



# Chief Executive Officer (CEO)

September 2025

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## About EURORDIS – Rare Diseases Europe

EURORDIS is a unique, non-profit alliance of over 1,000 rare disease patient organisations from more than 70 countries. We work to improve the lives of the 30 million people living with a rare disease in Europe by connecting patients and families, strengthening the patient voice, and shaping research and policy at national and international levels.

With a strong network of patient organisations and a focus on advocacy, empowerment and partnership, EURORDIS plays a crucial role in advancing rare diseases awareness, research, healthcare, integrated care, therapeutical development and access to treatment, data, and digital health across Europe and beyond.

*"The EURORDIS Board of Directors is excited to launch the search for a new CEO to lead the organisation through it's next phase of development. Since 1997, EURORDIS has ensured that the voice people living with rare diseases is central to policy development, and that patients needs remain a public health priority. As a mature umbrella representing over 1000 member organisations, we are seeking a dynamic and visionary leader to work with our board and expert team to develop and implement a new strategy that is fit for purpose and results driven"*

Avril Daly  
President

## The Role

**Role:** Chief Executive Officer (CEO)

**Reports to:** President of the Board of Directors

**Location:** EURORDIS Headquarters – Plateforme Maladies Rares, 96 rue Didot, 75014 Paris, France



<b>Contract:</b>	Permanent, full-time
<b>Salary:</b>	€90,000 – €120,000 gross annually over 13 months, depending on experience
<b>Start Date:</b>	TBC

## Position Summary

We are seeking a visionary, values-driven leader to serve as Chief Executive Officer. The CEO will lead EURORDIS into its next phase of development by providing strategic direction, ensuring operational excellence and advocating effectively for people living with a rare disease (PLWRD). In addition the CEO will be required to meet the challenge facing NGOs in the current geo-political and economic climate, and adapt the EURORDIS organisation structure and its sources of funding to ensure the organisation's long-term sustainability.

This is a unique opportunity to lead one of Europe's most prominent NGOs in the rare disease field and to make a lasting impact on the lives of the 30 million people in Europe who live with a rare disease.

## Key Responsibilities

### 1. Strategic Leadership & Governance

- Work with the President and Board of Directors to define and implement EURORDIS' long-term strategy, aligned with its mission and values.
- Lead both a strategic renewal and organisational re-design to meet the challenges of the current rare diseases ecosystem.
- Ensure good governance practices and compliance with legal and reporting obligations.
- Support Board development, including recruitment, engagement, and transparent communication.
- Maintain and develop strong relationships with our networks and key national and international patient organisations, and all stakeholders to shape policies and initiatives that address the unmet needs of the rare diseases community.
- Identify and champion emerging issues within the rare disease ecosystem (e.g., horizon scanning, digital health, policy trends).



## 2. Organisational Leadership & People Management

- Lead, inspire and refocus a diverse team of expert staff and volunteers across a multilingual and multicultural environment.
- Manage, restructure and develop a high-performing senior leadership team.
- Re-energise the organisation by promoting a positive, inclusive, and empowering organisational culture that reflects the values of the rare disease community.
- Oversee HR, operations, and administrative processes to ensure efficiency and compliance.

## 3. Financial Management & Fundraising

- With the support of the Financial Controller, and in partnership with the Treasurer, develop and manage annual budgets and ensure sound financial stewardship.
- Design and execute a fundraising strategy to meet the increased challenge of diversify diversified revenue streams — including grants, individual giving, philanthropic foundations, and corporate partnerships.
- Cultivate relationships with donors and funding institutions, ensuring alignment with EURORDIS' mission.
- Ensure policies are in place to avoid conflicts of interest or competing priorities, and which promote transparency.

## 4. Advocacy & External Relations

- Represent EURORDIS externally, acting as a credible, authoritative voice for PLWRD and their families.
- Engage with patient organisations, academic & healthcare partners, industry partners, policymakers, and other relevant entities, to advocate for the needs of people living with rare diseases.
- Strengthen EURORDIS' position as a leading voice in the rare disease field through active participation in high-level policy dialogues, multi-stakeholders platforms, conferences, forums, and media engagements.
- Strengthen strategic partnerships with patient groups, industry, academia, public institutions, and policy stakeholders.
- Promote innovative approaches and shape the European health agenda to prioritise rare diseases.

