Review Board; 3) obtaining patient consent; and 4) contribution of data on an ongoing basis. All HTCs contribute data on basic demographics, diagnostics, and clinical variables included in the Minimal Data Set (MDS). HTCs may also choose to contribute to the Extended Data Set (EDS) to obtain more complete patient data. **Summary of results:** Since January 2018, 52 HTCs from 32 countries have received ethics approval and have enrolled > 2100 PWH (Figure 1, 2). Patients registered with the WBDR represent all regions of the world and all World Bank gross national income categories. Most patients enrolled are male (99%), with hemophilia A (86%) and severe disease (52%). The most frequent severity category among hemophilia A patients was severe (54%), while severe and moderate category have the same frequency among hemophilia B patients (41%) (Figure 3). The median age of patients in the registry is 17 years, with a ratio of children to adult participants of 51% : 49%. Median age at diagnosis is 20 months. Age at diagnosis decreased as GNI increased, from 37 months in low income countries, to 9 months in high income countries for all PWH, with a similar pattern among PWH with severe disease. **Conclusions:** The successful first year of the WBDR laid a solid foundation on which the registry will continue to expand. This global network of HTCs and patients has started providing real-world data, on which evidence to improve the quality of care worldwide will be generated. Further aggregate data is presented in the first WBDR Data Report, available online at: <https://www.wfh.org/en/our-work/wbdr/2018-data-report>. The WFH thanks the many dedicated health care providers and patients who are part of this important initiative. The WBDR is supported by our Visionary Partners: SOBI and Takeda; and our Collaborating Partners: Bayer, CSL Behring, Grifols, Pfizer, and Roche.