
EB RESEARCH PARTNERSHIP
impact report 2022


TEAM ELODIE

At EBRP, we have one bold audacious goal: heal and cure EB by 2030. In the process we're pioneering a model that can benefit the more than 400 million people affected by a rare disease. We are proud of the progress being made towards achieving that goal and our team is more inspired than ever to continue advancing life-saving treatments and cures for EB families across the globe.

2023 marked a major milestone: the first FDA approved treatment for EB and the first ever approved topical gene therapy: Krystal Biotech's VYJUVEK. EBRP invested in Krystal back in 2017 using our innovative Venture Philanthropy model and was able to generate a more than double return on our investment and reinvest that capital back into more EB projects. This is not only a landmark victory for individuals living with EB and their families, but also a huge milestone for the rare disease community at large. Currently, 95% of rare diseases lack an FDA approved treatment — and you all are a part of the team that is changing this statistic.

While this news is extremely exciting, our work is not done. In 2022, with your generous support, EBRP achieved a record year for research funding. We funded 19 innovative research projects in 6 countries, accelerating cutting-edge science with potential to heal all forms of EB, totaling over $6.6 million in grant awards. And we plan to set a new record in 2023.

Our funding spanned projects across the United States, France, Germany, India, Australia, and the UK for every EB subtype. They include a diverse portfolio of approaches including curative therapies, gene therapies, spray-on skin, ocular treatments, stem cell therapies, exon skipping, topical wound healing, squamous cell carcinoma treatments, drug repurposing, augmented intelligence cancer detection and prevention, immune therapies, and antibody therapies. We funded a mix of academic medical centers and universities, startups, and biotech and pharma companies. Our funding prioritizes two metrics above all else – urgency and ability to drastically improve daily life for families battling EB. These projects are (1) either already in clinical trials or have a strong strategy to be in patient's hands in the next 1 – 3 years and (2) will lead to a significant improvement in the quality of life of those living with EB or aim to be curative. In addition to the impact these projects can have for those battling EB, our world-renowned Scientific Advisory Board has also vetted this research for scalability to advance cures for thousands of other rare diseases.

Over the last 12 years, we have raised over $50 million to fund more than 120 EB research projects, directly transforming the clinical landscape for EB. Since our founding, the number of clinical trials in EB has increased more than 20 times, from just 2 clinical trials in 2011 to over 40 today.

In 12 short years we've made remarkable progress; our model and the research we fund can advance cures beyond EB for the 7,000 rare diseases that affect 400 million people around the world. In the last year, EBRP was highlighted for its leadership across academia, philanthropy, technology, and business. EBRP's Venture Philanthropy model was highlighted by Harvard Business School for its leadership and celebrated by Yale, where our model is being taught as a case study in venture philanthropy. EBRP was also awarded the Horizon Prize powered by MIT Solve for our innovative technology platform, and invited to share our expertise and mission at leading industry events such as the Social Innovation Summit, Concordia Summit and AWS re:Invent.

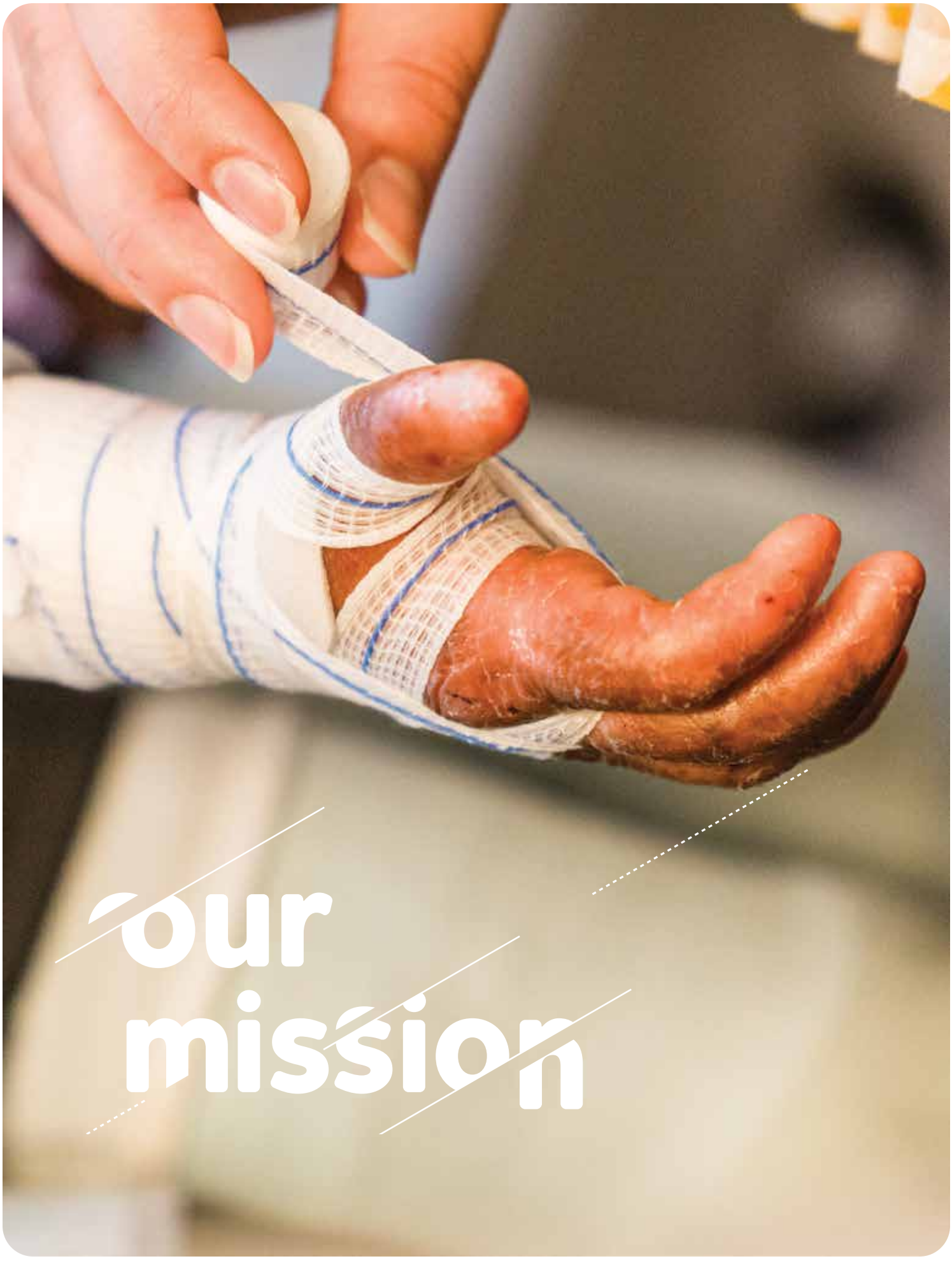
We thank you for joining us on this journey, and we're proud to provide this Impact Report to show you the meaningful difference your support has made in accelerating the path to heal EB.

