

The logo for 'Plunge For Elodie' is a stylized butterfly shape composed of two overlapping circles, one pink and one blue. The text 'Plunge For Elodie' is written in a playful, rounded font across the butterfly. 'Plunge' is in pink, 'For' is in white, and 'Elodie' is in white with a blue outline.

Plunge
For
Elodie

#healEB

2022 CORPORATE PARTNERSHIP

5th Annual Plunge for Elodie

March 26– March 27, 2022

Massachusetts, North Carolina, New York, Connecticut, Virtual

Making waves for children suffering from the rare genetic disorder Epidermolysis Bullosa (EB)

www.plungeforelodie.org



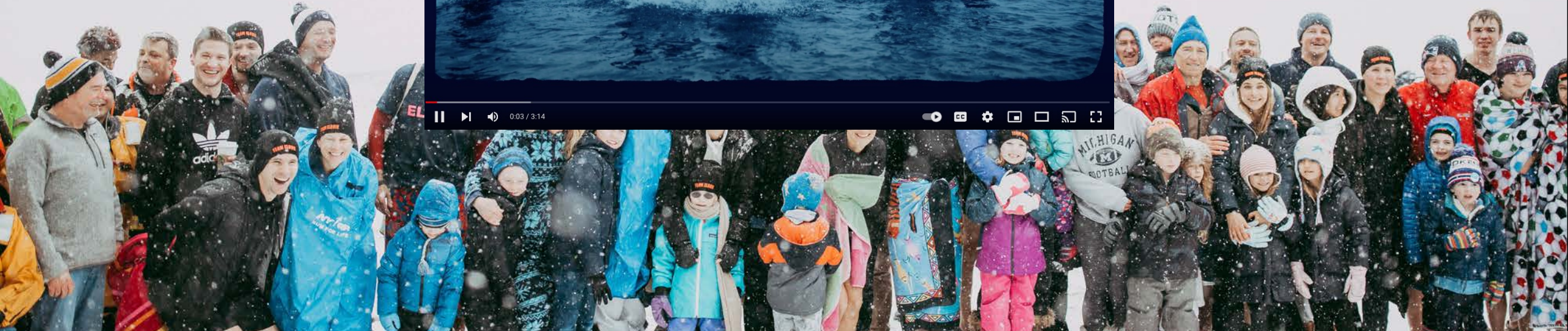
Plunge
For
Elodie

#healEB

Introducing: The 5th Annual Plunge for Elodie

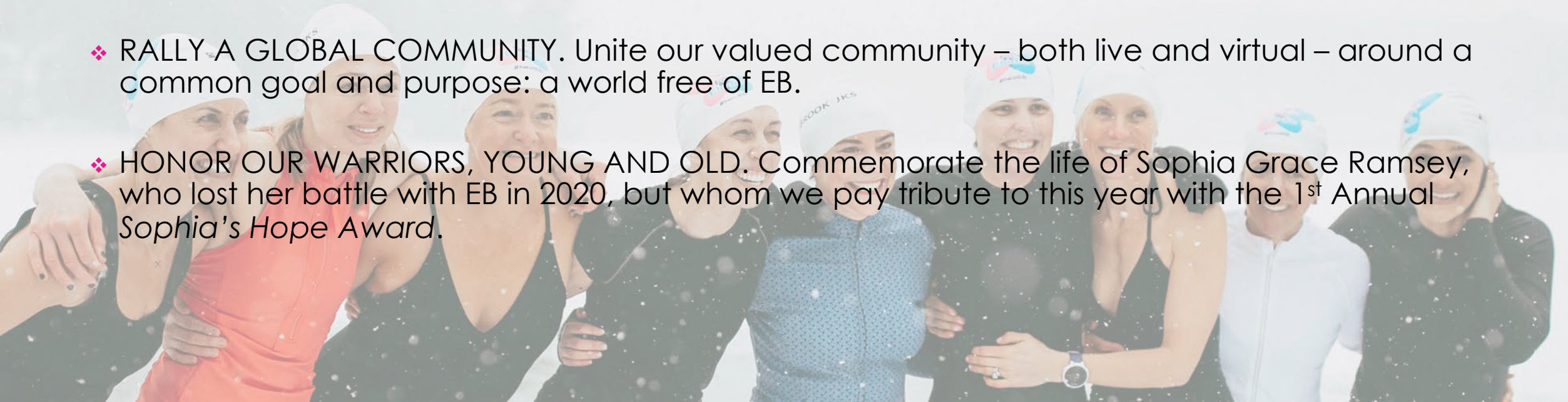
WATCH HERE!

