EB RESEARCH PARTNERSHIP

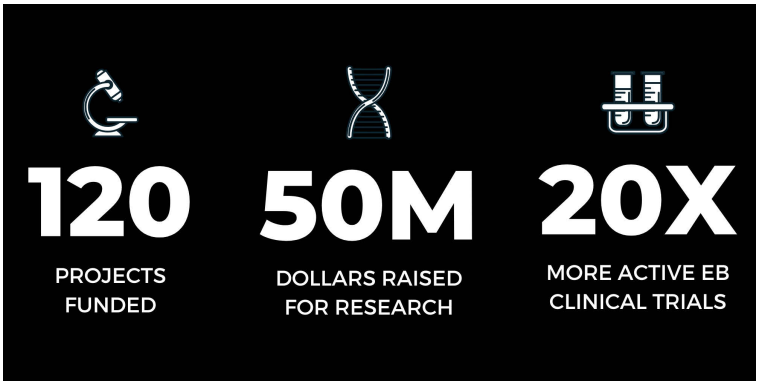
www.ebresearch.org

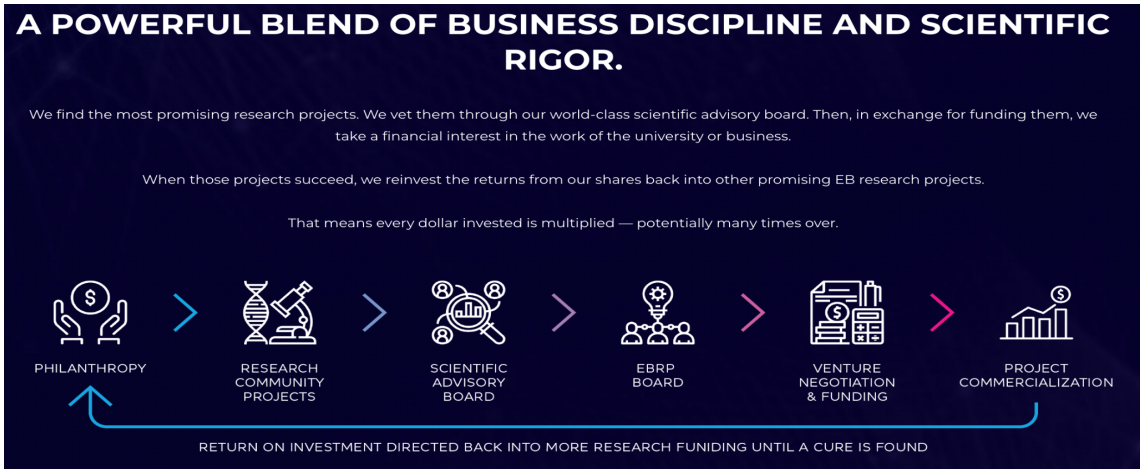
EB Research Partnership (EBRP) was founded in 2010 by a group of parents dedicated to saving their children's lives along with Jill and Eddie Vedder (Pearl Jam) with one bold audacious goal: treat and cure the devastating and life-threatening genetic rare skin disease epidermolysis bullosa (EB) by 2030 and in the process pioneer an innovative business and technology model to lead the way for 400 million people with a rare disease. As EB is typically caused by a single genetic mutation and treatments are observable on the surface of the skin, EB is first off the runway for impactful and curative medicine such as gene, stem cell, and immune therapies. Leading researchers believe a meaningful treatment or a cure is achievable before the end of this decade. While EB is a rare disease, there are 7,000 rare diseases that affect 1 in 10 people in the world, 95% which have no treatments, that can benefit from the research EBRP funds and its innovative venture philanthropy model - both of which are scalable to all rare diseases.

EB is a life-threatening genetic disorder that affects approximately 500,000 people worldwide. Called "Butterfly Children" because their skin is as fragile as the wings of a butterfly, children with EB face severe pain, open external and internal wounds, and a grueling daily bandaging process. There is currently no cure for EB, however EBRP's innovative model is helping to fast-track not only a cure for EB, but therapies that could affect thousands of other rare diseases.

EBRP utilizes a venture philanthropy business model which generates a return on investment from research that EBRP funds. It is under this model that EBRP invested in Krystal Biotech's VYJUVEK, the first ever FDA approved EB treatment, generated a more than double return on its investment, and reinvested that capital back into more EB projects. EBRP's pioneering model has been praised for its leadership by Harvard Business School, Yale University, and the Milken Institute FasterCures.

EBRP has always operated as a lean and high efficiency organization committed to the highest financial responsibility, directing nearly 90% of revenue to research and obtaining the highest charity accreditations (Charity Navigator Four Star Charity and Guidestar Platinum Transparency). EBRP has driven unprecedented impact, transforming the EB landscape from 2 to now nearly 40 clinical trials, including for the first time ever 4 Phase III clinical trials. The possibility of healing EB within the next decade is now within our grasp.





The biggest obstacle to curing EB isn't science — it's funding. EB Research Partnership has a proven history and plan to scale. In under a decade, we've raised over $50 million to fund over 120 projects, increased the number of EB clinical trials by 1,900% (from 2 to nearly 40), formed four new companies that have secured external investor funding, and struck nearly 100 venture philanthropy deals with businesses and universities. EBRP has directly funded 19 of those clinical trials and led to a complete clinical landscape transformation. For the first time, we have an FDA approved treatment, and 3 clinical trials are in the final phase before potential approval by the FDA giving us hope that more life-saving treatments will come in the near future. 2 of the 3 EBRP was an early investor in and generated a 2-6X ROI. In 2022 alone, EBRP funded 19 innovative research projects, accelerating cutting-edge technology with the potential to heal all subtypes of EB across 6 countries, totaling over $6.6M in grant awards. They included a diverse portfolio of approaches including curative therapies, gene therapies, spray-on skin, ocular treatments, stem cell therapies, topical wound healing, squamous cell carcinoma treatments, and antibody therapies. We have prioritized funding for projects that have a plan to be in the hands of patients in the next 1-4 years and will lead to significantly improving the quality of lives of those living with EB or are curative.

SHARE. COLLABORATE. CURE.

We have reached the threshold of a far more promising future for children born with EB. Leading researchers believe that both life-changing treatments and a cure are within reach. To realize our vision of a world without EB, we're building a research model based on three core pillars.

DATA PLATFORM
The largest gathering of EB data imaginable, including clinical, genomic, and patient data underlying the disease.

RESEARCH NETWORK
An open and fluid collaboration consortium that brings together the often siloed academic, medical, and patient communities.

IMPACT PORTFOLIO
Direct investment in the most promising projects, including disease controlling, changing, and curing therapies.

EB is just the beginning. We believe our method and model can accelerate how cures are found for 7,000 diseases impacting 350,000,000 people worldwide.

95% of Rare Diseases Have No Approved Treatment. Our Model Is Changing That.