



EB Research Partnership

2024 Corporate Partnership Program

REGISTER INTEREST

sponsorships@ebresearch.org



Our goal is to cure EB by

2030 and pioneer a path for the
400M+
affected by a rare disease.



Founded in 2010 by a group of dedicated parents and Jill and Eddie Vedder, EB Research Partnership (EBRP) is the largest global organization dedicated to funding research to treat and cure Epidermolysis Bullosa (EB).

EB is a life-threatening genetic skin disorder that affects children from birth. Individuals with EB, often called “Butterfly Children,” lack critical proteins that bind the skin’s two layers together. With skin as fragile as the wings of a butterfly, they experience blisters, severe pain, disfigurement, and internal and external wounds that may never heal.

Today, there is no cure for individuals battling EB, however, EB Research Partnership is dedicated to changing that.



Our Award-Winning Model

Since 2010, EBRP has made remarkable strides, including raising +\$50M for life-saving research, contributing to a 20x growth in EB clinical trials, and helping to fund the first-ever FDA approved topical gene therapy and treatment for EB families.

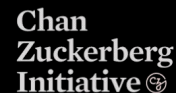
This progress would not be possible without our innovative **Venture Philanthropy Model**.

EBRP ensures sustainable funding for future EB research through a Venture Philanthropy Model. Instead of simply writing checks, EBRP funds research projects in exchange for a financial interest in the work. If those projects succeed, we use the returns from our shares to fund additional EB research.

With this Venture Philanthropy model, EBRP will continue to maximize ROI until EB is history – all the while creating a butterfly effect for thousands of other rare diseases.

EB is just the beginning.

Our model can accelerate cures for 7,000 other rare diseases.



Our Venture Philanthropy Model has been highlighted for its leadership by Harvard, Yale, MIT, the Milken Institute, Stanford Social Innovation Review, and more.



Our Progress

\$50M

raised for life-saving research

+120

innovative projects funded

20x

growth of EB clinical trials

1

FDA-approved EB treatment



**FIRST-EVER
FDA APPROVED
GENE THERAPY
FOR EB**

2023 Media & Press



Stanford SOCIAL
INNOVATION Review
NOW



Harvard
Business
School

Rolling Stone

billboard



Yale SCHOOL OF
MANAGEMENT



MILKEN
INSTITUTE
Faster Cures



THE
Hollywood
REPORTER

People

SPIN

Chan
Zuckerberg
Initiative 

CEO's
You Should
Know

MIT | SOLVE

*The Seattle
Times*

Forbes

**SEE PRESS
FEATURES**



THE EBRP COMMUNITY

500K+

EB families
worldwide

75K+

followers across
social media

60K+

email subscribers
& supporters

20+

events planned
globally in 2024

How to Get Involved

LEADERSHIP SPONSORSHIP

Our biggest supporters can join Team EBRP as Leadership Sponsors to have a presence across our website, marketing content, and a large variety of world-class and local community events EBRP is hosting both virtually and in-person across the US, AUS, EU, UK, and India.

EVENT SPONSORSHIP

Your company can choose to sponsor and join us for a selection of the incredible events we have slated for 2024 like Reportin' For Duty in Nashville, Venture Into Cures, Plunge for Elodie happening across the world, or Change for Charley Gala Dinner in Chicago.

COMMUNITY EVENTS & CONTENT

Community events & content sponsors are represented as lead EBRP supporters on the EBRP Community Events homepage and choose select Community Council webinars and/or campaigns for brand activation.



