During 2020, the COVID-19 pandemic presented a great deal of global challenges and uncertainty. Despite this backdrop, EB Research Partnership did not stop—and will not stop—working tirelessly to advance our mission of funding vital, life-saving research.

For a decade, EBRP’s work has been laser-focused on supporting the brave researchers, doctors, healthcare professionals, and families battling EB every day. Their reliance on EBRP’s support inspires us to work harder than ever. While the world seemed to stop during these trying times, time never stood still for those living with EB. For many, the pandemic accelerated the progression of their disease. The resources EBRP provides to advance research have taken on an even greater importance as significant philanthropic resources are understandably focused on solving a global pandemic. Our dedication to the EB community of patients, families, and researchers has never been stronger. We think of Teya, who lives with Recessive Dystrophic EB. The pain that she suffers and the grit that she demonstrates on a daily basis are her reality, regardless of a pandemic or not. We are reminded of our obligation to Teya’s future as we forge ahead.

“EB is a rare and awful condition that affects her body inside and out. Seeing your child struggle and not being able to help much is the worst feeling as a parent. Most of Teya’s body is always bandaged. Teya’s life is full of challenges, but her strength and positivity prevail over the evils of EB. We, as parents, look up to her as she has shown us first-hand what being resilient is and how to stay positive. Currently no cure exists for Teya or her friends battling EB. With your support, however, there is hope!”

— Milana and Aleks, Teya’s Parents

In the face of adversity, we at EBRP did what we have always done, what families like Teya’s do every day: adapt, innovate, and persist. In 2020, we awarded $7.2 million in research grants to 17 projects in five countries to fund life-saving treatments and potential cures for EB. Our total impact has increased to $40 million raised for 94 projects, helping transform the EB landscape from two clinical trials in 2010 to more than 32 in 2021—a 15x increase from when we began our work. For the first time ever, there are four Phase III clinical trials in EB, which is the last phase before approval by the FDA. The possibility for our first approved treatment in EB is on the horizon.

Thanks to supporters like you, now is a critical moment in time when life-changing EB therapies are becoming not an “if”, but a “when”. With the current momentum, adequate financial resources, and our innovative venture philanthropy model, we are accelerating the pace at which meaningful treatments will be available to help Teya and others with EB. Each day we are getting closer to making an EB-treated world a reality, and in the process, are pioneering a model to accelerate potential treatments and cures for the 7,000 rare diseases that affect 10% of the global population. With you standing beside us, nothing will stop us in our mission to treat and cure EB.

We thank you for joining us on this journey, and provide this Impact Report to show you the meaningful difference your support has made in accelerating the path to heal EB.

Sincerely,

Michael Hund
Chief Executive Officer
EB Research Partnership

Alexander Silver
Chairman
EB Research Partnership
partner with us in our mission to further life-saving research for EB

OUR MISSION

Founded in 2010 by a dedicated group of parents and Jill and Eddie Vedder of Pearl Jam, EB Research Partnership (EBRP) is the largest global 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 MODEL

Working around the clock with offices in the US and Australia, EBRP ensures sustainable funding for future EB research through our innovative venture philanthropy model. Instead of simply writing grants, EBRP funds research projects in exchange for a financial interest in the work. If those projects lead to commercially successful therapies, we use the returns from our shares to fund additional EB research until a cure is found. This means your generous donation has the potential to grow to multiples of its original value, maximizing your impact.
progress
to a cure
4 Phase 3 clinical trials in 2020, the last phase before potential FDA approval

15x the number of clinical trials in EB since founding

Projects Funded

$40M Raised

Active EB Clinical Trials

EBRP Research Spend

Projects Funded

Active EB Clinical Trials

Research Spend

94 Projects Funded

$40M Raised

research and data
EBRP accepts grant applications biannually and awards funding to competitive projects with potential to lead to treatments and cures for EB. Each application is reviewed by our distinguished Scientific Advisory Board (SAB) of experts in the fields of genetics, dermatology, basic science, and biotechnology. In 2020, we approved funding for nine new research projects and seven project renewals. In addition, we awarded funds to our EB Clinical Research Consortium, totaling over $7.5M in awards. EBRP funded all efforts, securing some matching funds on four projects from our partners EB Medical Research Foundation and Cure EB.

