



RARE
DISEASES
INTERNATIONAL



CEO, Rare Diseases International (RDI)

Candidate Pack | April 2026



About RDI

Rare Diseases International (RDI) is a leading global NGO dedicated to advocating for and empowering people living with rare conditions. Our vision is for a world where people living with rare conditions and their families are fully recognized, supported and empowered in all aspects of life. Our mission is to be the global advocacy leader and connector advancing equitable and inclusive outcomes for people living with rare conditions and their families worldwide.

We are a growing organisation, with members across six continents. Our global community of rare disease organisations represents regional and international federations working in the same rare disease area or groups of diseases, and national and regional rare disease alliances and networks. Our cultural diversity, and the range of rare conditions in our community, makes for a vibrant, multi-dimensional and complex dynamic.

RDI is building on the ground-breaking success of two global resolutions: the 2021 UN Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families”; and the 2025 World Health Assembly Resolution, “Rare Diseases: A Global Health Priority for

Equity and Inclusion”. We continue our work on Universal Health Coverage by 2030, as part of the UN’s Sustainable Development Goals, and are leading the current RDI-Lancet Commission for Rare Diseases, which is using a human-rights framework to set out equity and inclusion for diagnosis, treatment and care.

We are committed to ensuring that all individuals living with rare conditions have access to the health and social care they need to lead happy and healthy lives. At the core of RDI are our organizational values of equity and inclusion, striving to be the independent voice of lived experience in the realms of policy, research, treatment development and innovation. RDI aims to create a world where everyone living with a rare condition can participate in society without stigma or discrimination, but with equity and respect.

We are member-driven and strive to be community-centered, transparent and collaborative in our work with stakeholders, fostering open and respectful dialogue with the belief that everyone can contribute to building a better world for those living with rare conditions, and that no one should be left behind.





The Role

Role:

CEO

Reporting to:

Council of Directors

Type:

Permanent, Full Time

Salary Range:

€80,000 – €110,000 gross annually over 13 months, depending on experience.

Location:

Remote working. RDI is registered as an employer in France, Spain, and Italy. A European-based CEO is preferred, but non-European applicants will be considered.

Start Date:

To be agreed.

The Opportunity

We seek a **visionary, community-centred, and collaborative CEO** to lead RDI into its next phase of growth and impact. This is a unique opportunity to shape the future of rare disease advocacy, influence global health policy, and make a tangible difference in the lives of millions worldwide.

As CEO, you will drive **strategic leadership, operational excellence, and sustainable impact**, ensuring RDI remains the leading global voice for people living with rare conditions. You will navigate the challenges facing NGOs in today's geopolitical and economic climate, adapting the organisation's structure and funding sources to secure its long-term sustainability.





Key Responsibilities

1. Leadership and Governance

- Deliver and operationalise RDI's Strategic Framework 2026-2030, aligning RDI's mission with global rare disease priorities, together with the Council and staff.
- Maintain **robust governance, compliance, and ethical standards** across all operations.
- Ensure a **transparent, respectful, and productive** working relationship with the Council.

2. Operations & People Management

- Lead a **multidisciplinary, geographically dispersed team**, ensuring operational efficiency, staff empowerment, and high-performance.
- Oversee **systems and processes** to support RDI's growth and adaptability, fostering a culture of collaboration, accountability, and innovation.
- Champion **diversity, equity, and inclusion** in all organisational practices.

3. Financial Management & Fundraising

- Oversee **budgeting, financial planning, and risk management, together with the Head of Finance & HR**, to ensure long-term sustainability, leading diversified fundraising strategies.
- Drive **fundraising strategies**, together with the Resource Mobilisation & Partnerships Manager, including major gifts, grants, corporate partnerships, and innovative revenue streams, to secure sustainable resources for current operations and future expansion.
- Build and maintain relationships with **donors, foundations, and institutional funders**.