## 5. Programme & Impact Delivery

- Oversee the implementation of EURORDIS' action plan, ensuring strategic alignment, timely delivery, and measurable outcomes.
- Ensure efficient resource allocation across a complex, multi-project environment with annual and multi-annual frameworks.



- Promote a culture that is 'achievement-orientated' and which promotes continuous improvement and learning across the organisation.

## Candidate Profile

### Experience & Qualifications

- Minimum 10 years in a senior leadership role, ideally within the public health, patient advocacy, or NGO sector at the European or international level.
- Proven managerial track record in complex organisations and experience of multidisciplinary teams across multiple geographies.
- Demonstrable track record in strategic planning, financial oversight, and organisational growth.
- Strong fundraising experience, with success in donor engagement and revenue diversification.
- Familiarity with EU health policy, international advocacy, or NGO governance.
- Whilst experience in the rare disease landscape is preferred, demonstrable experience in a closely related area such as chronic diseases, health policy, patient advocacy, or orphan drug development is required.

### Knowledge & Skills

- Visionary and strategic thinker with the ability to anticipate challenges and identify opportunities for impact.
- Excellent interpersonal skills, capable of uniting and inspiring diverse stakeholders.
- Strong communication skills, written and verbal, for engaging with policy, media, and public audiences.
- Skilled in managing change, promoting innovation, and empowering teams.
- Resilient, able to take tough decisions and operate effectively in a challenging and sometimes high-pressure environment.
- Politically astute with strong negotiation and diplomacy skills.
- Deep empathy and credibility to represent the lived experience of PLWRD and guide action accordingly.
- Capacity to quickly develop expertise in European public affairs and navigate institutional landscapes.

### Education & Languages

- University degree is required with further education including master's degree preferred.
- Fluency in **English and French**. Proficiency in additional European languages is an asset.



- Willingness to travel regularly across Europe is essential.

## What We Offer

- A unique opportunity to lead one of Europe's most respected NGOs in the field of health and patient advocacy.
- The chance to shape the future of rare diseases in Europe and beyond, making tangible improvements to people's lives.
- A supportive, mission driven working environment.
- A permanent, full-time contract with flexible working hours.
- Position based in the Paris HQ Office
- A gross annual salary between €90,000 and €120,000 over 13 months, based on experience.
- Benefits including paid leave, health insurance, meal vouchers, and more (details shared during the recruitment process).

## How to Apply

All correspondence, at this stage, should be via Oxford HR. To apply for this post, click on the "Apply" button on the job advert page, complete our online application form, and submit your CV and cover letter as two different documents, which should be prepared before applying as they will be considered in the application process.

The cover letter should be no more than two pages long and explain why you are interested in this post and how your skills and experience make you a good fit.

The document should be saved in PDF in the following format: Your First Name-Your Last Name-Documents Name-Date (mmyy) e.g., Pat-Jones-CV-0925-EURORDIS or Pat-Jones-CoverLetter-0925-EURORDIS.

### Timeline

**Closing Date:** TBC

**First stage interviews:** TBC

**Final interviews:** TBC



## Selection Process

All candidates will receive an update regarding their application after the closing date. We advise candidates to add the role email to their safe senders list and regularly check their spam folder.

## Equality Statement

Equality and diversity are at the core of EURORDIS' values. Staff are expected to work collectively and individually to promote a constructive and sensitive approach to others from a variety of backgrounds, where the work of others is valued and respected.

## Queries

If you have any queries on any aspect of the appointment process, need additional information, or would like to have an informal discussion, please email at [mbillanou@oxfordhr.com](mailto:mbillanou@oxfordhr.com) in the first instance.

## About Oxford HR

Oxford HR is a B Corp certified leadership consultancy. Having worked within a diverse range of institutions, from not-for-profits and charities to governments and corporate environments, we've seen the powerful impact that the perfect team can have.

Finding innovative leaders can be a challenge; and yet their transition into leadership is vital to an organisation's mission and success. We work across the globe to search for and support remarkable leaders and teams, improve their board effectiveness and support on a range of leadership functions.

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