2024 EBRP Events Calendar



Q1'24
January – March

Q2'24
April – June

Q3'24
July – September

Q4'24
October – December

February 17 | Nashville
Reportin' For Duty 2

March – April | Global
Plunge for Elodie

Date TBD | Global
**Venture Into Cures
Digital Summit**

Fall | Chicago
**Change for Charley
Gala Dinner**

Fall | New York
**Venture Into Cures
Summit & Dinner**

February | Global
Rare Disease Day

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

Summer | Adelaide, AUS
**Aussie Rules Football
Charity Game**

October | Global
EB Awareness Week

March | New York
NYC Half Marathon

June | Savannah, GA
Butterfly Ball
Hosted by Heroes for Hallie Grace

October | Spring, TX
Golf Tournament
Hosted by Wesson's Wish

November | New York
NYC Marathon

Held 1x per Quarter
Community Council Webinars

Summer & Fall | Multiple Locations
Darin Mock Racing Community Events



Leadership Sponsorships

\$250,000

PREMIER SPONSOR

- Recognition as Premier Sponsor on EBRP Website
- Gold Sponsor Venture Into Cures *(Fall, NYC)*
- Presenting Sponsor for Venture Into Cures Digital
- Presenting Sponsor on EBRP Community Events Page
- Presenting Sponsor for 2x Community Council Webinars
- Presenting Sponsor for 1x Co-branded Content Campaign
- Title Sponsor for Change for Charley *(Chicago, IL)*
- Presenting Sponsor for Plunge for Elodie *(Multi Location + Digital)*
- Tax deductible donation

\$100,000

CHAMPION SPONSOR

- Recognition as Champion Sponsor on EBRP Website
- Silver Sponsor Venture Into Cures *(Fall, NYC)*
- Title Sponsor for Venture Into Cures Digital
- Gold Sponsorship for 1x Co-branded Content OR Community Council
- Gold Sponsor on EBRP Community Events Page
- Gold Sponsor for Change for Charley *(Chicago, IL)*
- Title Sponsor for Plunge for Elodie *(Multi Location + Digital)*
- Tax deductible donation

\$75,000

GUARDIAN SPONSOR

- Recognition as Guardian Sponsor on EBRP Website
- Silver Sponsor Venture Into Cures
- Silver Sponsor for 1 Community Council
- Silver Sponsorship on EBRP Community Events Page
- Gold Sponsor for Change for Charley *(Chicago, IL)*
- Title Sponsor for Plunge for Elodie *(Multi Location + Digital)*
- Tax deductible donation



Leadership Sponsorships

\$50,000

PLATINUM SPONSOR

- Bronze Sponsor Venture Into Cures
(Fall, NYC)
- Silver Sponsor for 1 Community Council
- Bronze Sponsorship on EBRP Community Events Page
- Gold Sponsor for Change for Charley
(Chicago, IL)
- Title Sponsor for Plunge for Elodie
(Multi Location + Digital)
- Tax deductible donation

\$25,000

GOLD SPONSOR

- Champion Sponsor Venture Into Cures
(Fall, NYC)
- Bronze Sponsor for 1 Community Council
- Bronze Sponsorship on EBRP Community Events Page
- Bronze Sponsor for Change for Charley
(Chicago, IL)
- Platinum Sponsor for Plunge for Elodie
(1 Location + Digital)
- Tax deductible donation



FLAGSHIP EVENTS

VENTURE INTO
CURES

OCTOBER 2023
SEATTLE, WA

TO BEHEALTHY PARTNERSHIP





VENTURE INTO CURES

From 2020-2022, the Venture Into Cures digital show has raised incredible awareness and funds for EB, raising over \$6M and reaching +225K unique viewers across more than 70 countries.

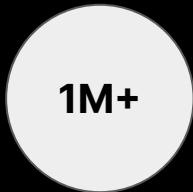
Building off of the momentum of these 3 digital shows, EBRP created an in person Venture Into Cures experience in 2023. EBRP brought together the brightest minds across medical research, tech, science, & more, for the inaugural **Venture into Cures Summit**. This inspiring day of interactive sessions and keynotes was followed by the **Venture Into Cures Dinner** at and two Eddie Vedder shows at Benaroya Hall with all proceeds supporting EBRP.

Raising over \$11M+ for life-saving research since 2020, the Venture Into Cures franchise has become a powerful force for good in the rare disease community.

In 2024, EBRP will put on another inspiring Venture Into Cures Summit & Dinner - it is not to be missed!