4. Advocacy & External Relations

- Coordinate representation with Council and staff at **global fora, policy discussions, and media engagements** to amplify the voice of people living with rare diseases (PLWRD) worldwide, actively positioning RDI as a trusted and influential partner with global institutions such as WHO, UN agencies, governments, and international stakeholders.
- Promote a strong **awareness-raising and advocacy strategy**, including campaigns to influence health and social policy, ensuring advocacy outcomes are measurable and focused on improving access to diagnosis, care, treatment and services worldwide.
- Strengthen partnerships with **advocacy organisations, healthcare providers, regional alliances, and industry leaders**, ensuring RDI remains inclusive, representative, and responsive to the diverse needs of the rare disease community.

5. Programme & Impact Delivery

- Ensure the **design, implementation, and evaluation** of programmes that align clearly with RDI's mission and vision, delivering measurable impact aligned with the strategic agenda—particularly in areas such as global recognition of rare conditions, access to care, and system-level transformation.
- Monitor and report on **impact metrics**, ensuring alignment with RDI's mission and donor expectations.
- Foster **knowledge-sharing and capacity-building** initiatives within the rare disease community.

Candidate Profile

About You

You are a **dynamic, empathetic, and results-driven leader** who can represent RDI with **vision, practicality, and humility**. While experience in the rare disease landscape is preferred, we welcome candidates with demonstrable experience in closely related areas such as chronic diseases, health policy, or patient advocacy.

Skills and Competencies

- **Proven leadership, preferably** in the non-profit sector, with at least **10 years of experience** in patient advocacy, health policy, or disability rights, and a track record of driving organisational growth, innovation, and adaptability.
- **Strategic thinker** with a **global vision**, capable of translating the long-term global agenda into clear, actionable strategies.
- **Strong programme management/oversight experience**, with the ability to negotiate effectively among conflicting priorities and deliver results-oriented outcomes.
- **Exceptional interpersonal skills**, with experience in **stakeholder engagement, collaboration, and diplomacy**, and the ability to inspire trust and build strong partnerships.
- **Strong financial acumen**, including fundraising, budget management, and revenue diversification, to ensure long-term financial sustainability.
- **Understanding of the importance of maintaining the independence, and the perception of independence, of the patient voice** in external relationships, finance and governance practices.

- **Excellent communication skills**, including the ability to represent an organisation at a range of local and international fora, in the media, and with the rare community.
- **Effective negotiation, collaboration, and influencing skills**, with the capacity to develop and maintain strong relationships at all levels among direct stakeholders, business and not-for-profit partners, and scientific and political communities.
- **Cultural competence** and ability to communicate effectively across diverse geographies and roles.
- **Experience** working with **Boards**, maintaining transparent, respectful, and productive collaboration.
- **Resilience and decisiveness**, with the ability to navigate complex, high-pressure environments.
- **Confident, empathetic, and results-driven** approach.
- Experience in **rare diseases, chronic illnesses, or global health advocacy** are strong assets.
- Existing **networks in the rare disease field** or related healthcare sectors an additional asset.

Education and Qualifications

- **Master's degree (or equivalent)** in public policy, politics, law, business management, or a related field.
- **Excellent oral and written communication skills in English;** proficiency in additional languages is a plus.
- **Willingness and ability to travel regularly and globally.**
- **Deep understanding of the healthcare sector**, with a focus on rare conditions.





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 the 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-Document Name-Date (mmyy)-RDI e.g., Myriem-Abbas-CV-0426-RDI or Myriem-Abbas-CoverLetter-0426-RDI.

Timeline

- **Closing Date:** May 20th, 2026 – 17:00 CET (*Please note that applications will be reviewed on a rolling basis and this may lead to an earlier closing date.*)
- **First Stage Interviews:** June 8th to 10th (online)
- **Final Interviews:** June 22nd–23rd or 24th in Paris

Selection Process

All candidates will receive an update regarding their application after the closing date. We advise candidates to add the Oxford HR Consultant email address (see below) to their safe senders list and regularly check their spam folder.

Equality Statement

RDI is an equal-opportunity employer. We celebrate diversity and are committed to creating an inclusive environment for all employees. We encourage applications from individuals of all backgrounds, including those with lived experience of rare conditions.

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 the consultant at 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.

Learn more at: oxfordhr.com





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