

EURORDIS-Rare Diseases Europe

Job vacancy – Patient Engagement Junior Manager – Healthcare, ePAGs, ERNs

Responsible to: Patient Engagement Senior Manager – Healthcare, ePAGs, ERNs

Contract type: Permanent, full-time

Salary: 28 000 – 32 000 euros per annum + one-month performance-based bonus

Location: EURORDIS Barcelona Office - Recinte Modernista Sant Pau - Pabellón de Santa Apolonia. Sant Antoni M^a Claret 167, 08025 Barcelona. Spain

Start date: ASAP

About EURORDIS-Rare Diseases Europe

EURORDIS is a unique, non-profit alliance of 970 rare disease patient organisations from over 70 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 and policies.



Main scope of the position

Following the transposition of the EU Cross-Border Healthcare Directive into domestic EU Member State law, Member States and the European Commission established the first 24 European Reference Networks (ERNs) in 2016. European Reference Networks connect scattered expertise, rare disease patients and data to improve access to high quality and safe highly specialised healthcare. EURORDIS created European Patient Advocacy Groups (ePAGs) in 2016 to support structured patient engagement in the ERNs.

The Patient Engagement Junior Manager - Healthcare, ePAGs, ERNs plays a key role supporting EURORDIS activities to enable sustainable patient engagement in the ERNs' activities and decision-making process. The post holder works within the ERN & Healthcare team that is part of EURORDIS Operations Unit.

S/he will support the Patient Engagement Senior Manager - Healthcare, ePAGs, ERNs to deliver a patient engagement strategy to support effective patient-clinician partnership in the ERNs. The position will also play a vital role in helping ePAG advocates to identify synergies and support each other. The role progressively may be asked to take more responsibility in supporting patient engagement in transversal cutting topics across more than 2 European Advocacy Groups, such as governance, research, clinical decision support tools, patient experience measurement, monitoring and evaluation and communication (to be decided upon the background and interest of the successful candidate).

The Patient Engagement Junior Manager will be supervised by the Patient Engagement Senior Manager - Healthcare, ePAGs, ERNs (operational reporting) and the ERN and Healthcare Director (functional reporting) and will liaise with relevant EURORDIS staff members to perform the tasks associated with the position, notably the Public Affairs Senior Manager who manages 4 ePAGs, and other EURORDIS managers

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supporting patient engagement in the areas of research, access and therapeutic development as well as with colleagues in the events and communications teams.

Key tasks & responsibilities

Support the involvement of ePAG advocates in the ERNs collaborative activities and strategic planning including but not limited to:

- Management and support of ePAGs including organisation of regular calls to enable ePAG advocates' involvement in ERN-related projects that require their participation and input;
- Support EURORDIS ERN & ePAGs Patient Engagement Senior Manager in developing tools and processes to plan, conduct and evaluate patient engagement in the ERNs;
- Manage and organise regular ePAG-related events and meetings including induction of new ePAG advocates, peer learning and systematic exchange of good practices;
- Support the development of training activities tailored at ePAG advocates to enhance their soft skills, such as communication, conflict resolution, negotiation, and other skills as required;
- Contribute to communicate and disseminate knowledge on patient engagement to enable wide access and use by ePAG advocates and the wider rare disease community;
- Develop communication materials for internal and external communication (e.g. slide decks, meeting reports, concept notes, etc.);
- Support the recruitment of new ePAG advocates and the renewal mandate process every 5 years to ensure optimal patient representation in all ERNs;
- Support in maintaining and updating EURORDIS contact database of ePAG advocates and Patient Organisations involved in the ERNs;
- Technical hosting and moderating of online meetings.

Experience & skills

Required

- Minimum BA degree in life sciences, public health, public policy (or equivalent).
- Minimum 3 years professional experience in non-profit organisations or equivalent business setting with a demonstrable track record in programme and/or project development.
- Strong organisational and analytical skills.
- Empathy, driven by patient needs and by rare diseases or other chronic medical conditions.
- Ability to work with patient advocacy groups and to support the work of volunteers (patients, carers, professionals) to empower them.
- Team worker and able to work under pressure.
- Strong interpersonal skills, good communicator and able to listen emphatically to build trust and confidence. Must be comfortable managing conflict between individuals and accepting criticism.
- Strong working knowledge of Excel, Word and PowerPoint. Able to use and manage contact databases.
- Excellent English (oral and written), fluency in two additional European languages highly desired.

Desirable:

- Experience in an international environment in the healthcare sector; knowledge of rare disease patient organisations or advocacy groups will be a plus.

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To apply

Please send your CV and cover letter in English to lenja.wiehe@eurordis.org

Deadline for applications: ASAP. Interviews will run through October.

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