## 2020 Newly Approved Research Projects

<table>
<thead>
<tr>
<th>UNIVERSITY/COMPANY</th>
<th>PROJECT NAME</th>
<th>PRINCIPAL INVESTIGATOR(S)</th>
<th>AMOUNT APPROVED</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of South Australia</td>
<td>Development of a systemic antibody therapy for the treatment of epidermolysis bullosa.</td>
<td>Allison Cowin, PhD</td>
<td>$120,795</td>
</tr>
<tr>
<td>Stanford University</td>
<td>Evaluating the Natural History of Recessive Dystrophic Epidermolysis Bullosa Wounds</td>
<td>Jean Y. Tang, MD, PhD</td>
<td>$498,023</td>
</tr>
<tr>
<td>Stanford University</td>
<td>EBCRC version 2.0: Investigator and patient portals on Amazon Web Services</td>
<td>Jean Y. Tang, MD, PhD</td>
<td>$730,382</td>
</tr>
<tr>
<td>INSERM</td>
<td>Strategies for efficient and long-term engraftment of Mesenchymal Stromal Cells for the treatment of Recessive Dystrophic Epidermolysis Bullosa.</td>
<td>Alain Hovnanian, MD, PhD</td>
<td>$144,351</td>
</tr>
<tr>
<td>Stanford University</td>
<td>An Anonymous Online International Survey of Prevalence and Impact of Cannabinoid Use in Patients with Epidermolysis Bullosa</td>
<td>Jean Y. Tang, MD, PhD, Emily S. Gorell, DO, MS</td>
<td>$ 35,986</td>
</tr>
<tr>
<td>University of Freiburg</td>
<td>Characterization Of Tissue Biomarkers For Fibrosis And Inflammation In Patients With Dystrophic Epidermolysis Bullosa</td>
<td>Dimitra Kiritsi, MD</td>
<td>$73,522</td>
</tr>
<tr>
<td>King’s College London, UCSF</td>
<td>Investigating the transcriptome of EB wounds at single-cell level</td>
<td>Alexandros Onoufriadis, PhD, John McGrath, MD, Raymond Cho, MD, Jeffrey Cheung, MD</td>
<td>$225,344</td>
</tr>
<tr>
<td>Northwestern University, University of Freiburg</td>
<td>Augmented Intelligence in EB: Using deep learning for early detection of squamous cell carcinoma in EB</td>
<td>Antonia Reimer-Taschenbrecker, MD, Abel N. Kho, MD, Amy S. Paller, MD</td>
<td>$379,267</td>
</tr>
<tr>
<td>University of Minnesota</td>
<td>Autologous Revertant Mosaic Fibroblasts for Wound Healing in Dystrophic Epidermolysis Bullosa</td>
<td>Jakub Tolar, MD, PhD</td>
<td>$1,000,000</td>
</tr>
</tbody>
</table>