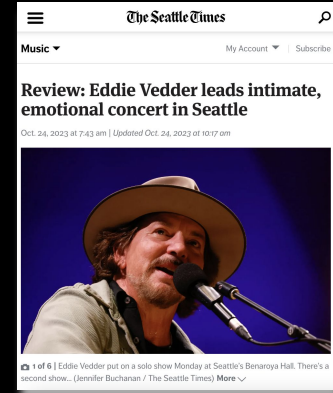
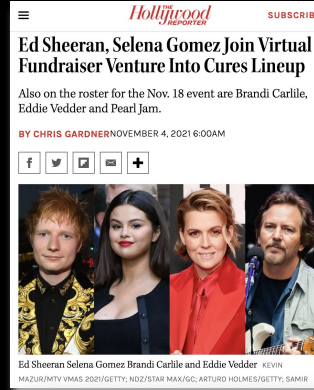
**IN-PERSON
ATTENDEES**



IMPRESSIONS



**RAISED
SINCE 2020**





VENTURE INTO CURES

PAST GUESTS





VENTURE INTO CURES

SPONSORSHIP LEVELS

\$250,000

PLATINUM SPONSOR

- 25 tickets to both Venture Into Cures Dinner
- 25 tickets to access Venture into Cures Summit
- Sponsorship of 10 EB families to attend the event
- Acknowledgement in commemorative booklet & at event
- Logo on Step & Repeat
- Logo on Photobooth
- 150-word corporate message on Venture into Cures website
- Company logo on Venture into Cures website with link to company's website
- 1x co-written Press Release
- 1x co-branded email blast
- 2x dedicated social media posts
- Tax deductible donation

\$100,000

GOLD SPONSOR

- 15 tickets to access Venture into Cures Summit
- 15 tickets to Venture into Cures Dinner
- Sponsorship of 4 EB families to attend the event
- Brand recognition in commemorative booklet & at event
- 100-word corporate message on Venture into Cures website
- Company logo on Venture into Cures website with link to company's website
- 2x dedicated social media post
- 1x co-branded email blast
- Tax deductible donation

\$50,000

SILVER SPONSOR

- 10 tickets to access Venture into Cures Summit
- 10 tickets to Venture into Cures Dinner
- Sponsorship of 2 EB families to attend the event
- Brand recognition in commemorative booklet and at event
- 50-word corporate message on Venture into Cures website
- Company logo on Venture into Cures website with link to company's website
- 1x dedicated social media post
- Tax deductible donation



VENTURE INTO CURES

SPONSORSHIP LEVELS

\$25,000

BRONZE SPONSOR

- 5 tickets to access Venture into Cures Summit
- 5 tickets to Venture into Cures Dinner
- Sponsorship of 1 EB family to attend the event
- Brand recognition in commemorative booklet
- Company logo on Venture into Cures website with link to company's website
- Tax deductible donation

\$10,000

CHAMPION SPONSOR

- 2 tickets to Venture Into Cures Dinner
- 2 tickets to access Venture into Cures Summit
- Sponsorship of 1 EB individual to attend the event
- Brand recognition in commemorative booklet
- Company logo on Venture into Cures website with link to company's website
- Tax deductible donation

\$5,000

ADVOCATE SPONSOR

- 1 ticket to access Venture into Cures Summit
- 1 ticket to access Venture into Cures Dinner
- Acknowledgement on Venture Into Cures website
- Tax deductible donation



DIGITAL

VENTURE INTO CURES

Filmed at the iconic Benaroya Hall, the Venture Into Cures Digital Summit EBRP will showcase inspiring panel conversations and keynote speeches from the inaugural Venture Into Cures Summit in Seattle.

The Venture Into Cures Digital Summit will showcase the brightest minds across medical research, tech, science, and more. These panels and keynotes will bring forth new ideas on how to advance treatments and cures for EB and beyond.

Sponsorship opportunities include, but are not limited to...

- Presenting Sponsor Opportunity
- Custom digital activation
- Co-Create additional session
- Co-Branded content distribution



4

POWERFUL
PANELS

2

WORLD-CLASS
KEYNOTES

20

INDUSTRY LEADING
SPEAKERS

This digital summit will feature powerful **patient voices** and industry leading speakers such as **Dr. Nicholas Christakis, Dr. Jean Tang, Former Sec. of HHS Eric Hargan, Dr. Eleni Linos, and Dr. Greg Licholai.**

VENTURE INTO CURES

DIGITAL



SPONSORSHIP LEVELS

\$50,000

PRESENTING SPONSOR

- Acknowledgement on Venture Into Cures digital homepage
- Acknowledgement as Presenting Sponsor for all marketing
- Co-create session with EBRP for Summit
- 1x co-written press release
- 1x email blast to EBRP distro list
- 5x social posts
- Tax deductible donation