<https://www.youtube.com/watch?v=Ksxzvb-YQFQ&feature=youtu.be>



PLUNGE FOR ELODIE MISSION

- ❖ RAISE AWARENESS. Educate the public about the life-threatening rare disease Epidermolysis Bullosa (EB).
- ❖ MAKE WAVES FOR **ALL** RARE DISEASES. Every dollar raised benefits the EB Research Partnership (EBRP), which funds research and trials aimed at treating and ultimately curing EB. The EBRP's vital work applies to many other rare diseases too, which impact over 350 million people globally, 50% of whom are children.
- ❖ RAISE CRITICAL FUNDS. In 2022, this event will surpass \$1 million raised for the cause. And we will not stop until a cure is reached.
- ❖ RALLY A GLOBAL COMMUNITY. Unite our valued community – both live and virtual – around a common goal and purpose: a world free of EB.
- ❖ HONOR OUR WARRIORS, YOUNG AND OLD. Commemorate the life of Sophia Grace Ramsey, who lost her battle with EB in 2020, but whom we pay tribute to this year with the 1st Annual *Sophia's Hope Award*.







PLUNGE FOR ELODIE

March 26 – 27, 2022

Every donation to the cause makes an impact.

100% of the funds raised will directly benefit the **EB Research Partnership (EBRP)**, the largest nonprofit organization in the world dedicated to funding EB research.

5-year-old Elodie Kubik suffers from the life-threatening genetic disorder Epidermolysis Bullosa (EB). Like all children born with EB, Elodie is missing a critical protein that binds the layers of her skin together, making it extremely fragile like the wings of a butterfly - and causing constant pain and severe internal and external wounds. **Today, there are no treatments or a cure for this devastating disease. The only option for care are extensive bandages that are changed twice daily.**

However, thanks to the work of the EB Research Partnership (EBRP), hope is on the horizon: promising clinical trials are in progress, with the goal of treating, and ultimately healing, EB.

The Plunge for Elodie has become a global movement, with a main Plunge in Wellesley, Massachusetts and satellite Plunges around the country. We welcome Plungers and spectators young and old to join us in any of our Plunge locations as we make waves for a cause. And for those who cannot join us live, we encourage you to take a *Virtual Plunge* for Elodie – plunge into any body of water (get creative!) and post your *Virtual Plunge* video to Instagram between February 28 -- March 27, 2022. Tag @plungeforelodie, hashtag #plungeforelodie in your post.

This year, we proudly announce the 1st Annual **Sophia's Hope Award**, created in honor of 1-year-old Sophia Ramsey who lost her battle with EB but whose legacy lives on. Our 2022 award recipient, Mike Fish, has shown a steadfast devotion to the cause since year 1. He has Plunged with us each year and donated countless hours to the cause. Thank you, Mike; and thank you to *all* those who help us make a splash for EB.

VISIT WWW.PLUNGEFORELODIE.ORG TO LEARN MORE AND DONATE NOW!

EVENT DETAILS



The 5th Annual Plunge for Elodie – Details at a Glance:

- ❖ **March 26 – 27, 2022.** Main Plunge in Massachusetts, with satellite Plunges in North Carolina, Connecticut and New York, with a global *Virtual* Plunge movement on social media.
- ❖ All “live” Plunge events are open to the public and welcome Plungers and spectators young and old. There is no fee to participate.
- ❖ Multi-channel Plunge promotion efforts planned, with extensive media coverage before, during, and after Plunge weekend.
- ❖ *Virtual* Plunge for Elodie details: *Virtual* Plungers should take the Plunge into any body of water (creativity encouraged!). Share your video on social media between National Rare Disease Day, February 28 – March 27, 2022 Tag @plungeforelodie, hashtag #plungeforelodie in your post.
- ❖ Visit www.plungeforelodie.org to make a donation to the cause. And, help us spread awareness: Follow @plungeforelodie on Instagram and Facebook; like, comment on, or share our posts!
- ❖ In 2022, our fundraising goal is \$200,000 – with even more global eyes on this worthy cause. **This will bring us to over \$1 million raised for the cause in just 5 years.**
- ❖ **Join us in making history – and accelerating treatments and a cure for EB.**



EVENT HISTORY

After Elodie Kubik was born with recessive dystrophic epidermolysis bullosa in 2016, Elodie's mom's family and friends from high school sprung to action. As we learned about EB and the larger rare disease community, it became clear how desperately diseases like EB need robust funding to find treatments and a cure.