We are honored to have you on the team that WILL cure EB – and pioneer a path for the hundreds of millions battling rare diseases worldwide. Thank you for joining us as we continue on our venture into cures, for EB and beyond.

With gratitude,

Michael Hund
Chief Executive Officer
EB Research Partnership

Jill Vedder
Co-Founder & Chairwoman
EB Research Partnership


our
mission

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). EB is 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 making grants, EBRP searches the globe to strengthen and accelerate the most promising research projects. These projects are vetted through EBRP's world-class Scientific Advisory Board and in exchange for funding, EBRP takes a financial interest in the work of research institutions. When those projects succeed, the returns are reinvested back into other promising EB research initiatives that are also scalable across thousands of other rare diseases. Every dollar invested at EBRP is multiplied — potentially many times over.


progress
to a cure

Research Funded in 2022:

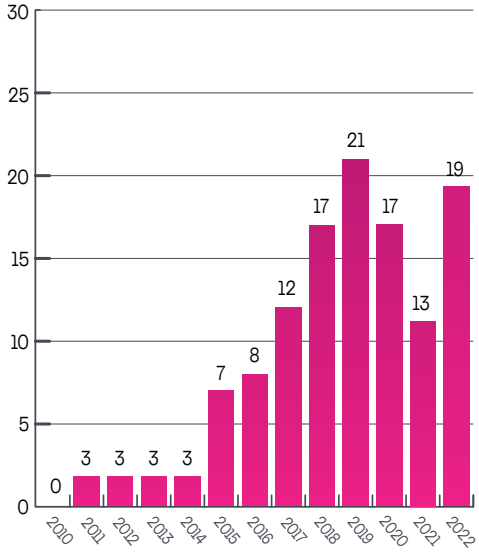
- Record-breaking year
- $6.6M in funding
- 19 projects
- 6 countries

May 2023 Update: Krystal Biotech's Vyjuvek became the first FDA approved EB treatment – a project partially funded by EBRP in 2017!

Research Funded to date:

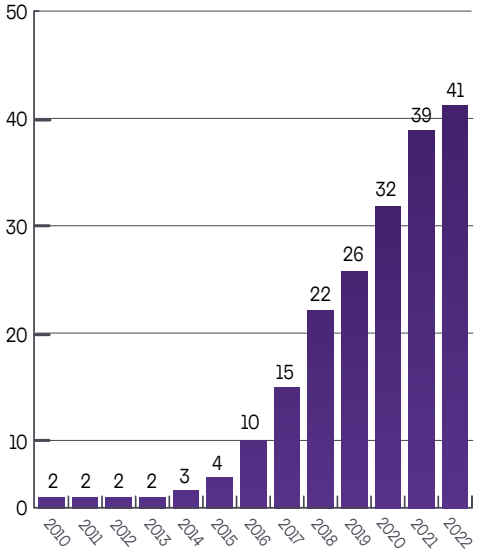
- 120+ projects
- $50M+
- 20x the number of clinical trials in EB since founding
- 4 Phase 3 clinical trials in 2022, the final phase before potential FDA approval
- Nearly 90% of revenue is directed towards research

Projects Funded



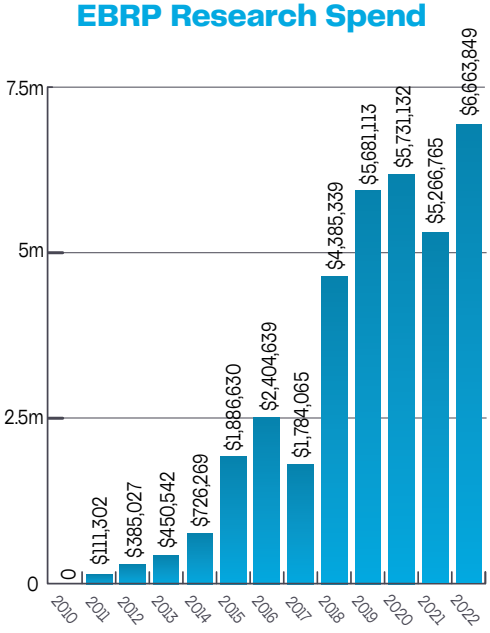
Projects Funded

Active EB Clinical Trials



Active EB Clinical Trials

EBRP Research Spend



Research Spend


research
and data

EBRP accepts grant applications biannually and awards funding to competitive projects with the highest potential to lead to treatments and cures for EB.

Each application is reviewed by our world-renowned Scientific Advisory Board (SAB), comprised of experts in the fields of genetics, dermatology, basic science, and biotechnology. In 2022, we approved funding for fifteen new research projects and three project renewals.

They include a diverse portfolio of approaches including curative therapies, gene therapies, spray-on skin, ocular treatments, stem cell therapies, exon skipping, topical wound healing, squamous cell carcinoma treatments, drug repurposing, augmented intelligence cancer detection and prevention, immune therapies, and antibody therapies.

We funded a mix of academic medical centers and universities, startups, and biotech and pharma companies. We prioritized funding for projects that are either already in clinical trials or have a strong strategy to be in the hands of patients in the next 1–3 years and will lead to significantly improving the quality of lives of those living with EB or aim to be curative. In addition, we awarded funds to our EB Clinical Research Consortium, bringing our 2022 research funding total to over $6.6M in awards.

