



EB RESEARCH
PARTNERSHIP

EB Research Partnership Announces the 3rd Annual Plunge for Elodie Fundraiser March 7 & 8, 2020, with Five Same-Weekend Plunges Around the Globe

Once a Small Hometown Fundraiser Planned by Friends, Plunge for Elodie Makes Big Waves for “Butterfly Children” Living with the Life-Threatening Skin Disease Epidermolysis Bullosa

February 29, 2020 – In honor of Global Rare Disease Day, EB Research Partnership (EBRP), the largest nonprofit dedicated to funding research aimed at treating and ultimately curing Epidermolysis Bullosa (EB), is pleased to announce the 3rd Annual [Plunge For Elodie](#), with five same-weekend Plunges taking place internationally on March 7 and 8, 2020 in Wellesley, MA; Staten Island, NY; San Francisco, CA; Greenwich, CT; and London, England. These Plunges come on the heels of global Rare Disease Week (February 25-28, 2020), and 100% of the proceeds benefit EBRP.

Plunge for Elodie, which began as a small hometown fundraiser in 2018 with a \$15,000 fundraising goal, has evolved in just three years' time into a global movement with a \$300,000 fundraising goal and millions of eyes on the cause thanks in part to the story capturing the hearts of so many, and also due to actress Jessica Biel learning about the cause and taking a *Virtual Plunge for Elodie* on [social media](#), which spread virally.

Plunge for Elodie is organized by a group of ten childhood friends to honor Emily Kubik's 3-year-old daughter, Elodie, who suffers from EB. “When Elodie was born, we asked Emily how we could help. She replied that the best gift we could give their family was to help them find a cure. Thus, the Plunge for Elodie began, as we strive to make big waves not just for Elodie, but for every child living with EB,” said Plunge for Elodie Co-Chair Kristan Fletcher Khtikian. Thanks to their steadfast commitment to the cause, the Plunge for Elodie Committee will receive an honorary EB Ambassador Award this year from EBRP.

A life-threatening genetic skin disease, it is estimated that 500,000 people worldwide have EB. Children with EB are called Butterfly Children because their skin is as fragile as the wings of a butterfly: they face severe pain, open wounds (both internal and external), and a grueling daily bandaging process, and their life expectancy is cut devastatingly short. There is currently no treatment or cure for EB, but EBRP is dedicated to changing that as swiftly as possible.

“When we started EB Research Partnership in 2010, there were only 2 clinical trials, today there are more than 20. While that is tremendous progress in less than a decade, there are still no approved treatments. However, leading researchers believe that both life-changing treatments and a cure are within reach. Our bold and singular goal is to accomplish this by bringing together the greatest minds and resources in research, medicine, industry and philanthropy, alongside dedicated and passionate ambassadors of the patient community, just like the Plunge for Elodie,” said Michael Hund, CEO of EBRP.

Each Plunge for Elodie event is open to the public, with no registration process or fee, and is followed by a post-Plunge celebration event. “99% of the people we communicate with about this event have never heard of EB, but they are immediately touched and want to help. Whether they live close to a Plunge site and take the Plunge for Elodie with us on March 7 or 8, or make a donation to the cause, we firmly believe that every ounce of support helps. It takes a village to generate awareness, and we will continue to forge forward with great determination in our hearts until a cure is found,” stated Fletcher Khtikian.

“We are moved by the support Plunge for Elodie continues to receive. Coupled with the inspiring work EBRP is doing, we have hope that there will come a day when all those with EB no longer have to suffer or feel pain,” said Elodie’s parents Emily and Dave Kubik, “And it’s that hope that keeps us going every day.”

Learn more at www.plungeforelodie.org

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About EB Research Partnership

Founded by a dedicated group of parents and 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. EBRP works to treat and cure EB as quickly as possible and fulfills their mission by partnering with non-profit and for-profit organizations, foundations, individual donors, and the EB and research communities.

EBRP utilizes an innovative business model of venture philanthropy, when making a grant to a research project they retain the added upside of generating a recurring revenue stream if the therapy or product is commercially successful, then use the return on investment to fund additional EB research until a cure is found. To learn more about EBRP visit www.ebresearch.org.