EURORDIS-Rare Diseases Europe

Job vacancy – Public Affairs Manager – EU & National Integrated Advocacy

Position: Public Affairs Manager – EU & National Integrated Advocacy

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

Contract type: Permanent, full-time (38h per week)

Salary: 38 – 45 000 euros gross per annum + *pécule de vacances* + additional expenses covered by the employer

Location: EURORDIS Brussels

Start date: ASAP

About EURORDIS-Rare Diseases Europe

EURORDIS is a unique, non-profit alliance of 864 rare disease patient organisations from 70 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.

Key tasks & responsibilities

The Public Affairs Manager – EU & National Integrated Advocacy is responsible for coordinating and empowering advocacy and outreach capabilities of national rare disease patient groups, notably National Alliances, namely by enhancing support to the advocacy activities of EURORDIS vis-à-vis EU Institutions. The Public Affairs Manager will be instrumental to ensure that the priorities and contributions of National Alliances feed into the planning and definition of advocacy activities, that feedback is regularly provided as well as guidance on the process to follow. Ultimately, the Public Affairs Manager will aim to reach a high level of integration between national and EU-level advocacy, by co-creating and implementing the tools and methods required to have a stronger impact and better policies for people living with rare diseases.

The position is based at the EURORDIS Brussels office. The EU and National Integrated Advocacy Manager works with the other colleagues dedicated to European or international advocacy, and works in close coordination with the Senior Manager of Relations with Patient Organisations (based in Paris).

The main scope of this post includes:

- Supporting the Brussels advocacy team in developing the Network of EU and National Parliamentary Advocates for Rare Diseases, namely:
  - establishing the strategic vision and the action plan of the Network, setting up its governance in view of the 5-year parliamentary term;
  - recruiting the newly elected MEPs, identifying and nurturing relations with MEPs who will lead the Network;

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    - establishing a recruitment plan for members of national parliaments, in coordination with EURORDIS' Council of National Alliances, and starting to recruit MPs in close cooperation with National Alliances.
- Managing the process to secure national patient groups' contributions to specific advocacy files, with EU relevance and impact, such as for example, the upcoming possible revision of pharmaceutical legislation, and/or legislation on orphan and paediatric medicines; health technology assessment; newborn screening; implementation of EURORDIS' holistic care position paper or the EURORDIS access to medicines position paper, etc., as well as any rare disease relevant legislation or policy;
- Supporting National Alliances with dedicated capacity-building activities, including developing distance learning tools, webinars, organising one-to-one country visits and F2F meetings with National Alliances, etc.;
- Supervising and coordinating activities in preparation for and during the "Rare Disease Day Week", EURORDIS' Rare Disease Day policy event with representatives of National Alliances, planned for February 2020 (Brussels);
- Supporting the Public Health Policy Advisor (Rare2030 Project Lead) in delivering the nationally focused activities within the pilot project Rare2030 – Participatory Foresight for Rare Diseases Policy, namely the 6 national conferences planned therein, and /or other national conferences on rare diseases promoted by the National Alliances;
- Coordinating and supporting National Alliances' contribution to the EU wide resources 'State of the Art of Rare Disease Policy', developed with the support of National Alliances within each national Data Contribution Committee;
- Contributing to the agenda of the Council of National Alliances and maintaining close and regular relations with the Senior Manager of Relations with Patient Organisations.

Experience & skills

- Graduate/undergraduate degree in Political Science, International Relations, EU Studies, Law, or a related field;
- 7 years minimum of experience in EU public affairs and advocacy;
- Interest in and experience with EU affairs and patient / civil society advocacy;
- English mother tongue or equivalent: the working language of EURORDIS-Rare Diseases Europe is English. Good level in at least two other languages, preferably French, Spanish, German.
- Excellent verbal and written communication skills, reflecting an appreciation that each audience requires its own approach;
- Strong analytical skills and attention to details;
- Highly organised, detail-orientated and able to prioritise/ cope under pressure;
- Ability to work independently, pro-actively, around the clock, even when travelling.
- Personal and professional integrity;
- Motivation to work for an NGO (experience working for an NGO desirable but not required);
- Sensitive to EURORDIS' mission;
- Team worker, able to work closely with a wide variety of people;
- Able to develop trust relations, motivational, supportive and reliable;
- Willingness and ability to travel within Europe. Travelling may require up to one-third of the time.

To apply

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

Deadline for applications: 4 October 2019

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