2022 Newly Approved Research Projects

INSTITUTION	PROJECT NAME	PRINCIPAL INVESTIGATOR(S)	AMOUNT APPROVED
Stanford University	Randomized Controlled Trial of a Neurokinin-1 Receptor Antagonist for the Treatment of Pruritus in Patients with Epidermolysis Bullosa	Albert Chiou, MD Jean Tang, MD, PhD	$75,000
Stanford University/ GeneDX	Stanford x GeneDX 50 Patient Genomic Sequencing Pilot	Jean Y. Tang, MD, PhD	$40,000
Curator	Direct to Patient Platform		$300,000
University of Minnesota	Autologous Revertant Mosaic Fibroblasts for Wound Healing in DEB	Jakub Tolar, MD	$327,837
University of Southern California	Repurposing Anti-malarial Artemisinin to Inhibit RDEB Fibrosis and Scarring	Mei Chen, PhD David Woodley, MD	$183,750
Thomas Jefferson University	Rigosertib for recessive dystrophic epidermolysis bullosa-associated squamous cell carcinoma	Andrew South, PhD Neda Nikbakht, MD, Ph	$332,620
Stanford University	Validation of an Investigator's Global Assessment Scale for Assessing Disease Severity in Epidermolysis Bullosa Simplex Clinical Trials	Alexandros Onoufriadis, PhD John McGrath, MD Raymond Cho, MD, PhD Jeffrey Cheung, MD	$106,582
APTEEUS, University of Freiburg	TEE002 repositioning in epidermolysis bullosa	Terence Berghyn, PharmD, PhD Alexander Nystrom, PhD Thibaut Vausselin, PhD	$259,000
Centre for Human Genetics	Development of a Registry for Epidermolysis Bullosa in India	Ravi Hiremagalore, MD Gurudatta Baraka, PhD Arun Inamadar, MD Sacchidanand, MD	$149,500
Phoenicis	3 Therapies		$1,000,000

APPROVED RESEARCH PROJECTS CONTINUED ►

Research

APPROVED RESEARCH PROJECTS CONTINUED FROM PREVIOUS PAGE

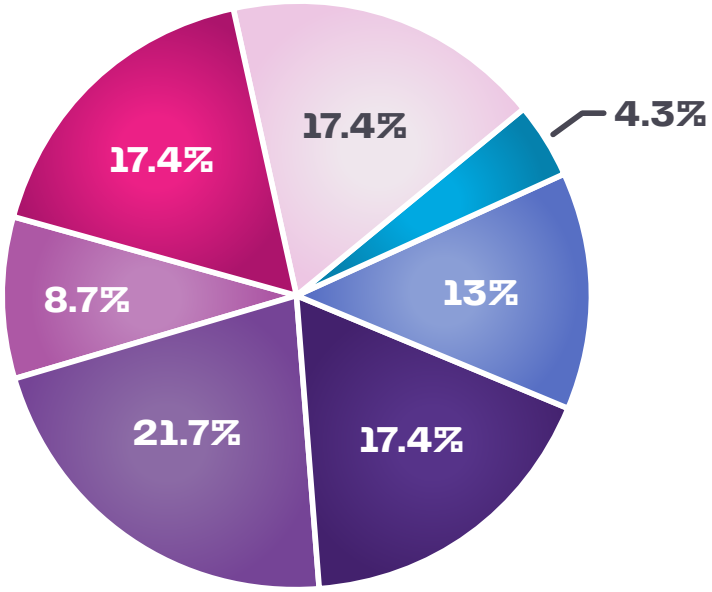
Stanford University	Optimizing induced Skin Composite Delivery Through Electrospray-on-Skin Technology	Anthony Oro, MD, PhD	$288,478
Eliksa Therapeutics	Development of a Novel Ophthalmic Solution to Treat Ocular Manifestations of Recessive Dystrophic Epidermolysis Bullosa	Armen Karamanian, MD, PhD John Phillips, PhD Andrew South, PhD Vicki Chen, MD Francis Palisson, MD Ignacia Fuentes, PhD Arturo Kantor, MD Felipe Mellado, MD	$850,000
University of Colorado Anschutz Medical Campus	Adapting the induced pluripotent stem cell-based therapy for recessive dystrophic epidermolysis bullosa to an automated platform to facilitate clinical translation	Dennis Roop, PhD Ganna Bilousova, PhD Igor Kogut, PhD	$999,724
Stanford University	A Randomized Phase 2 Clinical Trial to Evaluate a Temporary Skin Substitute (Spincare™ Matrix) for Wound Healing in RDEB patients	Jean Tang, MD, PhD Dawn Siegel, MD	$744,145
Cincinnati Children's Hospital Medical Center	Evaluation of Squamous Cell Carcinoma in Recessive Dystrophic Epidermolysis Bullosa: Clinical, Molecular, and Pathologic Characteristics and Outcomes	Anne Lucky, MD Emily Gorell, DO Brian Turpin, DO	$351,121
		TOTAL AWARDED	**$5,719,279**

2022 Renewal Research Projects

INSTITUTION	PROJECT NAME	PRINCIPAL INVESTIGATOR(S)	AMOUNT APPROVED
Department of Dermatology and Institute for Augmented Intelligence in Medicine, The Feinberg School of Medicine Northwestern	Augmented Intelligence in EB: Using deep learning for early detection of squamous cell carcinoma in EB	Amy Paller, MD Antonia Reimer-Taschenbrecker, MD Abel Kho, MD	$464,072
Thomas Jefferson University	Repurposing daclatasvir for RDEB therapy	Andrew South, PhD	$97,727
Future Industries Institute	Development of a systemic antibody therapy for the treatment of epidermolysis bullosa	Allison Cowin, PhD Zlatko Kopecki, PhD	$252,802
		TOTAL AWARDED	**$814,601**

Total Combined 2022 Research Projects Awarded: $6,533,880

2022 Projects: Breakdown



Research Highlights

Title: Optimizing Induced Skin Composite Delivery Through Electrospray-on-Skin Technology

Institution:
Stanford University

Award Amount:
$288,478

Principal Investigators:
Anthony Oro, MD, PhD

Patient Population:
All EB Subtypes

About: This study aims to determine the wound healing and wound closure capabilities of electrospray-on-skin delivered via SpinCare matrix. The autologous, genetically-corrected induced pluripotent dystrophic EB cell therapy (DEBCT) itself already demonstrates both pre-clinical efficacy and safety, but the delivery method remains to be tested. This "spray-on-skin" stem cell therapy would be a cure for all EB patients.

"Validation of electrospray-on-skin technology will enable a clinical platform for delivery of other types of stem cells to epithelial wounds all over the body, including those traditionally difficult to treat due to topology issues such as hands and feet."

— Dr. Anthony Oro

Title: TEE002 Repositioning in Epidermolysis Bullosa

Institution:
APTEEUS, University of Freiburg

Award Amount:
$259,000

Principal Investigators:
Terence Berghyn, PharmD, PhD,
Alexander Nystrom, PhD, and
Thibaut Vausselin, PhD

Patient Population:
All EB Subtypes

About:
A pre-clinical study to enable the demonstration of the expected benefit of TEE002 on inflammation, fibrosis and scar formation, and lead to an in vivo proof-of-concept before engaging efforts in a pharmaceutical and clinical development. TEE002 is the active component of a drug marketed to treat mucosal ulcers and asthma. It is known to have anti-allergic and anti-inflammatory properties, and is of particular interest in addressing several pathophysiological mechanisms of RDEB.

