The World Federation of Hemophilia (WFH - http://www.wfh.org) is an international not-for-profit organization that provides global leadership to improve and sustain care for people with inherited bleeding disorders, including hemophilia, von Willebrand disease, rare factor deficiencies, and inherited platelet disorders. Established in 1963, the WFH works with member organizations in 140 countries as well as through a network of international volunteers and healthcare providers to achieve our vision of “Treatment For All” around the world.

The WFH is presently seeking a highly knowledgeable and effective, self-motivated, results-oriented Data and Research Manager - contract 1 yr (renewable), to manage multiple international data collection efforts, including the World Bleeding Disorders Registry and other WFH research projects, central to achieving the World Federation of Hemophilia’s mission of Treatment for All.

Category: full-time; 1-year (renewable)  
Location: WFH Headquarters, Montreal (downtown)  
Entry: IMMEDIATELY (latest Mar 1, 2020)

SUMMARY –  
Reporting to the Director of Research and Public Policy, the Data and Research Manager (bleeding disorders) – 1 year (renewable) is responsible for the management and coordination of the WFH’s research and data collection activities for the World Bleeding Disorders Registry (WDBR). The incumbent will also manage the other related research projects.

MAIN DUTIES & RESPONSIBILITIES -

- Ensure the smooth and efficient day-to-day operation of research and data collection activities  
- Identify and initiate new hemophilia treatment centers (HTC) to participate in the WBDR globally; perform virtual site initiation and training sessions; provide assistance on regulatory and ethics approval; ensure compliance with the patient-consent process;  
- Monitor patient and HTC progress of the WBDR; track milestones and implement corrective measures when necessary;  
- With the director, strategize and implement activities related to the WBDR: research support program; implementation of additional features such as a patient mobile application;  
- Manage development of additional features for the WBDR: patient summary, data dashboard; etc.  
- Manage data linkage project with existing hemophilia registries  
- Perform data analytics, identify trends, track progress and prepare reports and manuscripts as needed  
- Employ advanced data visualization techniques for the effective communication of WFH data  
- Work with the database provider with ongoing projects requiring their input;  
- Participate in the development of research designs, data collection methods, and strategies for data management and reporting  
- Develop and implement training programs and workshops on data collection and research methodology for hemophilia treatment centers (HTCs) and/or national member organizations (NMOs)
• Represent the WFH and Research & Public Policy Department at International conferences and meetings to promote, encourage and engage HTCs and NMOs in data collection and research efforts
• Ensure that projects are executed successfully to meet established objectives
• Identify areas for expansion or improvement to contribute to efficiency and effectiveness
• Oversee the planning and coordination of operational committee meetings; liaise with staff and committees as needed
• Assume responsibilities and accomplish other tasks related to the position as required by the Director, Research & Public Policy.

REQUIREMENTS & QUALIFICATIONS:

- Graduate degree in public health, epidemiology or related field;
- 6-9 years of relevant experience in research management, data collection, database design, clinical trial design, data analysis and/or research methodology in the non-profit or public sector;
- Exceptional project management and time management skills; able to prioritize multiple tasks;
- Experience in developing and facilitating research related training programs and workshops;
- Demonstrable experience in managing research studies: proficient with research protocols, regulatory requirements, and good clinical-practice regulations;
- Adept at clinical study initiation visits, training site personnel, monitoring & tracking progress of studies, supervising study conduct, fostering continued engagement with study personnel;
- Experience in data analytics and data visualization;
- Ability to solve problems and effectively manage priorities;
- Capacity to think critically, collaborate with others in a diverse team of staff and volunteers, as well as work autonomously
- Highly motivated and efficient individual
- Strong interpersonal, communication and presentation skills; ability to work well with volunteers and as part of an international team

- Superior English (written & oral) essential - primary language of this work; working knowledge of Spanish and/or French - an asset
- Excellent knowledge of Excel and statistical analysis techniques & software
- Willingness and flexibility to undertake international travel

Salary will be commensurate with experience.

Please send in confidence an English resume & cover letter AS SOON AS POSSIBLE to:

E: recrutement.recruiting@wfh.org     F: +1 514.875.8916

The World Federation of Hemophilia / Fédération mondiale de l’hémophilie http://www.wfh.org
Facebook: https://www.facebook.com/wfhemophilia    Twitter: https://twitter.com/wfhemophilia
LinkedIn: https://www.linkedin.com/company/world-federation-of-hemophilia
YouTube: https://www.youtube.com/user/WFHcommunications

We thank all candidates for their interest, however only short-listed candidates will be contacted. Une version française de l’affichage est disponible selon la demande.