**TOTAL AWARDED** $3,207,670
## 2020 Renewal Research Projects

<table>
<thead>
<tr>
<th>UNIVERSITY/COMPANY</th>
<th>PROJECT NAME</th>
<th>PRINCIPAL INVESTIGATOR(S)</th>
<th>AMOUNT APPROVED</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIBRX Tissue Repair</td>
<td>Development of Human Recombinant Decorin Core Protein as a Topical Anti-Scarring Therapy for Dystrophic Epidermolysis Bullosa</td>
<td>Jean Y. Tang, MD, PhD</td>
<td>$300,000</td>
</tr>
<tr>
<td>University of Minnesota</td>
<td>Next Generation Genome Editing for RDEB</td>
<td>Jakub Tolar, MD, PhD</td>
<td>$1,000,000</td>
</tr>
<tr>
<td>Tufts Medical Center</td>
<td>Development of a Collagen VII Eye Drop for the Treatment of Ocular Disease in Recessive Dystrophic Epidermolysis Bullosa</td>
<td>Vicki M. Chen, MD</td>
<td>$336,315</td>
</tr>
<tr>
<td>Stanford University</td>
<td>Randomized Controlled Trial of a Neurokinin-1 Receptor Antagonist for the Treatment of Pruritus in Patients with Epidermolysis Bullosa</td>
<td>Albert Chiou, MD, Jean Y. Tang, MD, PhD</td>
<td>$495,480</td>
</tr>
<tr>
<td>Stanford University</td>
<td>Bridge Funding for iPSC</td>
<td>Tony Oro, MD, PhD</td>
<td>$800,000</td>
</tr>
<tr>
<td>Thomas Jefferson University</td>
<td>Targeting fibrosis for RDEB therapy in preclinical animal models</td>
<td>Andrew South, PhD</td>
<td>$101,350</td>
</tr>
<tr>
<td>Wings Therapeutics</td>
<td>Clinical development of QR-313 for treatment of DEB</td>
<td>Mark De Souza, PhD</td>
<td>$1,000,000</td>
</tr>
<tr>
<td><strong>TOTAL AWARDED</strong></td>
<td></td>
<td></td>
<td><strong>$4,033,145</strong></td>
</tr>
</tbody>
</table>

**Total Combined 2020 Research Projects Awarded:** $7,240,815
**Research Highlights**

**Title:** Augmented Intelligence in EB: Using deep learning for early detection of squamous cell carcinoma in EB  

**Institution:** Northwestern University and University of Freiburg  
**Principal Investigator:** Amy S. Paller, MD  
Antonia Reimer-Taschenbrecker, MD  
Abel N. Kho, MD  

**Award Amount:** $379,267.00  
**Patient Population:** Recessive Dystrophic EB  

**About:** Squamous cell carcinoma (SCC) is the most common cause of death for individuals with RDEB, shortening life expectancy to just 30 years. Patients must have regular skin checks at their dermatologist to remove any SCCs, however, distinguishing SCCs from normal EB wounds is difficult, even for experts. This lab aims to utilize deep learning and augmented intelligence as an early detection tool for SCCs in RDEB patients, improving disease management and prolonging lives.  

“Squamous cell skin cancers are a common cause of death in adults with RDEB. Early diagnosis is critical. We plan to find patterns to facilitate diagnosis and identify best sites for biopsy. Ultimately, we hope to develop an app for helping families and physicians to interpret risk of cancer.”  

— Dr. Amy Paller  

---  

**Title:** Autologous Revertant Mosaic Fibroblasts for Wound Healing in Dystrophic Epidermolysis Bullosa  

**Institution:** University of Minnesota  
**Principal Investigator:** Jakub Tolar, MD, PhD  

**Award Amount:** $1,000,000  
**Patient Population:** Dystrophic EB (DEB)  

**About:** Some patients with DEB have naturally occurring unaffected patches of skin where the EB-causing mutation is corrected. This phenomenon is known as “revertant mosaicism”. Dr. Tolar’s lab is working on identifying and isolating these naturally corrected cells, growing them in the lab, and injecting them back into patients.  

“Our goals are to continue to optimize gene editing technologies towards gene therapy and to create gene-corrected cells and topical delivery systems for therapeutic use. We are also working to comprehensively understand the unique cellular functions of RDEB squamous cell carcinoma tumors with the goal of developing immune therapies and rapid diagnostic testing.”  

— Dr. Jakub Tolar
**Research Highlights Continued**

**Title:** Development of a systemic antibody therapy for the treatment of epidermolysis bullosa.

**Institution:** University of South Australia

**Principal Investigator:** Allison Cowin, PhD

**Award Amount:** $120,795.00

**Patient Population:** All EB Types

**About:**
Dr. Cowin has identified a protein that contributes to inflammation, which leads to itch, wounds, and scarring in individuals with EB. She is creating an antibody that binds to this harmful protein, rendering it ineffective. Immunotherapy has been a helpful tool to combat several diseases, most prevalently cancer, and its potential to improve quality of life for the EB community is promising.

“Our goal is to develop an antibody therapy that simultaneously improves healing of blistered skin while reducing the severity of internal ulcerations of the digestive tract for patients with RDEB.”