"We have shown recently that treating RDEB fibroblasts in culture with TEE002 inhibits the development of causative features of skin fibrosis. We hypothesize that TEE002 would be of interest in treating lesions of RDEB patients by reducing inflammation and fibrosis and in the long-term, eventually reduce the risk of cancer development."

— Dr. Terence Berghyn

Title: Rigosertib for Recessive Dystrophic Epidermolysis Bullosa-Associated Squamous Cell Carcinoma

Institution:
Thomas Jefferson University

Award Amount:
$332,620

Principal Investigator:
Andrew South, PhD and
Neda Nikbakht, MD, PhD

Patient Population:
Dystrophic EB (DEB) and Junctional EB (JEB)

About:
This is a first in EB clinical trial of rigosertib to assess tolerability and tumor targeting in patients with late stage, metastatic and/ or unresectable squamous cell carcinoma. The first patient to be treated with rigosertib in Europe has shown a complete response with all three target lesions being eliminated after six months. This grant award will be used to fund treatment of three patients in the US with intravenous rigosertib.

"We believe that with one more positive result with this drug for RDEB SCC we will have the momentum to seek approval of rigosertib for the treatment of RDEB SCC. Currently there are no standard of care interventions for RDEB SCC.

— Dr. Andrew South

UNIVERSITY OF MINNESOTA

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

Institution:
University of Minnesota

Award Amount:
$327,837

Principal Investigator:
Jakub Tolar, MD, PhD

Patient Population:
Dystrophic EB (DEB)

About: This research project will use revertant mosaic fibroblasts intradermally to assist in wound report and tissue regeneration in a two-year clinical trial of 10 patients to evaluate effectiveness and safety.

"With mosaic revertant epidermal cells capable of producing normal C7 in adequate amounts, the layers of skin are bonded together and the skin appears normal...We have shown that we can collect these revertant cells via a skin-punch biopsy and use existing culture methods to grow and harvest enough of the patient's revertant cells to be clinically useful in intradermally treating wounds."

— Dr. Jakub Tolar

Data

EB Clinical Research Consortium

EB Research Partnership founded the Epidermolysis Bullosa Clinical Research Consortium (EBCRC) with leading North American pediatric dermatologists. The vision of the EBCRC is to be an internationally-recognized collaborative group conducting high-quality clinical and translational research aimed at improving the diagnosis, manifestations, complications, and treatment of EB. By working collaboratively, the leading clinicians and researchers in the field of EB multiply the power of their individual efforts, enabling them to tackle important questions and gaps in knowledge and treatment for this devastating disease. The EBCRC is made up of 22 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.

2022 Awards: $279,468.50

Stanford University
Children's Hospital of Philadelphia
University of Colorado Anschutz Medical Campus
Columbia University
SUNY Downstate Medical Center
University of Minnesota
UC San Diego
Children's National
Northwestern University
Instituto Nacional de Pediatria
The Children's Hospital of San Antonio
dell children's Ascension
University of Miami
Cincinnati Children's
Phoenix Children's Hospital
College of Medicine Phoenix
Washington University in St. Louis
CHU Sainte-Justine
SickKids The Hospital for Sick Children
Henry Ford Health System
Seattle Children's

"The EBCRC continues to be an important tool to monitor outcomes over time and to serve as a repository of patients with this rare disease to be contacted as research becomes available. Collaborative research with the EBCRC has led to several publications... These projects would not have been possible without the support of the EBRP."

— Kimberly Morel,
Columbia University

Interviewing Allison Cowin, PhD & Zlatko Kopecki, PhD

Q | How will the work being done at the University of South Australia impact the EB community?

Our new immunotherapy approach not only promotes healing of the skin, but also healing of internal ulcers found in the mouth, throat, and gut. We believe that the simultaneous promotion of these healing responses will lead to stronger, more robust individuals, with improved quality of life and reduced pain which would be life-changing for people with EB.

Q | What is your biggest motivation for working on EB treatments?

We have been privileged to meet many patients with EB and have been so inspired by their bravery, by their courage. I was privileged to meet a young lady with EB called Kate. I met her when she was 16 and we learned how she dealt with living with EB. Unfortunately she passed away probably about four years ago now. She was a big collector of porcelain pigs and at her funeral, people who attended were allowed to take away one of her pigs. I have that pig on my desk, and I look at that pig regularly and I think "what can we do to make sure that I don't forget Kate?"

> **"In the last 20 years there's been enormous progress across different avenues to develop treatments for EB. In the following 10 years I hope that we will be able to progress that towards eventually having a cure."**

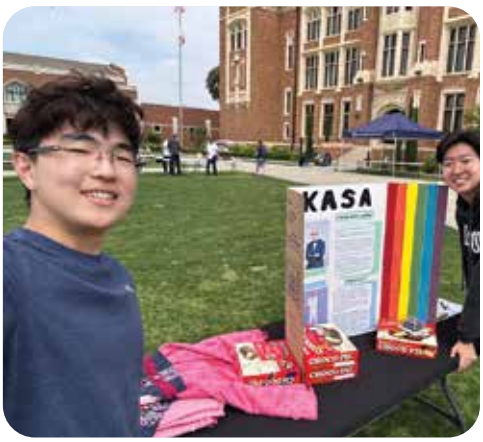
Q | What makes you hopeful that we will find a cure for EB?

In the last 20 years there's been enormous progress across different avenues to develop treatments for EB. In the following 10 years I hope that we will be able to progress that towards eventually having a cure. Understanding what these patients go through really gives us a drive to work hard in the laboratory and translate some of our research findings towards the clinic.

Patient Stories

Bowen
EB Simplex

"I was born with Epidermolysis Bullosa Simplex. I've always known that EB made me different. I quickly realized that I could not run for as long or participate in field trips like my friends. I became self-conscious about limping and disliked feeling pity from those who wanted to help me. But, when I turned eleven, I spent a week of my summer at Camp Wonder, a summer program for children with rare diseases. After meeting other campers whose subtypes of EB were much harsher than mine and being inspired by their optimism, my perspective on my skin disease changed. EB no longer made me different but instead, unique.



When I entered high school, I decided my high-school career would revolve around proving EB wrong. I am Co-Captain of my school's Congressional Debate Team and Co-Editor-in Chief of my school's newspaper because I want to prove to myself that despite being disabled, I still have a voice. Every summer, I research potential antibiotic treatments for EB at USC.

"When I entered high school, I decided my high-school career would revolve around proving EB wrong."

