



## A Cure for EB

Dedicated to transforming the lives of people living with EB



### Our Values

- DEBRA is a patient led organisation where every decision is driven by what is best for the people living with EB.
- We demonstrate unwavering commitment to the highest possible standards in everything we do.
- In all our relationships we are open, honest, and respectful and believe in collaboration.
- We recognise the fact that every EB journey is different and we tailor our resources to help families live as independently a life as is possible.
- We value every donation we receive and are always mindful that it is our duty to use the money to achieve the biggest possible impact for people living with EB

## WHAT IS EB?

- 🦋 EB = Epidermolysis Bullosa. A severe rare genetic skin blistering condition.
- 🦋 EB = Extraordinary Butterflies. EB skin is as fragile as the wings of a butterfly.
- 🦋 EB = Endless Blistering. Even gentle skin contact causes devastating wounds.
- 🦋 EB = Excruciating Bandaging. When dressings stick, the skin often comes away too.
- 🦋 EB = Exhausting Battle. There is no cure and a high risk of developing aggressive skin cancer.

**EB = the worst disease you've never heard of.**

**As a Director you can make a difference - helping with the care of patients and to find a cure.**

Debra continues to make a major positive difference in the lives of patients and families with EB. We recently worked with Crumlin to bring on board a nurse who can travel to families and help with the training of parents and family members with bandaging their children/relatives who have this painful condition. Our EB awareness week held in October each year has helped with creating awareness of EB and with fundraising to help with patient care and towards funding research in a search to cure this rare and severely painful condition. We have approved a new strategic plan where we plan to fund another 2 research projects over the next 3 years.

The board and management are passionate about providing patient care and helping to find a cure ....do volunteer to help us achieve our goals!

## **General Description of the Role**

### **DEBRA Ireland's Board of Directors & Management**

DEBRA Ireland is governed by a board of directors that have an overall responsibility for the governance, strategy and oversight of the organisation.

#### **Main responsibilities**

Decisions reserved for the board includes:

- Approval of the Strategic Plan annual financial statements
- Review and challenge of operational budgets and management accounts as presented to the Board.
- Appointment/removal of subcommittee members, auditors and the CEO
- Approval for borrowing/finance facilities.
- Approval to changes in memorandums and articles.
- Annual review of risk and internal control.
- Consideration and review of the charity's Staffing and Remuneration.
- Participation at the Board meetings as required (generally six times per year) Where your competence is relevant, you may be invited to join one of the board sub committees (e.g. Audit & Finance, Fundraising, and Research).
- Assisting in the implementation of Governance by ensuring that the organisation operates against standards expected of a charity, meets legislative requirements and adheres to best practice. DEBRA Ireland's board is committed to achieving high standards of governance. The charity continues to operate in compliance with the Guiding Principles of Fundraising.

#### **Attributes for the role**

- Understanding and experience of governance and board activity.
- Time available to review board documents and contribute to the board meetings (Approx 6 per year)
- Passion to help patients with this rare skin disease.

#### **Specific capabilities of benefit to the board: One or more of the following**

- Fundraising especially in the charity sector
- IT, social media skills
- Research. An interest in contributions that can help drive the research agenda. A knowledge of research funding also of benefit
- Finance – audit, and preparation of financial accounts
- Risk and Control – Internal audit, compliance, legal, operational risk and / or control

The Director is encouraged to attend DEBRA Ireland's events and promote the organisation's work to their networks.

**As a board member you will play a critical role in shaping DEBRA's future and this will impact on the daily lives of the families, carers and people living with EB. We are working with DEBRA's all over the world to assign EB to the medical history books.**