

EURORDIS-Rare Diseases Europe

Job vacancy – EU Public Affairs Senior Manager

Responsible to: Public Affairs Director, Head of European Advocacy

Contract type: Permanent, full-time

Salary: 38 – 42 000 euros gross per annum + pécule de vacances + additional expenses covered by employer

Location: EURORDIS Brussels

Start date: ASAP

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.



Main scope of the position

The Public Affairs (Senior) Manager supports the advocacy activities of EURORDIS across relevant policy areas and develops advocacy outputs for EURORDIS, members and the relevant networks of stakeholders EURORDIS interacts with.

As a member of EURORDIS's advocacy team, s/he works with the other colleagues dedicated to European or international advocacy and contributes to EU-level advocacy work on policies and legislation to improve the quality of life of people living with rare diseases.

S/he will be able to coordinate work across a team of colleagues with expertise on relevant files (research, healthcare, digital, regulatory, diagnosis, treatment information and access, social, international) to develop policy material, also using the patient evidence generated basis (RareBarometer and other sources). Where necessary, s/he will lead on the development and implementation of advocacy strategies and policy campaigning on specific policy files, in close cooperation with the advocacy team members.

S/he reports to the Public Affairs Director, Head of European and International Advocacy..

Key tasks & responsibilities

- Develop material for different audiences and stakeholders to support advocacy activities across a variety of topic areas, including policy positions, briefings, letters, contributions to consultations, toolkits, etc.;
- Work with policy leads to plan and execute internal process to engage with members: in particular, help ensure that the priorities and contributions of EURORDIS' members feed into the planning and definition of advocacy activities, and that feedback is regularly provided.

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- Work with the Communications Manager to ensure a strong integrated communications narrative on policy issues;
- Monitor and evaluate advocacy actions to measure impact of work and support strategic advocacy planning on upcoming files;
- Lead on specific policy files to develop and execute the relevant advocacy strategy: elicit support from, strengthening and proactively cultivating relationships with key decision-makers, independently liaising with and gathering inputs from external stakeholders, including civil society, academia and technical experts and keeping an active network; represent the organisation in external structures, such as NGO groupings on specific topics, expert meetings, debates, etc.;
- Consolidate and lead the strategic relations with WHO Europe across key policy files (e.g. newborn screening, access to medicines, networks...) in coordination with relevant colleagues;
- Ensure the link between European and international advocacy by contributing to the work of Rare Disease International (RDI) and representing EURORDIS, as appropriate, in RDI governance.

Experience & skills

- Graduate/undergraduate degree in Political Science, International Relations, EU Studies, Law, Public Health or a related field;
- At least 5 years of experience in EU public affairs and advocacy, with excellent knowledge of processes, interactions and dynamics of the EU policy-making;
- Interest and experience in patient / civil society advocacy. Sensitive to EURORDIS' mission and motivation to work for an NGO (experience working for an NGO desirable but not required);
- Excellent English language skills. Any other language is desirable;
- Excellent verbal and written communication skills;
- Strong analytical and organisational skills with attention to details and the ability to prioritise between concurrent tasks and under pressure;
- Team worker, able to work closely with a wide variety of people;
- Personal and professional integrity.

To apply

Please send your CV and cover letter in English to pam-eu@eurordis.org

Deadline for applications: 23 September 2022

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