

# EURORDIS-Rare Diseases Europe

## Job vacancy – Research & Policy Project Manager

**Position:** Research & Policy Project Manager

**Responsible to:** Scientific Director

**Contract type:** Permanent, full time

**Salary:** 34 – 38 000 euros per annum

**Location:** EURORDIS Paris Office

**Start date:** 1 September 2018

### About EURORDIS-Rare Diseases Europe

EURORDIS is a unique, non-profit alliance of 792 rare disease patient organisations from 69 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.



### Key tasks & responsibilities

The Research & Policy Project Manager (RPPM) is responsible for the support of EURORDIS' involvement in Research Projects comprising activities related to rare disease research, diagnostics, infrastructures and technologies as well as related ethical issues.

The RPPM will work closely with the Scientific Director, Therapeutic Development Director, ERN & Healthcare Director, Patient Engagement Senior Manager and other team members to develop the healthcare and research networks and infrastructure to meet the needs of the rare disease community.

The main scope of this post includes:

- Support project management of the EU-funded clinical research and research infrastructure projects, specifically C4C, RD-Connect and Solve-RD, by being responsible for the preparation of activity reports, deliverables, project communication and representing EURORDIS in management and advisory committee meetings.
- Represent EURORDIS in several research initiatives and consortia (BBMRI-ERIC, EU RD Platform, EJP for RD, Go-FAIR Rare Disease Network, Undiagnosed Disease Network International, SWAN Europe, etc.).
- Assist the Scientific Director and the Public Affairs Team on public affairs and advocacy topics relevant to rare disease research & policy, ensuring all relevant research policy areas are addressed in a comprehensive way in line with EURORDIS' key priorities.

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- Empower patient advocates through travelling to attend meetings related to the different projects and consortia; contributing to the current information on the EURORDIS website; and contributing to any peer-reviewed or other publications within the scope of this position.

## Experience & skills

- Minimum MSc degree in biomedical or life sciences (or equivalent)
- Minimum 5 years of research and/or research policy experience preferably in the academic and public sectors
- Excellent level of English and a minimum “working level” in French
- Experience with EU funded or large projects with several partners including analysis and reporting
- Self-driven, 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
- Excellent communication and written skills
- Proven ability to work with different stakeholders and to communicate / engage effectively with high level academics
- Team working ability; common sense and capacity to evaluate priorities

## To apply

Please send your CV and cover letter in English to [susan.foster@eurordis.org](mailto:susan.foster@eurordis.org)

**Deadline for applications: 30 April 2018**

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