However, by far, my most meaningful experience has been leading Little Hands Make a Big Difference. When I first founded this organization, I posted articles about EB on a website and hosted a Poker Fundraiser to benefit an EB charity. However, within a few years, seventy students from three school districts joined my cause. I taught them about EB and how the disease represents the need for more representation of the rare disease community. Together, we partnered with an apparel company in Los Angeles to host clothing sales and donate those proceeds to fund critical work in the EB space. Through hosting fundraisers, legos and book drives, and even speaking to Congresswoman Young Kim, I strive to make EB known."

Natasa
Dystrophic EB

"I was diagnosed with Epidermolysis Bullosa immediately at birth. As a result of this diagnosis, I need help with basic daily activities and needs, and I have open wounds, blisters, bandages, blood, pain, itching, deformities, difficulty swallowing and walking, and numerous limitations and obstacles in my everyday life. Luckily, my family are my biggest supporters and their support means everything.

Despite the daily battle to try and stop it, my EB is progressing. There are frequent hospitalizations, infections, numerous hand operations, narrowing of the esophagus, transfusions, therapies, medical examinations, check–ups, an amputation surgery, which represents the biggest challenge that EB has brought me and a major turning point in my life...and skin cancer, the most serious complication of this disease. I have operated on it twice, but this fight is still going on. It is another one of the many palette wounds I have. It is there to remind me to appreciate every new moment in this earthly life, with hope and faith in a better and more beautiful one.

"In order for a caterpillar to become a butterfly, it must accept and survive many pains. But after that she will certainly take off much stronger, more powerful. And become a butterfly."

Over time, I began to express my emotions, thoughts and feelings through drawing, which has now, through the profession of graphic and brand design, become my job. I also have a diploma that I obtained during my high school education, which was very challenging but also a very inspiring moment.

For me, graphic design is not just a job, but a place where creativity, with will, effort and work, overcomes barriers, shortcomings and limitations. When I'm designing logos, branding, advertisements, and many other graphic products, I face the same challenge every day – to create something different, innovative, unique. It is a very inspiring and motivating challenge for me because it reminds me every day that being different is not a flaw, and that each of us is created by the careful hand of an artist who created us according to his plan.

In order for a caterpillar to become a butterfly, it must accept and survive many pains. But after that she will certainly take off much stronger, more powerful. And become a butterfly."

Shirvani
Dystrophic EB

"My name is Shirvani Naran and I was born with Dystrophic Epidermolysis Bullosa. The prognosis was very poor, and I was given 6 months to live. My parents were told to take me home, make me as comfortable as they could, and to not get attached to me because my survival was unlikely.

Just like every other little girl, I grew up watching princess fairytales and beauty pageants, the likes of Miss World and Miss Universe. As a child, my cousins and I would play pretend pageants and choose the countries that we wanted to be.

But I never realized at that age how different I was and how non-inclusive and cruel the world around me could be until I was a bit older. I was forced to cover up, not just to protect my skin, but to protect my emotional well-being. Growing up I never saw women like me represented anywhere. Not in the media, on runways, in movies or pageants, and I became more aware of what society saw as normal, and I realized that it wasn't me. I was forced to put aside many dreams.

I thought my time was over, until I came across the Mrs Globe South Africa call for entry. What attracted me to the pageant was its non-discriminatory entry criteria. Unlike other "Mrs" pageants, the only main criteria was that you had to be within a certain age bracket. The pageant promised to be unique and empowering and aimed to give women the opportunity and platform to leave their own legacy. I decided to give it a try.

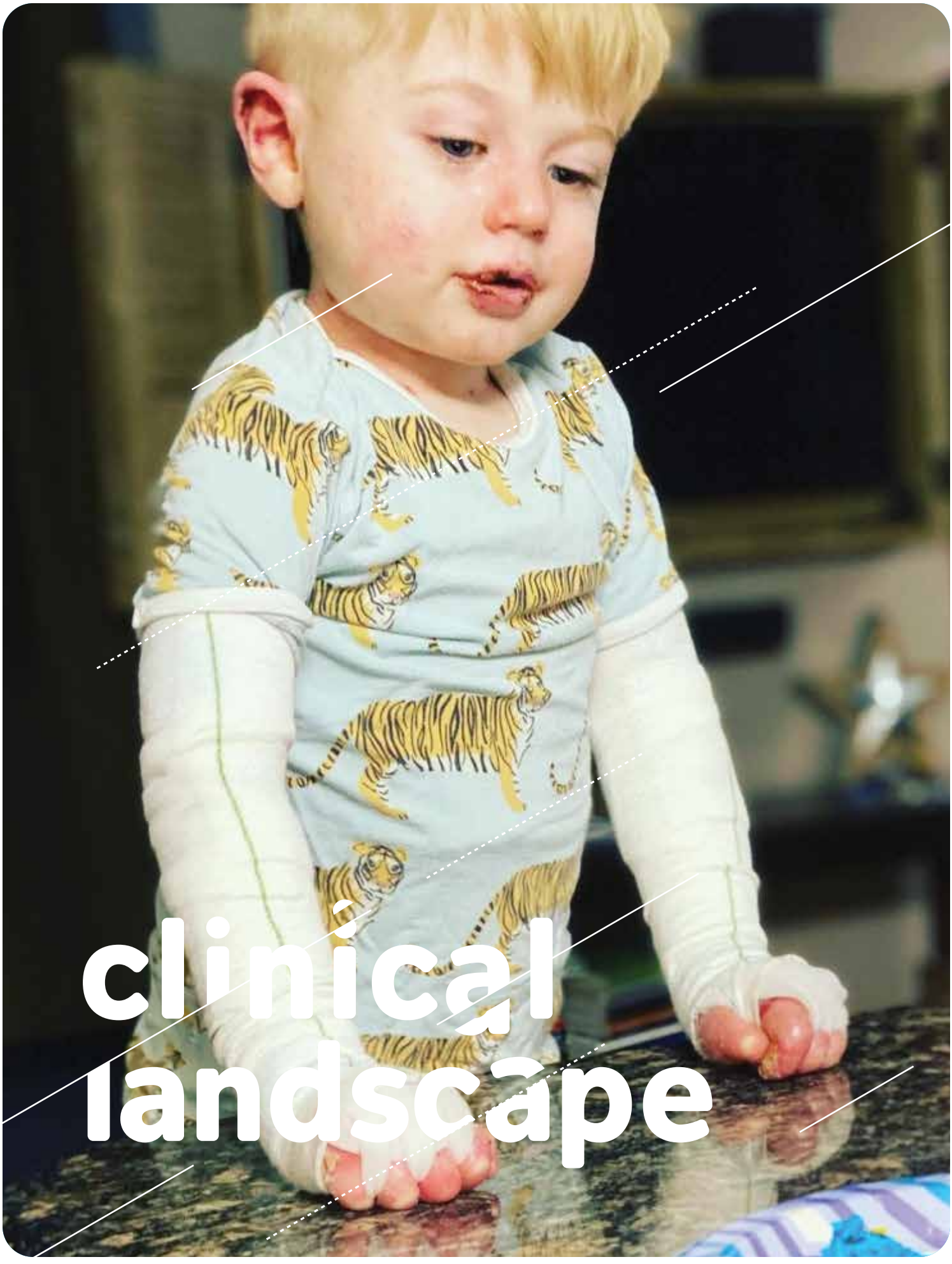
"I wanted a platform to share my journey of being isolated and rejected, then coming into my own and finding the courage to step out in boldness and confidence, to make my dreams a reality despite my physical limitations."

