

## Scientific Project Manager for Rare Diseases

### Job Description

**Role** Responsible for administration

**Classification (BAP)** J – Management

**Functions**

- He/she implements the activities outlined in the H2020 project “European Joint Programme on Rare Diseases” (EJP RD) in connection with (1) the strategic activities of alignment with national strategies in the field of rare diseases and (2) sustainability activities of the EJP RD. He/she plans and follows the timeline of actions, prepares the documents provided for in the EJP RD Grant Agreement and organizes the meetings. He/she ensures the interface with National Mirror Groups (NMGs) on rare diseases. He/she provides support to the leaders of the Work Packages (WP) concerned.

**Main activities**

- Develop the strategic support system of the EJP RD coordination team for the creation and support of rare diseases NMGs in each country involved in the EJP RD
- Support the leaders of the Work Packages concerned
- Assure the proper execution of the EJP RD Grant Agreement
- Contribute to the writing of deliverables planned in WP2 and WP3 of the EJP RD
- Organize activities in agreement with the EJP RD coordinator
- Ensure the traceability of decisions and the organization of shared documents
- Monitor the proper execution of decisions
- Organize meetings of the French rare disease NMG and contribute to the organization of mirror group meetings in other countries
- Contribute to the meetings organization of the EJP RD’s General Assembly, Policy Board and Executive Committee
- Participate in the elaboration of the Annual Work Plan (scientific/technical) of the EJP RD
- Participate in the preparation of annual and final reports for the European Commission
- Participate in the organization of scientific conferences of the EJP RD
- Ensure the interface between the various project partners and the European Commission
- Write meeting reports and activity reports

**Associated activities**

- Monitor the activities of related projects and networks: “National Plans/ Strategies for Rare Diseases”
- Inform the communication manager about the communication and dissemination needs
- Contribute to the drafting of annual reports on research trends in the field of rare diseases and to the improvement of the identification and analysis of these trends

**Knowledge**

- Good project management skills
- In-depth knowledge of both institutional and policy research environment, as well as the scientific and technical, national and international communities in the field
- Awareness of the rare disease environment and more particularly the interactions between the national activities of the 27 EU member countries (EU27) and European activities

**Expertise**

- Identify the aims and objectives of the project
- Establish project specifications
- Put in place tools and resources for executing and monitoring the project

- Process a request as a study problem
- Search and review strategic information
- Evaluate the reliability and validity of sources and information
- Write systematic reviews and summary documents
- Define procedures for information generation and processing adapted to the needs
- Follow and ensure compliance to ethical and professional principles related to the field of activity
- Elicit the meaning of a policy, regulation, or a given action to the actors concerned through the implementation of written or oral communication actions
- Master oral and written presentation techniques
- Use different teaching methods to transmit knowledge to different audiences
- Write training material

### Aptitudes

- Be responsive and proactive particularly in international meetings
- Be autonomous, methodical, and organized
- Take initiative
- Analytical and strategic thinking
- Good writing skills
- Good interpersonal skills and team spirit
- Good listening skills
- Know how to effectively report actions

### Specific Requirements of the position

English environment: bilingual or level C1 English minimum (CEFR)

Multiple interactions:

- Internally:
  - Works under the responsibility of the IT GGB Assistant Director delegated to the coordination of the EJP RD program
  - As a member of the EJP RD team, with the Management of the GGB Thematic Institute and the members of the team
- Externally: with national authorities (ministries, strategic establishments, etc.), with the European Commission, the partners of the EJP RD program

### Experience desired

- Minimum experience of 3 years in the field of management of European projects. Experience in the international medical research sector. Proven experience in projects or institutions involved in the elaboration of national rare disease strategies (e.g., Joint Action for Rare Diseases, Orphanet, Eurordis, European Reference Networks).

### Qualifications desired

- Holder of a doctoral thesis in biology/health/medicine

## Organization

**Unit code** DR Paris 6/12

### Title

### Person-in-charge

Camille CHAUDONNERET, Inserm Regional Officer Paris 6/12

Daria JULKOWSKA, Assistant Director, Thematic Institute of Genetics, Genomics & Bioinformatics, INSERM/ EJP RD coordinator & IRDiRC Scientific Secretariat Coordinator

### Composition

### Address

### Regional Delegation

Paris 6

## Contract

<b>Type</b>	CDD
<b>Duration</b>	One (1) year renewable
<b>Remuneration</b>	Application of the contractual worker scale of Inserm: Between 2620.85 € and 3286.92 €, then according to the professional experience acquired
<b>Start date</b>	01/01/2022 (Please note that INSERM recruitment procedures can take from 6-8 weeks from the time the candidate is chosen)

## To apply

Send your **CV** and **cover letter** to:

- Daria Julkowska
- E-mail: [daria.julkowska@inserm.fr](mailto:daria.julkowska@inserm.fr)
- Phone: 06 20 14 13 81
- For more information on EJP RD: [www.ejprarediseases.org](http://www.ejprarediseases.org)