



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

External posting / Affichage externe

Gene Therapy Program Manager (bleeding disorders; NFP) - CONTRACT 1 year, renewable /
Gestionnaire, Programme de thérapie génétique
(OSBL, santé mondiale)

*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.*

Category: full-time; 1-year contractual (possibility of regular position);
MUST BE entitled (current work permit) to live & work in Canada

Reporting to: Director, Research & Public Policy

Location: WFH Headquarters, Montreal (downtown)

SUMMARY

Reporting to the Director of Research and Public Policy, the **Gene Therapy Program Manager** (bleeding disorders) – **contract 1 yr** (renewable) is responsible for **managing and contributing to the development** of all aspects of the WFH Gene Therapy Program, including the WFH World Hemophilia Gene Therapy Registry, the WFH Gene Therapy Round Table, and future organizational initiatives in gene therapy.

PRINCIPAL DUTIES & RESPONSIBILITIES -

- Lead and develop WFH expertise in the area of gene therapy for hemophilia
 - Attend relevant international meetings.
 - Closely follow all gene therapy in hemophilia clinical trials and their regulatory status. Develop a dissemination strategy for updating community on a regular basis (WFH website; social media).
 - Promote WFH activities in gene therapy.
 - Advocate for improved access to gene therapy around the world.
 - Be familiar with the WFH Education strategy in gene therapy.
- Manage the WFH Gene Therapy Registry
 - Work with the World Hemophilia Gene Therapy Registry (WHGTR) Steering Committee to develop the registry, the minimal data set and implementation plan.
 - Identify and work with the database provider to develop the WHGTR database.

- Contribute expertise in the development of the case report form(s) and database(s).
 - Site identification, outreach and enrollment of HTC's into the WHGTR.
 - Provide training and support to HTC's, including the development of training materials and webinars.
 - Develop tracking systems and evaluation tools to monitor progress and key milestones of the registry; adhere to overall timelines.
 - Coordinate the data quality activities for the WHGTR.
 - Coordinate data reporting activities for the WHGTR (Annual reports).
 - Ensure inclusion and promotion of the WHGTR at international meetings, conferences.
 - Develop promotional tools for the WHGTR (i.e., data dashboard) and coordinate all marketing and promotional activities of the WHGTR.
 - Coordinate all WHGTR SC calls.
- Manage the WFH Gene Therapy Round Table meetings.
 - With Director and the WFH GTRT program committee, develop the program for GTRT 2020 and all subsequent meetings.
 - Plan and coordinate all WFH activities surrounding the GTRT (ie., surveys, consensus, manuscripts, etc).
 - Work with the Congress department on the planning and logistics for the meeting.
 - Plan and coordinate regular program committee meetings.
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QUALIFICATIONS & REQUIREMENTS –

- **Graduate degree** in health policy, **public health, epidemiology**, or related field
- Minimum **7 years of relevant work experience** in **health program management / research development** in the **non-profit or public sector** (preferred); **international organization** or **world healthcare** setting – an asset
- **Experience** in **database design**, maintenance, query; **demonstrated understanding** of the **principles of data collection**, preferably in an international context
- Background in **developing & facilitating** research **program-related training/workshops**
- **Highly motivated** and efficient individual
- Ability to **think critically, resourceful, adept at taking initiative** and **following through, solving problems** effectively; **excels** in a **fast-paced, ambiguous/changing environment**
- Strong **interpersonal, communication and presentation** skills; ability to **work** well with volunteers working in diverse cultures and countries as **part of an international team**
- Ability to **form alliances easily, work & collaborate well** in a **team environment**; equally **autonomous, self-motivated**
- Ability to **balance, prioritize multiple tasks**, work on **projects simultaneously**; excellent **time & program management skills** (budgeting, reporting)
- **Mastery of MS Office**; **high** level functioning with **Excel or similar database**
- **Superior oral and written communication** skills in **English** (main language of work); working knowledge of French, Spanish, and/or other international language(s) – preferred
- Willingness and flexibility to undertake **international travel**
- **Entitled to live & work in Quebec, Canada**

Salary will be commensurate with background and experience.

Please send in confidence an **English** resume **& motivation letter IMMEDIATELY** to:

E: recrutement.recruiting@wfh.org

Fx: +1 514.875.8916

The World Federation of Hemophilia / Fédération mondiale de l'hémophilie <http://www.wfh.org>

Gestionnaire ressources humaines - HR Manager / 1200 - 1425, boulevard René-Lévesque ouest Montréal, Qc H3G 1T7

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.