

# EURORDIS-Rare Diseases Europe

## Job vacancy – Public Affairs Director

**Responsible to:** Public Affairs Director, Head of European Advocacy

**Contract type:** Permanent, full-time

**Salary:** 70 – 75 000 euros per annum + benefits packages

**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 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.

### Main scope of the position

The Public Affairs Director will operate within the European Advocacy team, most members of which are based in Brussels. They will enable the organisation to maintain and increase EURORDIS influence on EU policies and programmes on behalf of people living with rare diseases (PLWRDs) in Europe, to promote rare diseases as a public health priority, in order to improve the situation of PLWRDs.

The mission of the Public Affairs Director is to empower EURORDIS to stay firmly abreast of major European policy developments and initiatives of relevance for PLWRDs, but also to be able to shape the policy debate in the years to come i.e.:

1. to play a leading role in identifying such developments and initiatives sufficiently in advance.
2. to contribute to forming an accurate assessment of any opportunity or threat for EURORDIS.
3. to provide strategic advice and contribution to the appropriate course of action for the organisation, in close coordination with the Head of European Advocacy, and as appropriate with the CEO, the Board, the rest of the team as well as all relevant internal groups and committees.

### Key tasks & responsibilities

The Public Affairs Director works within the framework of the EURORDIS Strategy 2020- 2025 and of its Annual Work Programmes. In close coordination with the CEO and the Head of European Advocacy, s/he helps define,

implement and measure the success of EURORDIS public affairs strategies and advocacy actions undertaken by the organisation.

By reporting directly to the Head of European Advocacy, the Public Affairs Director will:

- Represent EURORDIS and be a key voice of the organisation externally in conversations relating to healthcare policy and rare diseases issues, notably the issues in her/his area of action, as well as in relevant policy platforms and forums, in which the Public Affairs Director shall manifest the needs and expectations of PLWRDs.
- Establish, maintain and strengthen relations with key contacts and partners within European institutions, with a view to constantly expanding and consolidating EURORDIS's network of contacts and access to relevant decision-makers.
- Be a catalyst as and when needed for internal discussions on the orientations of EURORDIS's policy and advocacy work, and to involve other members of the team as appropriate (e.g., as contributors, as advisors, etc.) in relevant dimensions of his/her ongoing work.
- Be responsible for the proper circulation of all information pertaining to their policy and advocacy work in the direction of - and, as relevant, for engaging with - the wider team, but also of the EURORDIS membership, in good intelligence with the members of the team responsible for the communications and membership.
- On specific assignments, building the capacity of the EURORDIS team and members, particularly national member organisations, may be required.

All the above applies to the areas of:

- Development and access to orphan medicines, with a focus on existing delays and inequalities observed across Europe, on underlying challenges in the field of the value assessment and pricing and reimbursement of orphan medicines, and on current efforts/ initiatives towards improved access.
- Promoting stronger cooperation between EU Member States in the field of access to medicines – ranging from horizon scanning and value assessment all the way to price negotiations (see “Breaking the Access Deadlock” and «Rare2030 Foresight Study” for reference).

The Public Affairs Director role also entails:

- Establishing and maintaining working relationships with and representing EURORDIS at other major organisations sharing common interests with EURORDIS – e.g., sectoral bodies (EFPIA (European Federation of Pharmaceutical Industries and Associations), EUCOPE (European Confederation of Pharmaceutical Entrepreneurs), EuropaBio), think tanks (Friends of Europe) and any other relevant platforms.
- Supporting the Resources Development and Corporate Relations team and serving as secondary contact point for private sector organisations. Helping expand and diversify EURORDIS's financial resources by identifying opportunities for public funding and contributing to writing relevant applications.
- Leading ECRD (European Conference on Rare Diseases and Orphan Drugs) sessions on access to therapies & Programme Committee; contributing to ERTC (European Round Table of companies) workshops as recurring content & programme developer.
- Regular travelling is required to EURORDIS offices in Paris and Barcelona, to attend institutional meetings and relevant conferences and events outside Brussels.

## Experience & skills

- Background in law, public policy, political science, pharmaceutical or economics with any other relevant degree to be considered.
- Familiarity with the field of rare diseases, pharmaceutical legislation, and orphan medicines, with the issues at the core of the work of EURORDIS, and with the objectives of EURORDIS in general.
- Approximately 7 to 10 years of relevant experience in the field of public affairs and advocacy – a previous role in a European institution, a government body or an organisation active in the field of public health will be a plus.
- Fluency in written and spoken English absolute must – proficiency in other European languages will be a plus.
- Robust understanding of the current major drivers of the public health policy debate in Europe, particularly issues related to access to medicines and sustainability of national healthcare systems.
- Autonomy, flexibility, and ability to take initiative and exert good judgment with minimal supervision.
- Dynamic personality with a natural ability to engage with stakeholders, nourish and develop professional relations to expand one's network.

## About the offer

- Joining a team of experienced advocacy professionals, who work daily on advancing the rights and conditions of millions of affected patients
- A role with a substantial amount of visibility and potential to learn accompanied by monthly travel and events
- Full-time contract and a benefits package
- Possibility of hybrid work arrangement

## To apply

EURORDIS and MAVENCE (Executive Search firm mandated for this recruitment) are committed to diversity and inclusion, which is why we encourage all applicants no matter their age, race, nationality, sexual orientation, disability, sex and gender identity, religion, or political affiliation to apply for vacancies.

Please send your CV and cover letter in English to Sergey Golyshin, Director Recruitment – Mavence at [sergey.golyshin@mavence.com](mailto:sergey.golyshin@mavence.com)

**Deadline for applications: 18 May 2024 (but 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