We hosted the first Plunge for Elodie in 2018 and are now in our 5th consecutive year. The event has grown beyond our wildest dreams as we near \$1 million raised. This event has become an opportunity to fund critical research and trials aimed at curing rare diseases, and it has united communities as we all come together and do something brave for a worthy cause. We will continue to do all we can to make waves for this cause, and we look forward to celebrating together when EB is cured.

With thanks for your support,

THE 2022 PLUNGE FOR ELODIE COMMITTEE

Emily St. Thomas Kubik

Bill Weidlein

Tim & Katie Ramsey

Elizabeth Krupp Fish

Kristan Fletcher Khtikian

Kate Boardman Hall

Kristin Dutcher Jonash

Alissa Tofias

Julie Febiger

Jane Crowley Cullinan

Caitlin Brennan Layng

Jaclyn Gilman Reich

Jennifer Keiser Neundorfer





Introducing the 1st Annual Sophia's Hope Award

This year we lovingly introduce the 1st Annual **Sophia's Hope Award**. This Award celebrates the life of 1-year-old Sophia Grace Ramsey who lost her battle with EB in 2020, but whose light and legacy live on.

Our 2022 honoree, Mike Fish, has shown a steadfast devotion to the Plunge for Elodie every front. We thank Mike for his contributions, we and look forward to honoring him on March 27th.

Follow @Sophiasebhope on Instagram and Facebook to learn more Sophia's family's mission to help cure EB in her memory.

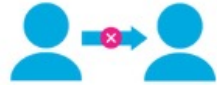


ABOUT EB



EB is a family of genetic disorders.

EB is not specific to any ethnicity or gender.



EB is not contagious.

EB is a chronic disease.



EB is estimated to affect 500,000 individuals worldwide.



Four Types of EB

1 EB Simplex (EBS)

- Most common type of EB
- Blisters form in the epidermis
- Caused by mutations in the genes **KRT5** or **KRT14**, which make the proteins **keratin 5** and **keratin 14**.
- Four major subtypes: Localized, Dowling-Meara, Generalized, EBS with Mottled Pigmentation
- Depending on subtype:
 - Mild to severe symptoms
 - Blisters commonly found on hands and feet, but can be widespread

2 Junctional (JEB)

- Blisters form between the dermis and epidermis, in the basement membrane zone
- Blisters occur on the skin and inside the body
- Caused by mutations in the genes **LAMA3**, **LAMB3**, **LAMC2**, which make the protein **laminin 332**, and the gene **COL17A1**, which makes the protein **collagen 17**.
- Two subtypes:
 - **Herlitz**
 - Severe symptoms
 - Often fatal in infancy
 - **Non-Herlitz**
 - Mild symptoms
 - Normal life expectancy

3 Dystrophic EB (DEB)

- Blisters form in the dermis
- Mild to severe symptoms
- Caused by mutations in the gene **COL7A1**, which makes the protein **collagen 7**.
- Two main subtypes:
 - **Dominant**
 - Blisters generally occur on hands, elbows, knees, and feet
 - **Recessive**
 - Blisters occur on the skin and inside the body
 - Increased risk for squamous cell carcinoma
 - Life expectancy is age 30

4 Kindler Syndrome

- Rarest type of EB
- Blisters form in any skin layer and internal organs
- Caused by mutations in the gene **FERMT1**, which makes the protein **kindlin-1**.
- High sensitivity to UV rays from the sun
- Increased risk for squamous cell carcinoma, especially in the mouth.

WITH MORE THAN 7,000 RARE DISEASES AFFECTING 400 MILLION PEOPLE WORLDWIDE, RARE DISEASE IS EVERYWHERE. FIND OUT JUST HOW FAR RARE DISEASES REACH.



You are not alone. These RARE facts show the impact of rare disease. Share these statistics with your communities to let them know that rare really is everywhere.

