

# Job vacancy – EU Public Affairs Manager

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

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

**Salary:** 35 – 42 000 euros per annum (according to years of experience) + *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 974 rare disease patient organisations from 74 countries that work together to improve the lives of the 30 million persons 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 legislations and policies.



## Main scope of the position

The Public Affairs Manager is responsible for a meaningful engagement of the European Network of Parliamentarian Advocates for Rare Diseases and ensuring support to the advocacy activities of EURORDIS via-à-vis EU Institutions on specific advocacy files, varying over time.

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 to improve the quality of life of people living with rare diseases. S/he works across a team of experts on relevant files (research, healthcare, digital, regulatory, diagnosis, treatment information and access, social, international), using the patient evidence generated basis (RareBarometer and other sources).

## Key tasks & responsibilities

- Consolidating the Network of EU and National Parliamentary Advocates for Rare Diseases; in particular, by:
  - Strengthening relations with MEPs including organising meetings, initiating and coordinating joint activities and ensuring adequate follow-up, eliciting support to specific advocacy files, submitting briefings and amendments.
  - Establishing a recruitment plan for members of national parliaments in coordination with the Council of National Alliances (CNA) and recruiting MPs in cooperation with National Alliances.
  - Organising events at the European Parliament with co-chairs and leading MEPs of the network to elevate rare disease issues in relevant legislative and policy areas.
  - Communicating about the network on EURORDIS' website, eNews, social media, events, and regular communication to the members of the network.
- Establishing closer and more regulations with EU Member States Permanent Representations in Brussels in the framework of relevant advocacy activities and campaigns.

Job announcement last updated: 3 November 2021

- Supervising and coordinating activities in preparation and during the “Rare Disease Day Week”, EURORDIS’ Rare Disease Day advocacy training and outreach programme for rare disease patient representatives, organised on an annual basis in Brussels.
- Contributing to the development and implementation of advocacy strategies and policy campaigning in close cooperation with the advocacy team members in diverse areas:
  - Eliciting 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.
  - Tracking and analysing relevant policy processes and trends, identifying and leveraging opportunities for people living with rare diseases.
  - Supporting the team in preparing advocacy materials, position papers, briefings, inputs to relevant policy consultations.
  - Helping ensure that the priorities and contributions of EURORDIS’ members feed into the planning and definition of advocacy activities and feedback is regularly provided. In particular, by supporting the process to ensure that national patient groups and other members contribute to specific EU policy and legislation with an impact on person’s living with rare diseases.
  - Represent the organisation in external structures, such as NGO groupings on specific topics, expert meetings, debates, etc.

## Experience & skills

- Graduate/undergraduate degree in Political Science, International Relations, EU Studies, Law, or a related field.
- 3 to 5 years of experience in EU public affairs and advocacy, with excellent knowledge of processes, interactions and dynamics of the EU policymaking. Experience in working with or within the European Parliament, although not required, will be appreciated.
- Interest in and experience in patient / civil society advocacy. Sensitive to EURORDIS’ mission & motivation to work for an NGO (experience working for an NGO desirable but not required).
- Excellent English language skills are essential for this position. Any other language is desirable.
- Excellent verbal and written communication skills, reflecting an appreciation that each audience requires its own approach.
- 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.

## What we offer

- A meaningful job with an impact on European policymaking and on the lives of the community we represent.
- A varied and challenging role in a friendly, multicultural, and multilingual environment.
- Development and further training opportunities.
- Team spirit, purpose-driven, result-oriented, with a passion for health issues and social inclusion.

## To apply

Please send your CV and cover letter in English to [pam-eu@eurordis.org](mailto:pam-eu@eurordis.org) .

**Deadline for applications: 8 December 2021.**

Job announcement last updated: 3 November 2021