I wanted a platform to share my journey of being isolated and rejected, then coming into my own and finding the courage to step out in boldness and confidence, to make my dreams a reality despite my physical limitations. I wish to bring hope to other women and young girls living with a disabling illness or condition, to be someone that they can look up to and say, if she can be so brave and confident, then I can too. The stereotypes and the skewed ideas of what inclusion, representation and diversity really are, have to be challenged further because the current media platforms and big brands act as if those of us with disabling chronic conditions don't exist. We still aren't being adequately represented but we too are consumers of beauty, fashion, food and lifestyle products. This is why I've entered the social media space as a disabled micro-influencer and an advocate for body-positivity and inclusion. Women should be able to embrace the bodies they are in, without the fear of what society finds acceptable."

Ryan
Junctional EB

"EB Sucks. It's a hard disease to have and I sometimes feel left out and alone. No one really understands how painful it is. Because of EB, I am in a wheelchair and I have a trach to help me breathe. The trach can be very scary, and worries me a lot. I hope to be able to travel more with my family in the future. I love to see and experience new things. Having EB has made it difficult to travel because of all of my equipment and supplies. If I was cured of EB, I would travel the world. I try very hard to live a normal life like everyone else. I love my friends and play-dates, and my family...and video games, too! I dig music and am involved in band; last year I played the quarter-sized cello, and this year I am a percussionist. I am a member of the town's youth football team with all of my friends, and call plays from the sideline as well as support the team. I hope to run the length of the field in my wheelchair with a game winning touchdown!!!! I also play baseball and love attending hockey games."

"Thank you for reading my story."



clinical landscape

Since EBRP was founded in 2010, the number of clinical trials in EB has increased dramatically, from just two to over forty today — a 20x increase. 2022 was a landmark year with four EB clinical trials in Phase 3, and a potential treatment scheduled to be up for approval in 2023!

As of May 19 2023, this treatment was approved, making it the first ever FDA approved EB treatment.

Highlight: Krystal Biotech Submits Biologics License Application (BLA) to FDA

In June 2022, Krystal Biotech filed their BLA to seek FDA approval of their drug B-VEC for the treatment of patients with Dystrophic EB. B-VEC is an investigational non-invasive, topical gene therapy designed to treat DEB at the molecular level by providing the patient's skin cells with two copies of the COL7A1 gene to make functional COL7 protein, thereby addressing the fundamental disease-causing mechanism. Thanks to donors like you, EBRP was an early investor in this project back in 2017!

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 wound healing topicals to protein therapies and gene therapies.

	Phase 2	Phase 3	FDA Review	Approval
Wound Healing Topicals	**Stanford University:** A Neurokinin-1 Receptor Antagonist for the Treatment of Pruritus for EB		**Amryt Pharma:** Efficacy and Safety Study of Oleogel-S10 for EB	
Protein Therapy	**Phoenix Tissue Repair:** A Study of PTR-01 in RDEB			
Gene Therapy	**Wings Therapeutics:** QR-313 for Treatment of DEB Due to Mutation(s) in Exon 73	**Abeona Therapeutics:** EB-101 for the Treatment of RDEB		
	University of Southern California: Gentamicin for JEB	**Castle Creek Biosciences:** A Study of FCX-007 for RDEB (DEFI-RDEB)		
	University of Minnesota: Stem Cell Transplant for Severe EB		**Krystal Biotech:** Efficacy and Safety of B-VEC for DEB	


events

+$1.16M raised through EB Active events hosted by our community members in 2022.

We are so grateful to be back hosting in-person events, and we're very thankful to all of our event organizers, sponsors, and supporters for joining us to #healEB!

2022 EBRP Events

Plunge for Elodie
March 26 & 27
Old Greenwich, CT
Wellesley, MA
Greensboro, NC
Mooresville, NC
Breezy Point, NY

Take Flight Triathlon
August 12–28
Virtual Event

Grateful for Graham 5K Run/Walk
April 30
Utica, NY

Community Council
April 12
Virtual Event

Adelaide Crows Australian Football Match
July 2
Adelaide, Australia

Plunge for Elodie

Adelaide Crows Australian Football Match

Grateful for Graham 5K Run/Walk


eb active

In 2022, EBRP launched a new way for our supporters to engage their communities: EB Active.

EB Active is a way for inspired individuals to create their own fundraiser in their community to raise awareness and funds for EB Research Partnership and help us find a cure for EB. This year, we saw our supporters get EB Active in a variety of unique ways, from hot chocolate stands to slime stores to starting their own 5Ks!

Plunge for Elodie

Named after 6-year-old Elodie Kubik, the Plunge began as a local effort in Wellesley, Massachusetts, organized by childhood friends of Elodie's mom. They wanted to do more for the family than just offer emotional support, and as they learned about EB and the larger rare disease community, it became clear how desperately diseases like EB need funding to find treatments and cures. In short: every dollar truly matters. Thus, the first Plunge for Elodie took place in 2018. Now in its 6th consecutive year, the event has grown into an international movement and has surpassed $1.5 million raised for critical research aimed at curing EB!

Grateful for Graham

This community-led 5K was inspired by 3-year-old Graham Robertello. Graham's mom is an avid runner, who says that running has helped her cope with Graham's diagnosis. When she wanted a way to raise funds for EB research and to create awareness, a new 5K was born! Graham loves going out on runs in his stroller with his mom, so the family-friendly race also featured a stroller division. "Graham's Gang" rallied together to raise over $37,000 in their first year!