1 in 10

People are Affected by Rare Disease

1 in 2

Rare Diseases Don't Have a Foundation or Research Support Group

1 in 2

Patients Diagnosed with a Rare Disease is a Child

3 in 10

Children with a Rare Disease Won't Live to See Their 5th Birthday

350

Million People Suffer From a Rare Disease Globally (greater than the population of the U.S.)

8 in 10

Rare Diseases are Caused by a Faulty Gene

8 Years:

The Average Time it Takes for Rare Patients to Receive an Accurate Diagnosis

95%

of Rare Diseases Lack an FDA Approved Treatment

RARE

Diseases Impact More People Than Cancer and AIDS Combined

7000

Types of Rare Diseases

ABOUT EB RESEARCH PARTNERSHIP

Beneficiary of All Plunge for Elodie Funds

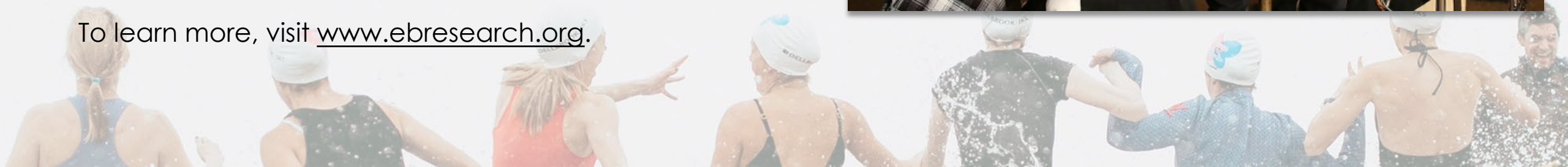


Founded in 2010 by a dedicated group of parents and Jill and Eddie Vedder, EB Research Partnership (EBRP) is the largest global non-profit dedicated to funding research aimed at treating and ultimately curing Epidermolysis Bullosa (EB), a group of devastating and life-threatening skin disorders that affect children from birth.

Working around the clock with offices in the US and Australia, EBRP utilizes an innovative venture philanthropy business model. 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, visit www.ebresearch.org.



