

EURORDIS-Rare Diseases Europe

Job vacancy – Governance Manager

Responsible to: Chief Executive Officer

Contract type: Permanent, full-time

Salary: 36 – 40 000 euros per annum + one-month performance-based bonus

Location: EURORDIS Paris

Start date: August 2021

About EURORDIS-Rare Diseases Europe

[EURORDIS](#) is a unique, non-profit alliance of 962 rare disease patient organisations from 73 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 Governance Manager, within the Governance & Advocacy Unit, works closely with the Chief Executive Officer (CEO) and the Core Leadership Team (CLT) to ensure:

- Highest standard in governance rules and practice, with quality support to Board activities;
- Timely and quality development and delivery of annual work programme and reports;
- Successful development and management of the Operating Grant supporting core operations
- A meaningful liaison between the CEO, the Board, the CLT and staff at large with quality internal communication.

The Governance Manager takes on-demand additional assignments from the CEO.

Key tasks & responsibilities

Support the Board of Directors and statutory activities

- Board of Directors (BoD) (3 two-day BoD meetings per year in March, July, Nov) and Board of Officers (BoO) (4-6 BoO Conf Call per year): anticipate meetings and agenda items, reflect on editorial line and expected outcomes of meetings, draft agenda with CEO and President, timely preparedness of documents or slides and master slide deck, support development of documents and slides by relevant staff, supervise the good preparation of the meetings.

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- Draft Minutes of BoD and Table of Actions & Decisions (TAD) of BoO; ensure timely and meaningful communication of actions and decisions made to concerned staff; follow-up, update and monitor the Tracking Table of Actions and take actions when necessary
- Annual General Assembly (AGA) (once a year in May-June): anticipate meeting, draft agenda items and resolutions, support Board elections and organise voting. Ensure that documents are ready and disseminated based on the legal requirements for EURORDIS. Prepare slides and support Board members and CEO in their presentations. Draft minutes of the AGA and follow-up on decisions and election results of the General Assembly. Update relevant information in French public administration register.
- Support a high level of Board engagement: promote and support Board members active participation in most relevant EURORDIS' activities ;
- Membership: work closely with the Senior Manager of Relations with Patient Organisations and the Board's General Secretary on processes related to membership, ensuring compliance to policy and by-laws, relevance through regular update, sound decisions, transparency.
- By –Laws: regularly review and update EURORDIS by-laws to maintain a high level of accuracy, relevance and meaningfulness; ensure adoption by BoO and BoD; support revisions of Volunteer Charter and policies to support an active participation of volunteers; draft or update Terms of Reference for each Committee or Task Forces with relevant managers to ensure that they are fit for purpose, consistent, compliant; support revision of Internal Staff Rules; Provide ad hoc guidance on governance issues to EURORDIS staff when needed
- Website content: maintain the section on "Who we are?" which includes Eurordis In-Brief, Our Vision & Mission, Our Strategy, Our main Achievements, Annual Activity Reports, By-Laws, Board members, Staff member

Support the Core Leadership Team; Liaise between CEO & Board & CLT & All Staff

- Overall, ensure an organic liaison between CEO, CLT and Board with information, instruction/consultation, decision, implementation/follow-up at the right levels, in an accurate, meaningful, proportionate and timely manner.
- The Core Leadership Team (CLT) is made up of the CEO, COO, CFO and European Public Affairs Director: support the CLT in their weekly meetings, prepare the agenda, take notes and follow up on the group's actions and decisions as needed; inform BoD/BoO as necessary.
- Write and send regular reports and information emails to BoD and BoO members for their information/consultation/decision; to the BoD on all matters related to our eco-system, policy environment, advocacy, strategy, major achievements or challenges; to the BoO on organisational and management matters, decision follow-up, engagements, representations
- Monday Meetings, a weekly 1h all staff meetings (MM): anticipate meetings and support the development of the MM agenda, chaired by Core Leadership Team member
- Monthly Internal Staff Affairs Working Group Meetings (CSE and Informal): anticipate meetings and discussion items, chair meetings, prepare short notes, review issues with CEO and CFO, monitor implementation of actions and decisions. (This task will be re-assessed)
- Plan, organise and supervise the annual All-Staff meeting
- Take on assignment from CEO on special projects or initiatives on an ad hoc basis (such as providing support for certain recruitments, creation of new governance processes when needed)

Work Programme and Operating Grant

- Prepare the annual Work Programme (Sept-Oct) under the supervision of the CLT: the action plan (with CEO and Leadership Team), budget (with Finance Director and CEO), annual planning of events, team chart and governance chart; with input from EURORDIS managers

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- Prepare the annual Activity Report (Dec-March) with input from EURORDIS managers and with support from the Communications' team
- Preparation of EC Operating Grant applications: Framework Partnership Agreement (FPA - multiyear application) and Specific Partnership Agreement (annual application) under the supervision of the CLT with strategic input by CEO, budget by CFO and general supervision by European Public Affairs Director
- Partake in the monthly Operations Meetings run by the COO to identify and monitor the implementation of SGA activities and take relevant action; write short reports.
- Support negotiation of contracts and amendments to the SGA with the CFO
- Prepare the annual Final Report of the Specific Grant Agreement (due end of February) with the support of the CFO for budget, of the COO for the reporting on actions, and under the guidance of the European Public Affairs Director
- Strategic Partnerships: support the CEO and relevant staff in the development and management of strategic partnerships with partner NGOs and Learned Societies. Keep track of all external partnership and representations into the Governance (External) Chart.

Experience & skills

Required

- Preferably education in political science, law, literature, humanities or management
- 5 years' experience
- A robust and technical governance manager, motivated by NGO work,
- Extremely well organised, rigorous, multitasking, engaging, self-driven, energetic, with a sense of decisions and limits,
- Excellent at team work and internal communication,
- Excellent writing and communication skills
- Excellent English (oral and written)

Desirable

- Fluent in two other European languages
- European or international culture with personal, educational or professional experience
- NGO experience or health experience
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To apply

Please send your CV and cover letter in **English** to adsg-117594@cvmail.com

Deadline for applications: 2 July 2021

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