Adelaide Crows Match

The Adelaide Football Club partnered with EBRP to raise awareness and funds for EB. The Adelaide Crows used their Round 16 home game against Melbourne to support the EBRP in the hope of helping to find a cure. Crows CEO Tim Silvers said the Club had been inspired to play a part in helping the fight against EB. "We were taken by the passion and values of the EB Research Partnership and the mission they are on to find a cure for this traumatic and devastating disease," Silvers said. "People and families who are impacted by the disease are battling this every day, they do not get a break from it, and we admire their courage. Currently there is no cure and we are hoping to help, even if only in a small way, to help them try to find one."

Events

Venture Into Cures

November 20, 2022

On November 20 2022, EBRP presented the third annual Venture Into Cures. Over the three years, this inspiring digital event has raised incredible awareness and funds for EB, totaling over $6M. We are so grateful to have been joined by EB community members, doctors and researchers, and a host of celebrity friends over the past three shows, including Billie Eilish, Will Ferrell, Tom Holland, John Legend, Chris Pratt, Keanu Reeves, Olivia Rodrigo, Emma Watson, and more.

Venture Into Cures Celebrity Friends

Broken Social Scene

Jonathan Brown

Dana Carvey

Billie Eilish

Will Ferrell

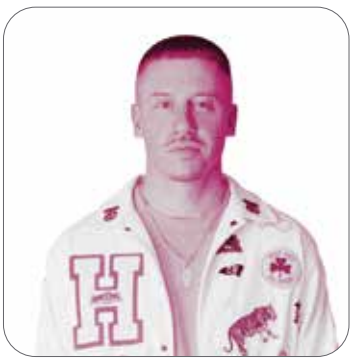
FINNEAS

Tom Holland

Joe Jonas

Kermit the Frog

John Legend



Macklemore

Lamorne Morris

Joy Oladokun

Chris Pratt

Red Hot Chili Peppers

Keanu Reeves

Olivia Rodrigo

Molly Shannon

Hannah Simone

David Spade

Lauren Spencer-Smith

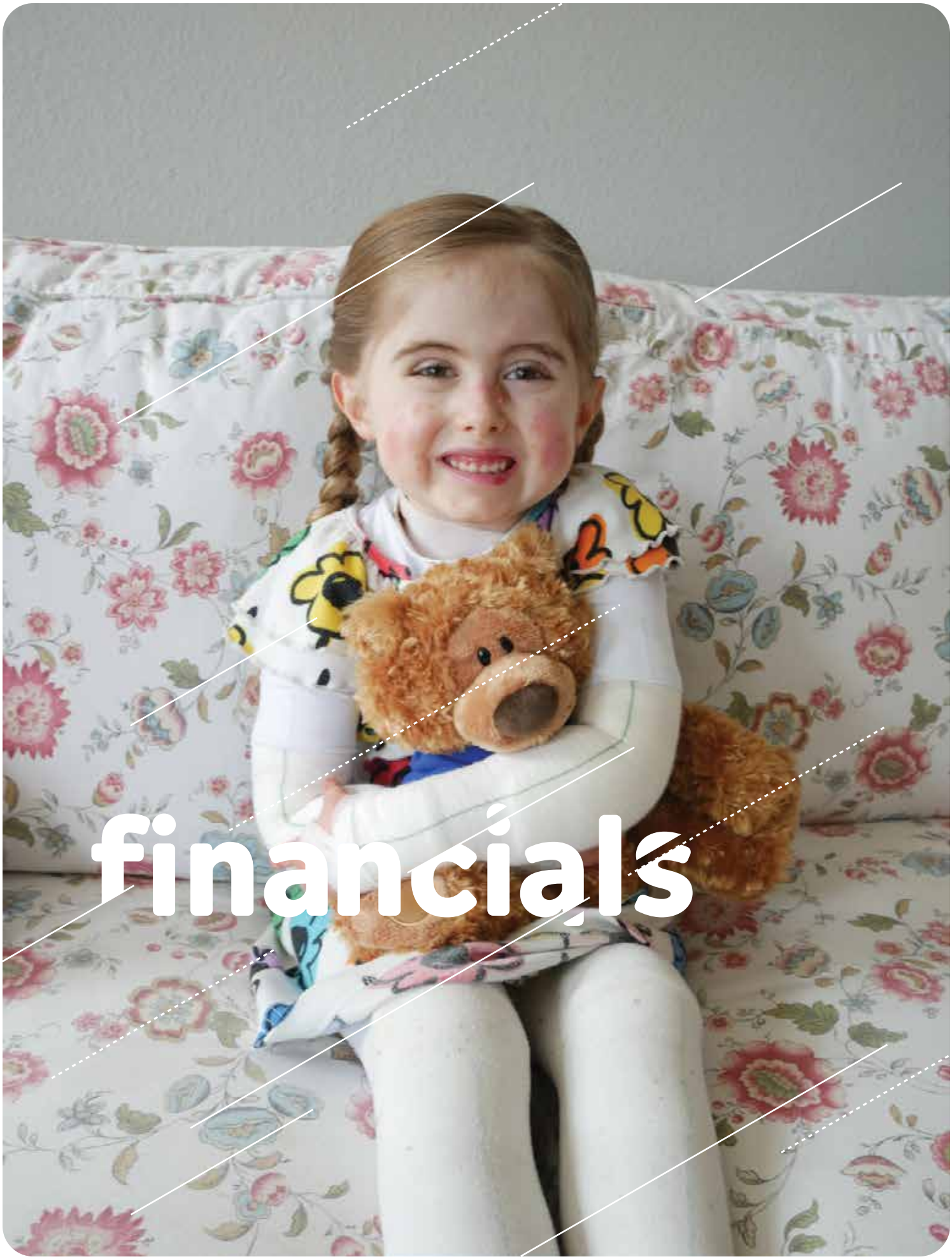
Liz Trinnear

Eddie Vedder

Jill Vedder

Emma Watson

Venus Willams



financials

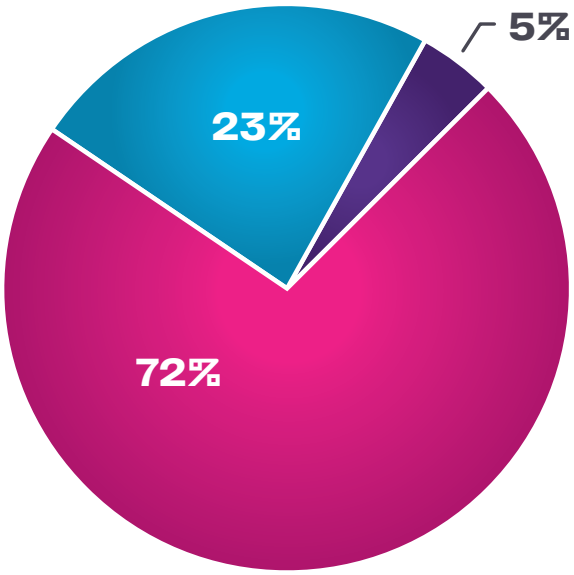
2022 Financial Summary

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.