\$25,000

TITLE SPONSOR

- Acknowledgement on Venture Into Cures digital homepage
- Acknowledgement as Title Sponsor for all marketing
- 1x email blast to EBRP distro list
- 3x social posts
- Tax deductible donation

\$10,000

ADVOCATE SPONSOR

- Acknowledgement on Venture Into Cures digital homepage
- Acknowledgement as Advocate Sponsor for all marketing
- 1x social post
- Tax deductible donation



Plunge for Elodie 2024

Named after 7-year-old Elodie Kubik, who lives with a severe form of EB, the Plunge began as a local effort in Massachusetts, organized by childhood friends of Elodie's mom. They wanted to do more for the family than just offer emotional support. Thus, the first Plunge for Elodie took place in 2018.

Our goal in 2024 is to raise \$500K, which will bring our total impact to \$2.5M!

As we enter the 7th year of the Plunge, we are filled with more hope than ever. In May 2023, we saw the first-ever FDA approved EB treatment. Funds raised from the Plunge for Elodie will go directly towards EB Research Partnership so they can continue to fund critical, life-saving research until there is a cure.



WATCH OUR STORY



**SUPPORTERS
OF THE PLUNGE**



**FUNDS RAISED
SINCE 2018**



**CITIES INVOLVED
FOR 2024**

**PLUNGE
IN THE
PRESS**

POPSUGAR.

BRIT+CO

The Boston Globe

greenwich
time





Plunge for Elodie 2024

15 PLUNGE LOCATIONS...& COUNTING!

UNITED STATES & CANADA

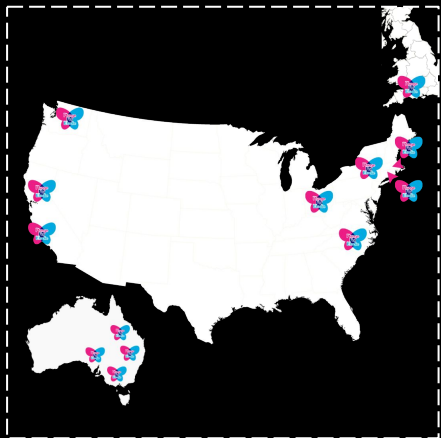
- ★ Boston, MA
- ★ Chicago, IL
- ★ Cleveland, OH
- ★ Greensboro, NC
- ★ Los Angeles, CA
- ★ Nashville, TN
- ★ New York, NY
- ★ Pittsburgh, PA
- ★ San Francisco, CA
- ★ Seattle, WA
- ★ Utica, NY
- ★ Wellesley, MA

AUSTRALIA

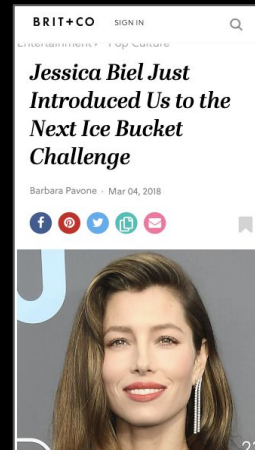
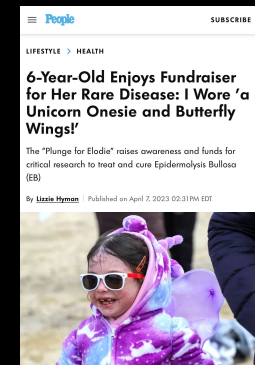
- ★ Sydney
- ★ Gold Coast
- ★ Adelaide
- ★ Melbourne

UNITED KINGDOM

- ★ London
- ★ North Devon



PLUNGE IN THE PRESS





SPONSORSHIP LEVELS

\$20,000

PRESENTING SPONSOR

- Headline banner on Plunge for Elodie flagship website
- 3x Social media promotions (EBRP, EBRPA, Plunge for Elodie)
- Dedicated email blast to Plunge for Elodie participants
- 1x EBRP join Press Release
- Special recognition during all Plunge live events
- Logo on all event signage
- Tax deductible donation

