Position: RDI Programme Manager (Junior)

Responsible to: RDI Programme Director

Contract duration: Permanent

Location: Remote

**Rare Diseases International** (RDI) is the global alliance of Persons Living with a Rare Disease (PLWRD) of all nationalities and across all rare diseases. RDI is a network of more than 90 organizations representing patient groups active in over 150 countries worldwide. These Members include national alliances of rare disease patient organisations, regional organisations, and disease-specific international federations.

Do you care to offer a BETTER LIFE to Persons Living with a Rare Disease (PLWRD)? Are you keen to actively support RDI's mission to be a STRONG VOICE for PLWRD and their families worldwide?

RDI has an immediate opening for a (Junior) Programme Manager to support RDI Global Programme, which encompasses numerous projects aimed at improving patient journey; to shorten the rare disease diagnostic odyssey, to foster equitable access to diagnosis and care for PLWRD around the world.

**Main scope of the position**

The Programme Manager (PM) contributes to Rare Diseases International (RDI)'s Global Programme and more specifically, in projects comprising activities related to rare disease healthcare, diagnostics, research, infrastructures and technologies.

The PM will work closely with the RDI Programme Director and the RDI Secretariat to manage day-to-day activities of the Global Programme projects. The PM will contribute to the development and management of these projects aimed at addressing the needs of individuals living with rare diseases and their families, with a specific emphasis on improving access to diagnosis and care. The primary responsibilities of this role include:

- Support the development and execution of strategies for the Global Program on global access, ensuring alignment with RDI's vision and mission.
- Collaborate with Programme Director to plan and coordinate global projects, including defining project scope, objectives, timeline and resource requirements.
- Coordinate and execute tasks related to the global projects, ensuring that tasks are executed according to the project plan.

**Specific Responsibilities**
The Programme Manager is responsible for:

1. **Operational and strategic collaborations with the WHO**
   - Developing and executing activities pertinent to the WHO-RDI collaboration, including technical research for the Global Network for Rare Diseases, mapping of global Centre of Excellence and Rare Diseases expertise, supporting regional hub discussions, project planning and engagement of the Panel of Experts.
   - Supporting the development of RDI-WHO collaboration on Essential In Vitro Diagnostics List (EDL) and Essential Medicines List (EML); supporting and empowering organisations to understand the formation of the Model Lists and utility;
   - Drafting of key documentations including project proposal, powerpoint presentations, and technical reports.
   - Monitoring WHO recommendations or outputs that are relevant to RDI vision and programme (e.g. Universal Health Coverage, Diagnosis, Essential Medicines, Genomics, Cell and Gene Therapies, M-Health).

2. **Support to RDI Global Programme**
   - Support engagement of RDI Membership and external collaborations in scientific or health care areas. Promote opportunities to RDI Members to engage in Global Programme.
   - When appropriate, deliver informative presentations to internal and external audiences or at events, showcasing Global Programme highlights and key insights.
   - Assist in maintaining Programme documentation, contact database, tracking of in-kind contributions of volunteers or organisations.
   - Identify opportunities for further strategic collaborations and promote opportunities to RDI members to engage in RDI Global Programme;
   - Support the organisation of online or in-person events related to the Global Programme

**Essential requirements**

**Experience**
- Graduate degree in Health Policy, Public Health, Health Management or Healthcare services;
- Minimum 3 years of project management experience in healthcare, healthcare sector
- Knowledge of rare disease patient organisations or policy environment is desirable;

**Skills**
- Understanding project’s aim to tailoring the organizational path to operationalising it across multiple partners,
- Excellent verbal and written communication skills in English (C1 minimum); Any other language is desirable;
• Highly organized with ability to prioritize workload;
• Problem solving, analytical skills and attention to detail;
• Mastery of MS-Office (including PowerPoint and Excel); use of digital coworking platforms (Google Workspace, Office365, Zoom) and project management tools;
• Motivation to work for a Non-Governmental Organization.

To apply, please send your CV and cover letter in English to Mary Wang, RDI Programme Director, mary.wang@rarediseasesint.org.