2022 EBRP Support & Revenue

$6,595,819

- Contributions **$4,748,943**
- Fundraising Events **$1,561,116**
- Investment Income **$285,760**

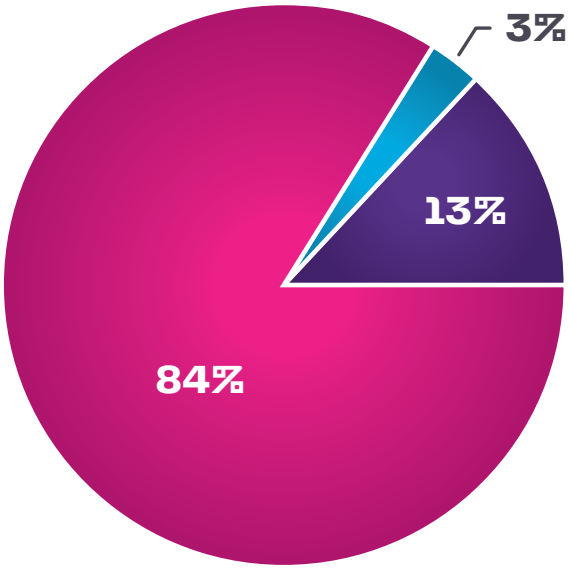


2022 EBRP Spending Allocation

$8,995,216

- Program & Research* **$7,533,281**
- Management **$278,012**
- Fundraising **$1,183,923**

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



Ending Net Assets: $17,987,137


leadership

Executive Board

Jill Vedder
Co-Founder & Chairwoman

Eddie Vedder
Co-Founder

Ari Deshe
Vice Chairman

Emily Kubik
Treasurer

Directors

Tracy Baldwin

Chad Ceretto

Daniel Deshe

Faye Dilgen

Ric Firth

Corey Gray

Jennifer Kauf

Greg Licholai

Rob Veres

Staff

Michael Hund
Chief Executive Officer

Imani Ribadeneyra
Chief Marketing Officer

Craig Fox
Controller

Allison McGettigan
Community and Operations Director

Sarah Thyssen
Executive General Manager,
EBRP Australia

Scientific Advisory Board

Anne Lucky, MD, Chair

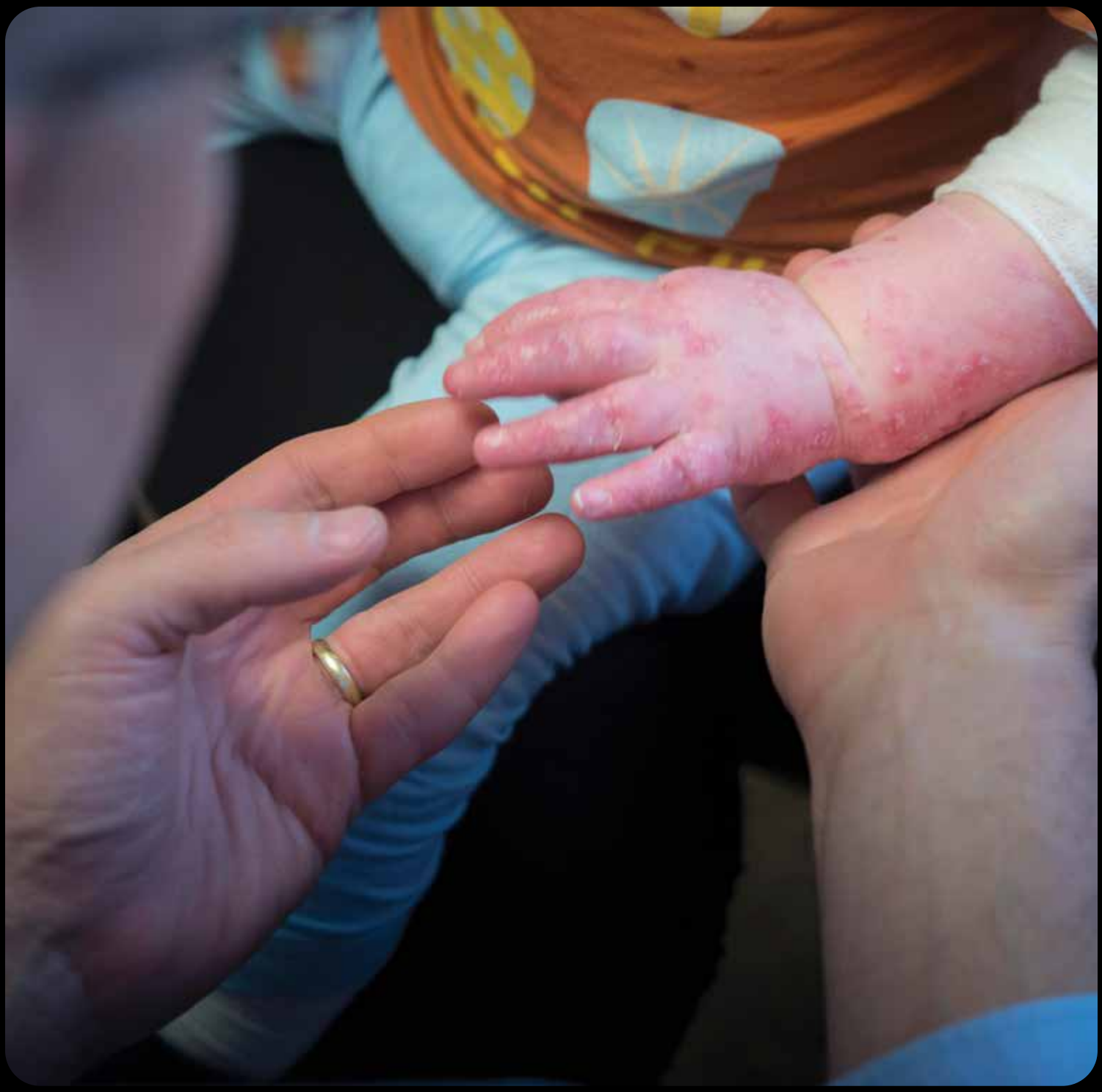
Greg Barsh, MD, PhD

Suephy Chen, MD, MS

Alain Hovnanian, MD, PhD

Christopher Sloey

Amy Paller, MD



EB RESEARCH PARTNERSHIP

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