

EURORDIS-Rare Diseases Europe

Job vacancy – EU Public Affairs Manager

Responsible to: Head of European Advocacy

Contract type: Permanent, full-time

Salary: 38 000 –43 500 € gross per annum

Location: EURORDIS - Brussels office

Start date: ASAP

About EURORDIS-Rare Diseases Europe

EURORDIS is a unique, non-profit alliance of over 1000 rare disease patient organisations from 75 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

By reporting directly to the Head of European Advocacy, the EU Public Affairs Manager will be:

- A member of EURORDIS' advocacy team, working alongside other colleagues dedicated to European advocacy and contributing to EU-level advocacy work on policies and legislation to improve the quality of life of people living with rare diseases.
- Supporting the advocacy activities of EURORDIS across a range of policy areas that are susceptible to have an impact on the lives of people living with rare diseases, with a specific focus on the areas of development and access to treatments, life science, health data and artificial intelligence.

Key tasks & responsibilities

- Developing material and advocacy outputs for different audiences and stakeholders, including EURORDIS members and the relevant networks of stakeholders EURORDIS interacts with, to support advocacy activities across a variety of topic areas, including policy positions, briefings, letters, contributions to consultations, toolkits, etc.
- Leading and implementing public affairs campaigns and policy actions in areas that are relevant for rare diseases.
- Working with EURORDIS' subject matter experts and policy leads to engage with members: in particular, helping ensure that the priorities and contributions of EURORDIS' members feed into the planning and definition of advocacy activities, and that feedback is regularly provided.
- Strengthening and proactively cultivating relationships with key decision-makers; independently liaising with and gathering inputs from external stakeholders (e.g., civil society, academia and technical experts).

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- Representing the organisation in external platforms and fora, such as NGOs coalitions on specific topics, trade associations and expert meetings, working group meetings etc.

Experience & skills

- Preferable university degree in Political Science, International Relations, EU Studies, Law, Public Health or any other relevant degree to be considered.
- 3 years or more of relevant experience within EU Public Affairs and/or Advocacy environment (e.g., previous experience at public affairs consultancies is a plus but not required).
- Very good understanding of EU legislation and the dynamics of EU policy-making processes.
- Interest and experience in patient / civil society advocacy, health policies and rare diseases. Previous work experience on the EU pharmaceutical legislation or European Health Data Space legislation is a plus.
- Excellent written and verbal communication/people skills in English
- Knowledge of other EU languages is desirable but not mandatory.
- Self-starter with the strong ability to effectively manage several emergencies/priorities at the same time without losing track of multiple other responsibilities.

Offer

- Joining a team of experienced advocacy professionals, who work daily on advancing the rights and conditions of millions of people living with a rare disease.
- A role with a substantial amount of visibility and potential to learn accompanied by travel and events.
- Full time contract and a benefits package.
- A position based at the Brussels' office of EURORDIS, with possibility of hybrid work arrangement.
- Salary range will be between €38 000 and €43 500.

How to apply

- Interested candidates are asked to submit their applications to Mr Elias Barth: elias.barth@eurordis.org by **24 January 2025**.
- Applications will consist of a Cover Letter and a recent Curriculum Vitae and will be processed on a rolling basis until the position is filled. The recruitment process may close earlier if a suitable candidate is identified.
- Please note that due to the anticipated high volume of applications, only shortlisted candidates will be contacted.

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