



## **JOB TITLE: EXECUTIVE DIRECTOR**

*Location: Europe with a preference for Spain; open to any location for the right candidate*

*Full-time | Permanent | Reports to: President of the Board of Directors*

### **About DEBRA International**

DEBRA International is the global alliance of national DEBRA groups working to improve the lives of people living with Epidermolysis Bullosa (EB), a rare and debilitating genetic skin condition. We are an international non-profit patient advocacy organisation supporting member groups, shaping global policy, improving access to care, driving EB research and engaging with all relevant key stakeholders.

### **Role Overview**

We are looking for a **hands-on, delivery-focused Executive Director** who thrives in operational environments, builds strong teams and partnerships, and gets things done. This is not a figurehead or purely strategic role — we are seeking someone who is as comfortable rolling up their sleeves to run day-to-day operations as they are representing DEBRA International on the global stage. The Executive Director will take DEBRA International to a new level in a unique moment of scientific advancements, first therapies approval, rare diseases international policies progress and new opportunities.

This person will **strengthen and streamline** DEBRA International's core operations, foster a culture of execution and accountability, and align the team of staff, freelancers and volunteers behind clear deliverables. You'll lead a small, dedicated international team collaborate with our national DEBRA groups, and support major research, advocacy, and partnership initiatives that make a real difference in patients' lives.

A key responsibility of this role is **fundraising** — particularly securing support from the health industry and private sector partners. The successful candidate must be comfortable with the business side of nonprofit leadership, actively advocating the cause of EB to external stakeholders, and translating DEBRA's mission into funding and development opportunities.

As **Executive Director**, you'll lead the day-to-day work of **DEBRA International**, guiding a small global team and making sure ideas turn into action. You'll create structures that are missing, build systems that help people work together, and bring clarity and focus across programs.



This isn't about sitting back — it's about leaning in. You'll represent **DEBRA International** with credibility and purpose, but you'll also be **hands-on** with operations, team support, **fundraising**, and logistics.

## **Key Responsibilities**

### **Governance support, Operational Execution and Delivery**

- Support the President and the officers to engage the members of the Board of Directors; to incorporate good practice of governance in keeping with organisational statutes and mission; to establish strong partnerships; and to translate strategic goals into concrete action plans, budget and projects, with clear methodology, milestones and outcomes.
- Lead and manage the day-to-day operations of DEBRA International with attention to efficiency, transparency, and timely delivery.
- Manage DEBRA International's budget with a focus on long-term sustainability and transparency.
- Create practical workflows and internal systems that support coordination across time zones and cultures.

### **Team Building and Culture**

- Recruit, mentor, and support a small, value-driven team.
- Build a collaborative, accountable, and purpose-led culture.
- Promote transparency and shared learning across DEBRA's global network.

### **Fundraising, Resource Mobilization**

- Lead and execute practical fundraising from public, private, and philanthropic sources.
- Build and strengthen partnerships with industry and member donors — and confidently communicate the impact and urgency of our mission.
- Prepare compelling proposals and funding pitches that align with partner interests.

### **Research Coordination and Stakeholder Engagement**

- Actively coordinate and manage our research related commitments and partnerships.
- Connect researchers, patient groups, and industry stakeholders to advance meaningful initiatives.
- Promote patient voices and lived experience as a core input to research and innovation.



## **External Relations and Representation - *Represent the Cause***

- Serve as an active, credible representative of DEBRA International in external meetings, policy discussions, and collaborative platforms.
- Engage with national DEBRA groups, clinicians, researchers, and policymakers to listen, align, and act.
- Represent DEBRA not just with vision, but with practicality, humility, and results.

## **Ideal Profile**

### **Required Experience and Skills**

- Proven track record of strategic thinking, operations and results oriented, team leadership in non-profit, healthcare, or research-based organizations.
- Prior experience fundraising and mobilizing resources,
- Skilled at engaging stakeholders and converting relationships into partnerships.
- Strong project management skills, from planning to reporting.
- Fluent English (spoken and written); additional languages, preferably Spanish, are an asset.
- International experience.
- Ability to work both autonomously and as part of a remote team.
- Comfortable with International travel.

### **Key Personal Attributes**

- Willing and eager to engage and lead by example; this is a role for someone who wants to **build, connect, and deliver**.
- Strong sense of ownership and commitment to results.
- Ability to communicate clearly and diplomatically across cultures and roles.
- Empathetic leadership and collaborative decision-making style.
- Proactive and able to thrive in dynamic and complex environments.

## **What DEBRA International Offers**



- A unique opportunity to lead an established and globally respected patient organisation.
- Competitive salary based on experience and location.
- A meaningful leadership role where your daily work directly improves lives.

### **How to Apply**

Please send (in English):

- Your CV (max. 5 pages)
- A cover letter (max. 2 pages) explaining your motivation and alignment with this role, current location and salary.

To: [emeline@debra-international.org](mailto:emeline@debra-international.org)

Deadline: **Friday 22<sup>nd</sup> August 2025 11:59pm CET**