

## **Debra Ireland: Advocacy Lead** **(<https://www.activelink.ie/node/111797>)**



### **Debra Advocacy Lead**

#### **Overview**

**Salary:** Negotiable – commensurate with experience

**Hours:** Full-time but open to a four day week

**Location:** 8 Clanwilliam Terrace, Grand Canal Quay, Dublin 2 with Dublin city based meetings

#### **About Debra**

Debra is a national charity established in 1988 to provide support and drive research into treatments for those living with the rare skin condition, Epidermolysis Bullosa (EB). EB is an extremely painful skin-blistering condition, which leaves the skin as fragile as the wings of a butterfly.

We are a person-led charity, with an ambitious and passionate team, who care deeply about the people we work with. We actively live our core values of Togetherness, Person-Centredness, Passion, Boldness and Integrity, with people at the heart of everything we do.

#### **Role Overview**

The key elements of this role are to implement and monitor Debra's advocacy strategy against key measurable outcomes and in line with Debra's strategic goals. The successful candidate will work as part of a passionate, supportive, patient-centred team. Working with public representatives, health and social care services and civic organisations where there are links to joint advocacy and/or public engagement initiatives. The successful candidate will be responsible for leading Debra's advocacy and policy work and for the development of all advocacy campaigns. This presents an exciting opportunity for a highly motivated advocacy professional to make a meaningful impact for those affected by EB in Ireland.

This job description acts as a guide to the role. The role may change to meet the changing requirements of the organisation at any time, after discussion with the post holder.

#### **Main Duties And Responsibilities**

- Drive and implement Debra's advocacy strategy.
- Monitor and continuously assess progress of Debra's advocacy strategy as required.
- Lead the development of all Debra advocacy campaigns and drive campaigns from start to finish, including evaluation. Such campaigns may include an annual pre-budget submission campaign, Election 2025 campaign and a campaign on access to medicines.
- Communicate advocacy campaigns and successes to key stakeholders, including people impacted by EB.
- Work closely with the family support team to ensure advocacy campaigns reflect the needs of people living with or caring for someone with EB.
- Work closely with the research team in commissioning and overseeing evidence generation to support access to better services and treatments for those living with EB.
- Work closely with the communications team to develop campaign material and collateral and drive media and digital engagement.

- Implement the outputs of the 'EB Butterfly Review', a cross-functional research project reviewing access to EB services and supports and developing a blueprint for the future of services in Ireland.
- Lead the organisation's submissions and campaigns around access to medicines.
- Develop and maintain a diverse network of political and policy contacts and champions.
- Contribute to national advocacy forums and policy development.
- Engage with Debra International and other groups at an international level.
- Ensure adherence to the Regulation of Lobbying Act 2015 and make required returns.
- Develop internal Debra policies relating to advocacy.
- Contribute to the Senior Management Team and present to the Debra Board as required.
- Manage the advocacy budget.
- Carry out other roles or duties within the scope, spirit and purpose of the post, as requested.

## Knowledge/ Experience

### Essential

- A minimum of 5 years' experience in a related advocacy/campaigning field.
- Degree level qualification and postgraduate qualification in a related field.
- Experience in developing advocacy campaigns through stakeholder engagement.
- Strong knowledge of the Irish political environment, with a distinct advantage if this is in the area of health or disability.
- A clear ability to communicate concisely and directly in an accessible manner via various platforms and to varied audiences.
- Exceptional project management and computer skills, with excellent attention to detail.
- Flexibility to occasionally travel and work outside standard hours.
- Fluency in written and spoken English.
- Personable, with excellent communication skills and an ability to build relationships and work with professionals at all levels.
- Self-motivated, highly capable of working independently and with a strong work ethic.
- Disciplined, organised and thorough.
- Strong empathetic nature, with a genuine passion and care for people impacted by EB

### Desirable

- Experience working in the charity sector
- Experience working in a political environment

### Benefits

- Generous annual leave entitlement including five discretionary leave days: Good Friday, Christmas Eve, and working days between Christmas and New Year.
- Employer-matched Pension Scheme up to 6%, following a 6-month probationary period.
- Employee Assistance Programme.
- Bike to Work Scheme.
- Opportunity for flexible/hybrid working.

## To Apply

Applicants must hold a relevant visa to work in Ireland and be based in Dublin. The role is subject to garda vetting and reference checks. Interested candidates should submit a copy of their CV and cover letter to [info@debra.ie](mailto:info@debra.ie) (<mailto:info@debra.ie>)

Closing date for applications is the **30th of November 2024**

For informal queries please contact [sinead.hickey@debra.ie](mailto:sinead.hickey@debra.ie) (<mailto:sinead.hickey@debra.ie>)

*Debra is an equal opportunities employer.*

### Region

Dublin 8

### Date Entered/Updated

29th Oct, 2024

**Expiry Date**

30th Nov, 2024

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