— Dr. Allison Cowin

---

**Title:** Strategies for efficient and long-term engraftment of Mesenchymal Stromal Cells for the treatment of Recessive Dystrophic Epidermolysis Bullosa.

**Institution:** INSERM

**Principal Investigators:** Alain Hovnanian, MD, PhD

**Award Amount:** $144,351.00

**Patient Population:** Recessive Dystrophic EB

**About:**
Stem cells from healthy bone marrow have shown exciting therapeutic potential for patients with RDEB, especially for internal wounds that are difficult to treat. However, most of these cells fail to engraft and target affected areas, so they are unfortunately cleared from the patient’s body. This project aims to improve the survival, engraftment, and homing of stem cells following injection as well as discover the best strategy for these cells to provide long-term systemic benefit to patients.

“Mesenchymal Stromal Cells (MSCs) have the potential to improve wound healing and skin inflammation in RDEB patients. We aim to overcome existing limitations by optimizing in vitro conditioning prior to their injection. We can determine the best strategy for long-term engraftment of MSC to ensure long-lasting therapeutic benefits in multiple cutaneous and mucous sites in RDEB patients.”

— Dr. Alain Hovnanian
In October 2020, EBRP united with our longtime partners EB Research Foundation, based in Melbourne, Australia, to become the largest global organization focused on funding research to discover treatments and cures for EB. EBRF has come under the EBRP banner as “EB Research Partnership Australia.” Together, we will work around the clock to propel life-saving therapies into the hands of patients and families.

“Our shared mission to find treatments and cures for EB will be better served by uniting our organizations. We are looking forward to the great work our collective team will accomplish with combined resources and an established global presence.”

— Scott Didier AM, Chairman of EBRP Australia and Executive Board Member of EBRP

EB Research Foundation was founded by the Wilkes Family when their daughter Tilly was born with EB in 2011. Once they adjusted to the realities of raising a child with this devastating disorder, they sprung into action to create awareness in their network and raise funds for a cure, much like the founders of EBRP. Our shared mission brought the two organizations together in 2018 to fund promising EB research, and we’re ecstatic to have established EBRP Australia this year.
Data

EB Research Partnership founded the Epidermolysis Bullosa Clinical Research Consortium (EBCRC) with leading North American pediatric dermatologists. The EBCRC is made up of 20 prominent medical centers that contribute patient data to the EB Clinical Characterization and Outcomes Database (CCOD), which includes records on over 800 EB patients. Data drives progress, and EBRP is committed to accumulating the largest dataset possible to accelerate research for EB treatments and cures.

2020 Awards: $299,021
Q | How has the landscape of clinical trials in EB changed since you began working with EB patients?

The landscape is so different and hopeful and exciting all at the same time. We are now witnessing at least four Phase 3 clinical trials in EB! 10 years ago, we had nothing!

Q | Why is data important to advancing EB therapies?

EBRP is focused on data that will eventually lead to new treatments for EB. For example, they funded a natural history study of EB wounds at Stanford. These data are critical to show the FDA that EB wounds cover large surface areas of the body, they are painful, and never spontaneously heal. They are different from diabetic wounds or burn wounds, and need new “rules” for showing treatment efficacy. We are also focused on patient reported outcomes like pain, itch, and quality of life that are important to measure in future clinical trials.

“...The landscape is so different and hopeful and exciting all at the same time. We are now witnessing at least four Phase 3 clinical trials in EB! 10 years ago, we had nothing!”

— Jean Y. Tang, MD, PhD

Q | What makes you hopeful that we will find a cure for EB?

The world now knows about EB because of the good work, fundraising, and publicity from EBRP. Biotech and Pharma now care about rare diseases like EB and basic science advancements (like CRISPR technology, stem cells, etc.) that can now correct EB mutations. Protein replacement therapy like intravenous collagen is now being tested in trials. I am super hopeful that we will see an FDA approved drug for EB soon.
clinical landscape
Since EBRP was founded in 2010, the number of clinical trials in EB has increased dramatically, from just two to over 30 today — a 15x increase. 2020 was a landmark year with four EB clinical trials in Phase 3, the final phase before potential FDA approval, for the first time ever.