\$10,000

TITLE SPONSOR

- Presence on Plunge for Elodie flagship website
- 1x Social media promotions (EBRP, EBRPA, Plunge for Elodie)
- 1x EBRP join Press Release
- Special recognition during one live Plunge event
- Logo on all event signage at one Plunge live event
- Tax deductible donation

\$5,000

PLATINUM SPONSOR

- Presence on one Plunge location website & fundraising page
- 1x Social media promotions (EBRP, Plunge for Elodie)
- Special recognition during one live Plunge events
- Logo on all event signage at one Plunge live event
- Tax deductible donation



Change for Charley

Change for Charley was founded by the Kauf Family in honor of 11-year-old Charley Kauf, who lives with EB. Change for Charley is an inspiring event that has raised over \$1M raised to date. All proceeds benefit EB Research Partnership, the leading nonprofit searching for a cure.

Change for Charley, is an inspiring evening emceed by ESPN's Scott Van Pelt featuring an exclusive live auction, food & cocktails from local Chicago staples, and amazing entertainment.

CHANGE
FOR
CHARLEY



300+

ATTENDEES
EXPECTED

+\$1M

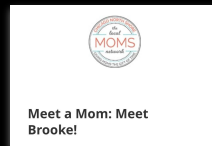
FUNDS RAISED
SINCE 2020

2M+

SCOTT VAN PELT
FOLLOWERS



IN THE
PRESS





SPONSORSHIP LEVELS

\$30,000

TITLE SPONSOR

- Private meet and greet with Scott Van Pelt at the event
- Recognition during the Live Program (Potential Award Given)
- Large corporate logo in all marketing materials at the event
- Listing on pre/post event outreach and communications as Title Sponsor
- Exclusive recognition at the bar areas
- 12 complimentary tickets to the event
- Tax deductible donation

\$20,000

PLATINUM SPONSOR

- Large corporate logo in all marketing materials at the event
- Listing on pre/post event outreach and communications as Platinum Sponsor
- 10 complimentary tickets to the event
- Tax deductible donation

\$12,500

GOLD SPONSOR

- Corporate logo in all marketing materials at the event
- Listing on pre/post event outreach and communications as Gold Sponsor
- 8 complimentary tickets to the event
- Tax deductible donation



Reportin' For Duty

TO BENEFIT EB RESEARCH PARTNERSHIP

The late, great entertainer Leslie Jordan coined the phrase 'Reportin' for Duty' to describe his personal calling to a life of service. In February 2023, a diverse group of artists including Eddie Vedder, Maren Morris, Brothers Osborne, Lukas Nelson, Ashley McBryde and more – came together on the Grand Ole Opry stage under to celebrate the light and love of Leslie Jordan and to benefit EB Research Partnership.

On Saturday, February 17, we will hold a **concert at Humble Baron at the Nearest Green Whiskey Distillery** with the important goal of raising money and awareness for children battling EB while delivering the ultimate, live event experience.

2024 HEADLINER



POST MALONE




5.7M



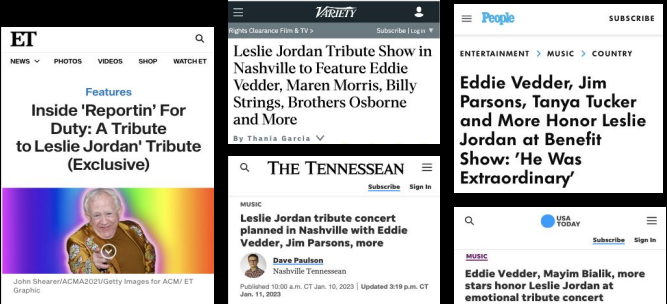
**LESLIE JORDAN
INSTAGRAM
FOLLOWERS**

25.1M



**POST MALONE
INSTAGRAM
FOLLOWERS**

IN THE PRESS





COMMUNITY EVENTS & CONTENT



Community Council Webinars

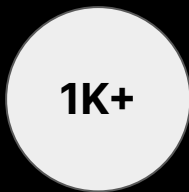
The Community Council helps drive research efforts by educating the EB community with reliable and up-to-date information from trusted specialists in the EB space.