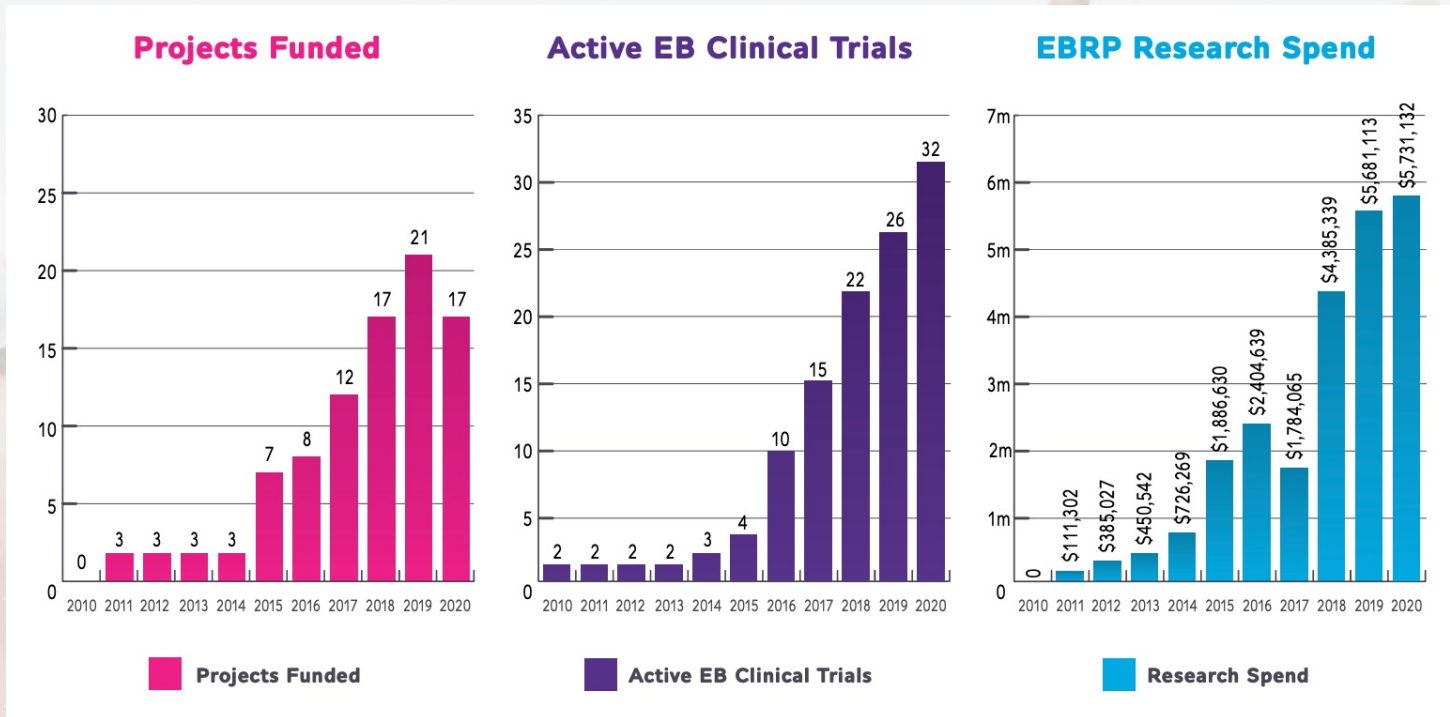
PROGRESS TO A CURE

Since EBRP was founded in 2010, they have raised over \$40M for 100 research projects with potential to treat and cure EB, transforming the clinical landscape from just 2 clinical trials to over 30 today. For the first time ever, there are 4 clinical trials in Phase 3, the final phase before approval by the FDA.

100
TOTAL EB RESEARCH
PROJECTS FUNDED

\$40M
RAISED FOR CRITICAL
EB RESEARCH

15X
THE NUMBER OF ACTIVE CLINICAL
TRIALS IN EB SINCE FOUNDING



EBRP IS FUNDING RESEARCH AND SUPPORTING BIOTECH IN MASSACHUSETTS

- ❖ EBRP has funded over \$2.4 million in research projects in Massachusetts in near-term, including \$500,000 in FIBRX funding, at institutions such as UMass and Tufts
- ❖ UMass participates in EBRP's research consortium, which is made up of 21 institutions globally that collect necessary data to support patients and trials
- ❖ Supporting Massachusetts-based biotech companies such as Constant Therapeutics, Phoenix Tissue Repair and Fibrx Tissue Repair, is a focus for EBRP.





OPPORTUNITY

Your company can be a part of this mission to raise awareness and funds towards **treatments, and a cure**, for this devastating rare disease – and so many other rare diseases as well. JOIN US AS WE MAKE WAVES.

- ❖ Gain **positive visibility** through any level of sponsorship for the live – and virtual – events and movement
- ❖ Be among corporations demonstrating their **commitment and compassion for curing rare diseases** that overwhelmingly affect children
- ❖ Amazing opportunity to **raise brand awareness and achieve valuable visibility** through multi-channel Plunge promotions including: website, extensive local and national media coverage, wide-reaching social media campaign, and marketing materials
- ❖ Significant Sponsor recognition opportunities – see *the next slides for Sponsorship Levels*