Highlight: Amryt Pharma Files New Drug Application with FDA

In May 2021, Amryt Pharma became the first company to complete their trial, the EASE Study, and submit a New Drug Application (NDA) for Oleogel S-10, a wound healing topical gel for individuals with Dystrophic and Junctional EB, to the FDA. Amryt was granted Priority Review for this application, meaning the FDA shortens the review period to just six months.

Take a look at other major clinical trials in the pipeline that EBRP was an early investor in, with your support. These studies test a wide range of interventions from topicals to protein therapies and gene therapies.
$2,434,952 was raised through events in 2020. We are so grateful to all event organizers, sponsors, and supporters for joining us virtually to #healEB

2020 EBRP Events

**Plunge for Elodie**
March 7 & 8
Wellesley, MA
Old Greenwich, CT
Staten Island, NY
San Francisco, CA

**All In For A Cure**
July 8
Virtual Event

**Take Flight 5K & Fun Run**
August 16-30
Virtual Event

**Venture Into Cures**
November 18
Virtual Event
Venture Into Cures
November 18, 2020
Virtual Event

Last fall, EBRP co-founders Jill and Eddie Vedder hosted the inaugural Venture Into Cures, an inspiring virtual event featuring moving stories about individuals and families living with Epidermolysis Bullosa (EB) alongside our celebrity friends. With more than 500,000 viewers, the event raised more than $2 million to fund EB research and pioneer our model to cure all rare disease.
Venture Into Cures
Celebrity Friends

Judd Apatow
Jon Batiste
Alessia Cara
Bradley Cooper
Andra Day
Laura Dern
Billie Eilish
Glen Hansard
Chris Hemsworth
Jimmy Kimmel
David Letterman
Adam Levine
Gaten Matarazzo
Keb’ Mo’
Lukas Nelson & Promise of the Real
with Micah and Willie Nelson
Luis “King Kong” Ortiz
Adam Sandler
Eddie Vedder
Jill Vedder
Renée Zellweger

Save the Date
This year’s Venture Into Cures will be on November 18, 2021
Learn more at:
www.ventureintocures.org
EBRP is committed to the highest financial responsibility and has received the top ratings from GuideStar, Platinum Seal of Transparency, and Charity Navigator, 4 stars. For complete audited financial information, please visit our website at www.ebresearch.org.

### 2020 EBRP Support & Revenue

- **Contributions** $2,262,326
- **Fundraising Events** $2,434,952
- **Investment Income** $29,063

**Total Support & Revenue**: $4,726,341

### 2020 EBRP Spending Allocation

- **Program & Research***: $6,113,699
- **Management** $348,482
- **Fundraising** $677,574

**Total Spending**: $7,139,755

*Includes funded EB research projects with academia and private/public companies

**Ending Net Assets**: $14,784,158
Executive Board

Alexander Silver  
Co-Founder & Chairman

Jill Vedder  
Co-Founder & Vice Chairman

Eddie Vedder  
Co-Founder

Jamie Silver  
Co-Founder

Heather Fullmer  
Co-Founder

Ari Deshe  
Scott Didier AM

Stephen Evans  
Edward Grossmann

Directors

Eileen Attar
Tracy Baldwin
Jeffrey Berger
Mark Bomback
Chad Ceretto
Eleanor Dehoney
Daniel Deshe
Faye Dilgen
Richard Grossmann
Matthew Holmes
Michael Kahn
Emily Kubik

Jennifer Kauf
Kate Lee
Alexander Lemos
Abbie Levine
Joshua Paulson
Matthew Prince
Whitney Pollack
Monique Sock
Jared Stern
Rob Veres
Donna Whiffin

Staff

Michael Hund  
Chief Executive Officer

Kiley Bergin  
Vice President of Development

Craig Fox  
Controller

Stephanie Ishoo  
Director of Communications

Maxson Thomas  
Development Associate

Michelle Hall  
Senior Accountant

Scientific Advisory Board

Anne Lucky, MD, Chair
Greg Barsh, MD, PhD
Suephy Chen, MD, MS
Alain Hovnanian, MD, PhD

Christopher Sloey
Amy Paller, MD