Throughout the year, EBRP hosts discussions on topics like current research, clinical trials, understanding EB, and more. All sessions are publicly available and archived on the **EBRP website** and **YouTube channel**.

Some previous topics for Community Councils have included wound care best practices and tips, clinical trials updates, caregiver and mental health resources, and more.



**LIVE ATTENDEES
ON AVERAGE**

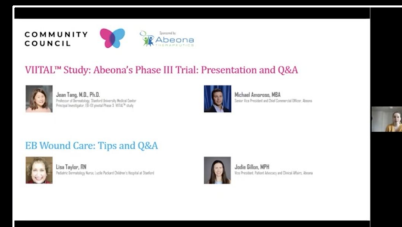


**EB PATIENTS &
FAMILIES INVITED**



**SOCIAL MEDIA
FOLLOWERS**

WATCH PAST COMMUNITY COUNCILS

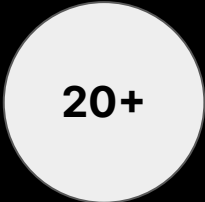


Community Events

Community events, or EB Active, is a way for inspired individuals to create their own events and fundraisers in their community to raise awareness and funds for EBRP. These are intimate events with high impact. Often led by an EB family, these are an opportunity to get to know our community of patients, caretakers, donors, and supporters – and have some fun!

Past community events have included plunges, hot coco stands, 5Ks, poker nights, Trans-Am car races, wine tasting, and more!

These events are run by local communities with full support from the EBRP team to ensure maximum impact and a great experience for hosts, partners and guests alike.



EVENTS PLANNED FOR 2024



SUPPORTERS IN 2023



RAISED IN 2023 ALONE



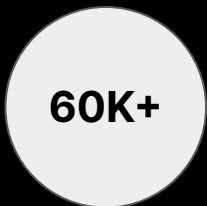


Co-Branded Content

We also invite our Annual Partners to co-create content with EB Research Partnership.

Whether it's a global brand campaign, a custom webinar, or a brand activation our Annual Partners will have the opportunity to engage with our community, followers, subscribers, and EB families and select EBRP ambassadors.

These co-branded campaigns are promoted across channels and platforms via EBRP's...



**EMAIL
SUBSCRIBERS**



**SOCIAL MEDIA
FOLLOWERS**

Venture Into Cures Summit
OCTOBER 22ND
Day | Benaroya Hall

EBRP will bring together the brightest minds across medical research, tech, science, and more for the inaugural Venture Into Cures Summit. This immersive event will put forth an agenda for advancing treatments and cures for EB and beyond. See below for full agenda.

LOCATION: Benaroya Hall | 1400 5th Ave | Seattle, WA 98101

ORISE EDGE Business Cloud

9:00 AM - 1:00 PM PST / 12:00 PM - 4:00 PM Your local time (4 Hr) View the event on Facebook

Portrait Studio

Stop by our portrait studio with your family, colleagues or friends to capture a moment that will be on site to capture this moment and give you a print to take home.

Sponsored By:

CASE STUDY

For our Venture Into Cures Summit in Seattle EBRP partnered with Abeona Therapeutics to execute a high quality portrait studio for patients and families. The portrait studio was conveniently located at the check in table at the Summit which produced incredible marketing images for Abeona, lots of user-generated social media content, and a memorable keepsake for attendees.





EBRP COMMUNITY SPONSORSHIP LEVELS

\$75,000

PRESENTING SPONSOR

- Presenting Sponsor for 2x Community Council Webinars with opportunity to present
- 1x Co-Branded Content Campaign
- Recognition as Presenting Sponsor on EBRP Community Events Page

\$20,000

GOLD SPONSOR

- 1x Co-Branded Content Campaign
- Gold Sponsor at 1x Community Council Webinar with opportunity to present
- Recognition as Gold Sponsor on EBRP Community Events Page

\$10,000

SILVER SPONSOR

- Silver Sponsor at 1x Community Council Webinar with opportunity to present
- Recognition as Silver Sponsor on EBRP Community Events Page

\$5,000

BRONZE SPONSOR

- Recognition as Bronze Sponsor on EBRP Community Events Page



THANK YOU!



REGISTER INTEREST

sponsorships@ebresearch.org