Position	**Research Infrastructure Projects Manager (RIPM)** *Registries, Biobanks, Clinical bioinformatics and -omics*
Responsible to	Scientific Director (SD)
Contract duration	Permanent (CDI)
Starting date	The contract may start as soon as Nov. 1st 2012
Salary	34,000-38,000 euros gross annual (39 hours/week - based on education, language skills and experience + 1 month performance related bonus & good health plan)
Location	EURORDIS Headquarters Paris: Plateforme Maladies Rares, 96 rue Didot, Paris 75014, France

Main scope of the post:

Management of activities related to EURORDIS' participation to the projects EPIRARE and RD-CONNECT focused on patient registries, biobanks, clinical bioinformatics, and -omics in the field of rare disease research.

EPIRARE is a 30-month DG-SANCO ongoing project (end October 2013) coordinated by the Istituto Superiore di Sanità (ISS, Italy) in collaboration with several high-level academic partners in Europe. The aim of the project is to build a consensus and create synergies to address regulatory, ethical and technical issues associated with the creation and development of rare disease (RD) patients' registries and to elaborate possible policy scenarios. EURORDIS is one of the ten associated partners and is specifically responsible for a) participating in project management through the Steering Committee; b) conducting a survey with RD patient groups across Europe on their experience and expectations as regards to RD patient registries; and c) implementing Work Package 5 (WP5) – Policy Scenarios on the Scope, Aims, Governance and long-term sustainability of registration of RD patients. The latter being an essential Deliverable for the basis of future EU policy on patient registries.

RD-CONNECT is a 6-year DG-Research project coordinated by Newcastle University (United Kingdom) in collaboration with several high-level academic partners in Europe, USA, Australia and Japan (official starting date of the project November 1st, 2012; Kick Off meeting 25-26th January, 2013). The project will build an integrated platform connecting databases, registries, biobanks and clinical bioinformatics for rare disease research. The project will provide a strong impetus for a global "trial-ready" infrastructure able to support the International Rare Diseases Research Consortium (IRDiRC) goals for the development of new diagnostics and therapies for rare diseases. EURORDIS

is one of the 26 full partners and it will represent the entire rare disease patient community. Specifically, EURORDIS will a) ensure the link with the patient organisations contributing to the preparation and delivery of educational material; b) consult rare disease patients on the various issues related to the research on -omics and the linkage of patient data across different infrastructures and across borders, e.g. ethical, societal issues, sensitive data protection, access and use of patient information and samples; c) contribute to RD-CONNECT work packages specifically dealing with biobanks and registries for rare diseases; d) ensure a strong interaction and coordination of the RD-CONNECT network with other initiatives inside and outside Europe and contribute to the dissemination of the project outcomes at the international level. In summary, EURORDIS will participate in several Work Packages: WP1 (coordination and management), WP2 (patient registries and databases), WP3 (biomaterial sharing), WP5 (integrated platform), WP6 (ethical, legal and social issues, where a major contribution from EURORDIS is expected) and WP7 (impact, innovation and implementation) as detailed in the project Description of Work (DoW).

The Research Infrastructure Projects Manager will be part of the EURORDIS Operations' Unit and under the direct supervision of the Scientific Director.

Responsibilities

The RIPM will be responsible for coordination of the above mentioned projects: i) internally, with staff and members ii) with partners and iii) with project coordinators, as well as for the achievement of milestones, deliverables and deadlines, writing reports and managing budgets in close contact and under the supervision of the SD.

In the context of EPIRARE, the RIPM will be responsible for the fulfilment of the remaining EURORDIS contractual obligations and engagements in the context of the project. In particular, he/she will monitor milestones, deliverables and deadlines related to the completion of WP5, which defines the scope and governance model for registries, representing the interests of relevant stakeholders (national and subnational public health authorities, research, pharma industry and Pharmaceutical Forum, patients and centres collecting data) in strategic decisions. The RIPM will a) participate in the setting up of a capacity-building workshop with patient organisations with the participation of academic registries and Centres of Expertise – in conjunction with EURORDIS Membership Meeting in May 2013; b) develop useful information for the EURORDIS' website section on registries; c) follow and analyse the EURORDIS Patients Survey on Rare Disease Registries.

In the context of RD-CONNECT, the RIPM will be responsible for the fulfilment of EURORDIS contractual obligations and engagements in the context of the project. In particular, he/she will monitor milestones, deliverables and deadlines related to the completion of the activities listed in the above mentioned WPs. In the contest of WP6, EURORDIS is focusing on a) developing best ethical practices for balancing patient-related interests associated with RD research using databases/registries, biobanks and -omics databases in global networks of clinicians and researchers; b) engaging with relevant stakeholders, e.g. patient organisations, clinical and research networks, legislators and policymakers, pharma industry; c) developing a proposal for an expedient regulatory framework for linkage of medical and personal data related to RD on a European and global level. The RIPM is specifically be responsible for the completion of the deliverable D6.12 - Publication of findings from patient workshops/focus groups and D6.13: Report on the outcome of Delphi-like exercise with expert patients/patient representatives. The RIPM will also manage EURORDIS involvement in WP1, WP2, WP5 and WP7 as described in the project DoW.

Overall, and as part of EURORDIS' activities in the field of empowering patients' advocates, the RIPM will also be prepared to travel to attend meetings related to the projects described, and contribute to the current information on the EURORDIS' website, and capacity building of members.

Background and Work experience

Background (mandatory):

- University degree in life sciences, social sciences, or public health

Pre-requisite:

- English mother tongue or equivalent or with several years of experience in an English-speaking environment and excellent English writing skills
- Minimum 3 years professional experience in a European or international academic environment, preferably in the non-profit, humanitarian or health sectors
- Experience in the international project management including working with several partners, reports and budget

Any other additional skills desired:

- Coordination of transnational projects
- Experience with EU funded projects (preferably DG Research), including reports and budget
- Experience with databases
- Experience with transnational surveys
- Experience with scientific communication to the lay public and training activities
- Experience in structured communication and consensus creating techniques (e.g. Delphi method)
- Previous employment or traineeship/studies in other EU Member States

Qualities:

- Organised, autonomous, reactive, reliable and flexible in order to keep track of different activities, in line with the multi-task aspect of the position
- Empathy; driven by patient needs; developed communication skills
- Ability to work with different stakeholders and to communicate / engage with patient advocacy groups and high level academics
- Team working ability; common sense and capacity to evaluate priorities; able to perform under stress and to take initiatives;
- Interest in technological innovations applied to science

IT: Word, Excel, PowerPoint

Deadline for application: October 12th, 2012

Please send your letter of motivation and CV in English to:
rdconnect@eurordis.org