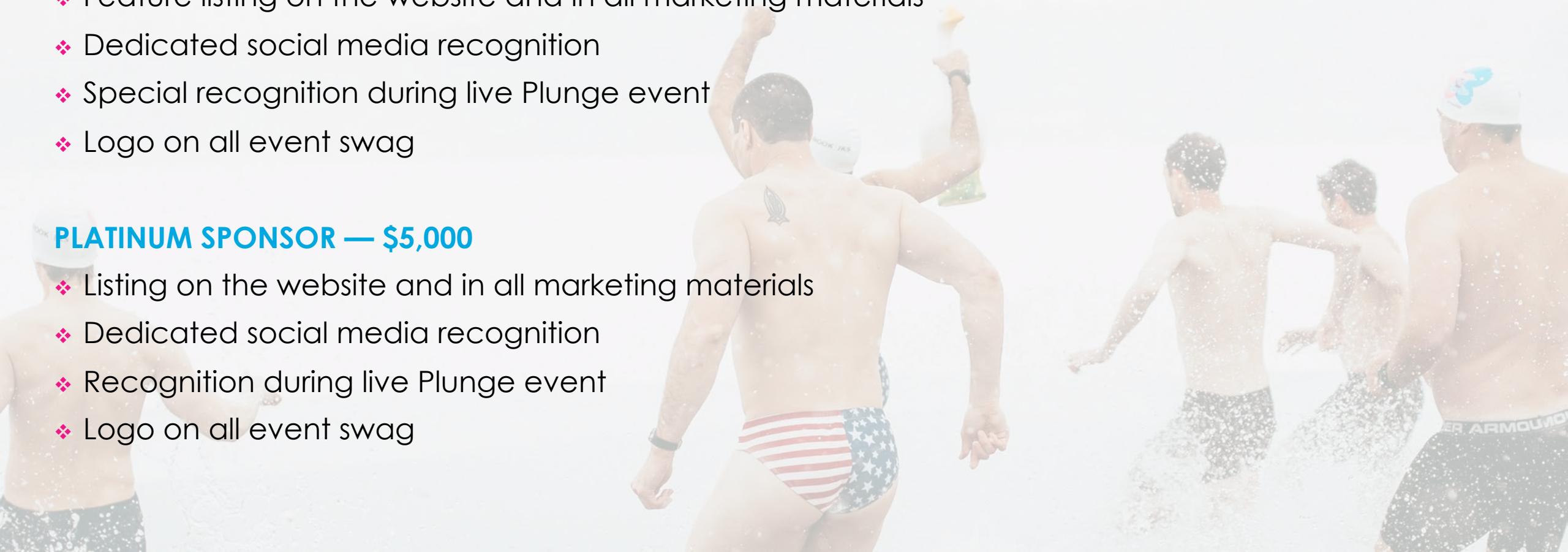
SPONSORSHIP LEVELS

TITLE SPONSOR — \$10,000

- ❖ Website banner: “The Plunge for Elodie, Brought to you by X (your company)”
- ❖ Feature listing on the website and in all marketing materials
- ❖ Dedicated social media recognition
- ❖ Special recognition during live Plunge event
- ❖ Logo on all event swag

PLATINUM SPONSOR — \$5,000

- ❖ Listing on the website and in all marketing materials
- ❖ Dedicated social media recognition
- ❖ Recognition during live Plunge event
- ❖ Logo on all event swag





SPONSORSHIP LEVELS

GOLD SPONSOR – \$2,500

- ❖ Listing on the website and in all marketing materials
- ❖ Recognition on social media
- ❖ Recognition during live Plunge event

SILVER SPONSOR – \$1,000

- ❖ Listing on the website and in all marketing materials
- ❖ Recognition on social media

FRIEND – \$500

- ❖ Listing on the website and in all marketing materials





LAST YEAR'S SPONSORS (2021)



RENNER CONSULTING LLC



CHOATE



FITCH



2021 SPONSOR LIST:

TITLE SPONSORS

Dellbrook JKS
Trans National Group

GOLD SPONSORS

CIBC
CBIZ
Renner Consulting
Choate
Castle Creek Biosciences
Abeona

SILVER SPONSORS

RINET
Fitch Law
Hayes Companies



PRESS HITS

PLUNGE FOR ELODIE 2021

Despite the pandemic and the cold, Elodie's champions plunge into Morses Pond

Cathy Brauner Wicked Local
Published 10:45 a.m. ET March 15, 2021 | Up

WICKEDLOCAL.com



5 for Good: Virtual polar plunge fights rare genetic condition

The Plunge for Elodie raises funds to research treatments, cures for epidermolysis bullosa



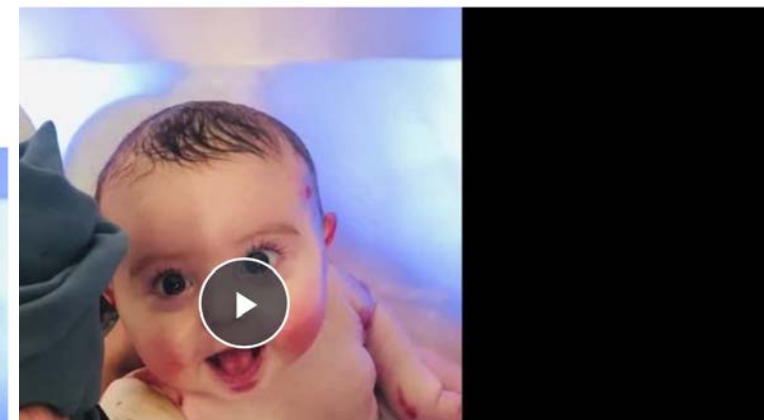
WCVB 5 Updated: 5:00 PM EDT Mar 15, 2021



