EB RESEARCH PARTNERSHIP

Conversation Guide

EB Research Partnership

Founded in 2010 by a group of dedicated parents along with Jill and Ed Vedder (Pearl Jam), EB Research Partnership (EBRP) is the largest 501(c)(3) nonprofit dedicated to funding research aimed at treating and ultimately curing Epidermolysis Bullosa (EB), a group of devastating and life-threatening skin disorders that affect children from birth.

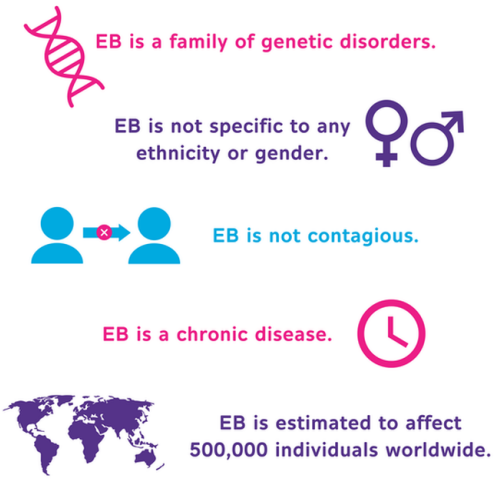
Our Mission

- EBRP works to treat and cure EB as quickly and efficiently as possible, fulfilling our mission through partnerships with non-profit and for-profit organizations, foundations, individual donors, and the EB and research communities.
- Leading researchers say treatments and a cure for EB are within reach. Though we have made significant progress, we need much greater resources in our pursuit of a cure.

Our Impact

Roughly 7,000 rare diseases affect millions of people worldwide. The results of EBRP-funded research can have an impact beyond EB.

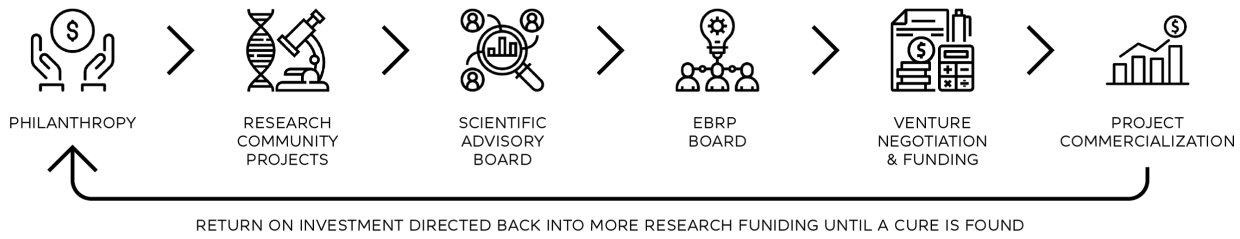
To date, EB Research Partnership has raised $40 million to fund innovative research aimed at finding treatments and cures for EB. EB is a genetic disease, so many of the projects we fund involve groundbreaking gene therapy techniques.



Venture Philanthropy

When EBRP makes a grant to a research project, we retain the added upside of generating a recurring donation stream if the therapy or product is commercially successful, then use this revenue to fund additional EB research.

Historically, non-profits have passed these financial benefits to universities and commercial companies. Instead, EBRP participates in them, making philanthropy more sustainable. Through partnerships with the University of Minnesota and Stanford University, EBRP pioneered the venture agreements that we now use for all grant-making.

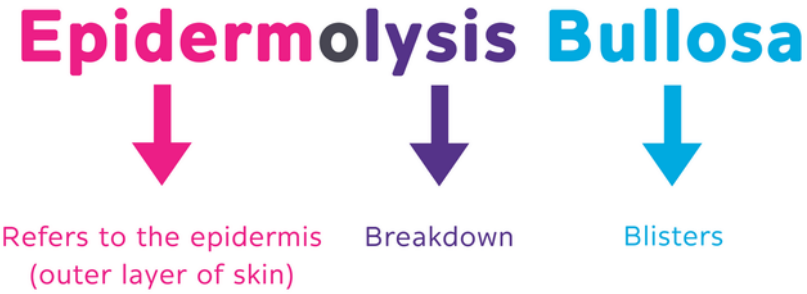


What is EB?

Epidermolysis Bullosa is a family of rare genetic disorders that affect the body's largest organ: the skin. Individuals with EB lack critical proteins that bind the skin's two layers together. Without these proteins, the skin tears apart, blisters, and shears off leading to severe pain, disfigurement, and wounds that may never heal.

There are 4 major subtypes of EB:

- EB Simplex (EBS)
- Junctional EB (JEB)
- Dystrophic EB (DEB)
- Kindler Syndrome



For more information, see our Impact Report, Venture into Cures Campaign, and EBRP Videos