

EURORDIS-Rare Diseases Europe

Job vacancy – ATMP Project Manager

Responsible to: Research Policy and Initiatives Director

Contract type: Short-term Contract, full-time, 18 months

Salary: 38 – 43 000 euros per annum + benefits package

Location: EURORDIS Paris or Barcelona Office

Start date: September 2024

About EURORDIS – Rare Diseases Europe

[EURORDIS](#) is a unique, non-profit alliance of over 1000 rare disease patient organisations from 74 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.

EURORDIS' vision is a world where all people living with a rare disease can have longer and better lives and achieve their full potential, in a society that values their well-being and leaves no one behind.

EURORDIS-Rare Diseases Europe is recruiting an ATMP Project Manager in the context of an EU-funded project, the European Rare Disease Research Alliance (ERDERA) that will start in September 2024.

In the past few years, EURORDIS has been involved in a few ATMP initiatives, namely RARE IMPACT and JOIN4ATMP. The [RARE IMPACT initiative](#) (2017-2021) aimed to identify and validate the challenges to patients' access to gene and cell therapies through engagement with HTA agencies, regulatory bodies, payers, patient groups, clinicians, manufacturers and other experts across Europe. The JOIN4ATMP (2024-2026) project aims to accelerate and de-risk European Advanced Therapy Medicinal Product (ATMP) development and ensure wide-spread ATMP access, through the mapping of obstacles to such development, the audit of real-world-based solutions and the definition of new paths forward.

As part of the European Rare Disease Research Alliance (ERDERA) where EURORDIS is a partner, an ATMP work package will be developed with a key contribution from EURORDIS over the first 18 months. This work package will collect procedures and methods to help identify which rare diseases could benefit from ATMPs developed in ERDERA, matching diseases with suitable technologies and simplifying the procedures to access ATMP clinical trials. Consensus will be reached through concertation with clinicians, technology experts and patients.

The ATMP Project Manager will be instrumental in preparing, delivering, and implementing EURORDIS contribution and strategy in ATMP related projects, in ERDERA and beyond.

Main scope of the position

The ATMP Project Manager will firstly be responsible for the end-to-end organisation and contribution in several tasks on the ERDERA ATMP Work Package, including desk research, organisation of multistakeholder workshop(s), survey of the RD community on ATMPs, communication and trainings.

S/he will work closely with the Research Policy & Initiatives Director (EURORDIS lead for ERDERA), EURORDIS Therapeutic Development Director, EURORDIS ERN and Healthcare Director as well as ERDERA academic partners and other external partners including industry representatives and other experts.

Key tasks & responsibilities

The ATMP project manager will undertake the following tasks:

- **Flesh out and Implement EURORDIS Tasks in the ERDERA ATMP Work package**
 - Project Management
 - Co-ordinate with internal colleagues working on ATMP and external partners
 - Support Finance and overall project co-ordinator with technical reporting and budget follow up
- **Desk research and watch on ATMPs**
 - Desk research, data gathering, and database assembly: support the search and gathering of relevant information in ATMPs
 - Keep updated about latest developments on ATMPs (science, regulatory, funding, etc.)
 - Write briefing notes and documents
- **Organise multi-stakeholders' workshop(s)**
 - Organise workshops with external stakeholders (topic definition, agenda, speakers' identification, coordination with ERDERA Partners, briefing calls, moderation, logistics, etc.)
 - Write reports on workshops organised
 - Support the implementation of recommendations issued from those workshops
- **Survey the RD community in ATMPs**
 - Creating short surveys to elicit RD community views on ATMPs in line with workshops and consultations organised
 - Drafting interview guidelines, conducting qualitative interviews or focus groups, analysing qualitative material, drafting reports.
- **Communications**
 - Handling inquiries and requests on behalf of team members and member organisations on the ERDERA ATMP track
 - Proactively liaise and develop connections with a broad group of stakeholders to advance EURORDIS task in the ERDERA ATMP track: patients, industry, clinicians, researchers, regulators, etc.
- **Contribute to training and awareness raising on ATMPs in the patient community**
- **Miscellaneous**
 - Maintain confidentiality and handle sensitive information with discretion.
 - Make links with Join4ATMP and other EURORDIS work on ATMPs

Experience & skills

- Background in life sciences, with affinity for project management, Master's degree or equivalent
- Approximately 3 to 5 years of relevant work experience. Two years of project management experience in biotech/pharmaceutical industry or the biomedical field will be a plus.
- Fluency in written and spoken English absolute must – proficiency in other European languages will be a plus.
- Motivation to work for an NGO in the health sector and driven by patient needs is imperative.
- Pro-active mindset and ability to anticipate needs.
- Self-motivated, flexible, yet able to prioritise and meet agreed deadlines.
- Proficiency in using MS Office Pack and ability to quickly learn how to use new IT tools/software for virtual meetings and online communication.
- Empathetic personality, with strong notions of empowerment and mentoring.

About the offer

- Joining a team of experienced professionals, who work daily on advancing the rights and conditions of millions of affected patients
- A role with a substantial amount of transversal contributions and potential to learn accompanied by regular travel
- Short-term contract of 18 months and a benefits package
- Possibility of hybrid work arrangement

To apply

Please send your CV and cover letter in English to Sarah Didier, HR Director, at: atmp-pm@eurordis.org

Deadline for applications: 24 June 2024 (this position being open internally then externally, we reserve the right to close applications earlier if required)

EURORDIS is a value-driven organisation, including:

Social Justice and Equity -This means our commitment to diversity is woven into the very fabric of our organisation, from our leadership to our members and volunteers. Together, we are making strides toward a more inclusive society where everyone's rights are protected, and everyone's voice is heard.

Collaborative - This means colleagues will work across siloes and support each other in the quest to improve lives for people living with a rare disease

Authentic - This means all colleagues are expected to be in touch with the needs and priorities of our members, and we welcome applications from people with experience in the volunteer sector and with lived experience with rare diseases

For a full list of our values and our mission please see our [values](#) page on our website