Monroe couple fights EB to keep daughter Sophia's memory alive

By Bill B

The Monroe Sun



WELLESLEY TOWNSMAN

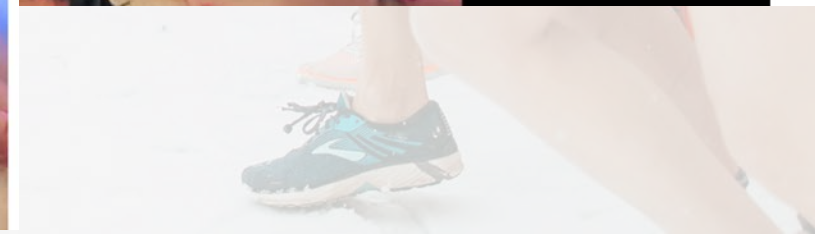
The Fourth Annual Plunge for Elodie goes virtual

Cathy Brauner Wicked Local
Published 2:25 p.m. ET March 2, 2021 | Updated 3:31 p.m. ET March 2, 2021



Most people have never heard of Recessive Dystrophic Epidermolysis Bullosa (EB), a rare and devastating condition that leaves the children born with it in constant pain and shortens their lives. But in Wellesley, helping to find a cure for EB started as a community cause that has since gone global.

At the center of this determination is Elodie Kubik of Connecticut, whose condition was diagnosed immediately after she was born on July 15, 2016 to Dave and Emily (St. Thomas) Kubik. Emily grew up on Norwich Road in Wellesley, where she formed a tight-knit group of friends from the Class of 1999.





PRESS HITS

PLUNGE FOR ELODIE 2021



The Swellesley Report

More than you really want to know about Wellesley, Mass.

Plunge for Elodie

March 28, 2021 @ 8:00 am - 5:00 pm

THE 4TH ANNUAL virtual

Plunge for Elodie

in honor of Sophia Ramsey

[click to join](#)

MARCH 28, 2021

Make waves with us for this worthy cause at



- NEWS
- WEATHER
- INVESTIGATIVE
- CORONAVIRUS

Monroe family spreads awareness about rare genetic skin disorder

Mar 23, 2021, 11:11pm • Updated on Mar 23, 2021

By: News 12 Staff



Katie Ramsey and husband, Tim, are hoping Newtown and area residents will take part in an event to support research for the very rare childhood illness **junctional epidermolysis bullosa**. Their daughter, Sophia, was born with the genetic illness, "which is debilitating, painful, and terminal in early childhood," Kate shares. "She was enrolled in a clinical trial that gave her months of joy despite all her pain, but it was not enough to save her. We continue fighting each day for a cure in Sophia's memory, and for all the children living with EB who desperately need treatments and a cure."

Through March 28, supporters are asked "to make waves for EB research by recording themselves running into a nearby lake or ocean, splashing themselves with water at home, or anything else they can think of and posting it to social media tagging @plungeforelodie @ebresearch @sophias.eb.hope and with #PlungeForElodie2021.

"The Plunge for Elodie event was created four years ago when a Connecticut family had a daughter [Elodie] born with recessive dystrophic epidermolysis bullosa, which is another debilitating and life limiting form of EB. The event partners with the EB Research Partnership to provide funding for clinical trials searching for viable treatments and a cure for Elodie and for all those with EB," Katie tells us.



PRESS HITS

PLUNGE FOR ELODIE 2020



POPSUGAR. FAMILY

A Little Girl's Life Expectancy Is 30 Due to a Rare Genetic Condition; Now Her Family's Trying to Find a Cure



March 3, 2020
by MURPHY MORONEY

444 Shares



ctpost

LOCAL

Rare skin disease won't stop Greenwich toddler



Tatiana Flowers
March 5, 2020 | Updated: March 6, 2020 12:53 a.m.





PRESS HITS

PLUNGE FOR ELODIE 2020

The Boston Globe

Wellesley residents support fund-raiser for 'Butterfly Children'

By Meghan Sorensen Globe Correspondent, Updated March 27, 2020, 1:55 p.m.



A fund-raiser known as [Plunge for Elodie](#) has raised over \$600,000 for research into a rare and presently incurable skin disease called Epidermolysis bullosa (EB) that notoriously makes children's skin as thin as a butterfly wing.

Plunge for Elodie was started in March 2018 after Emily St. Thomas Kubik's infant daughter, Elodie, was diagnosed with a severe skin condition.

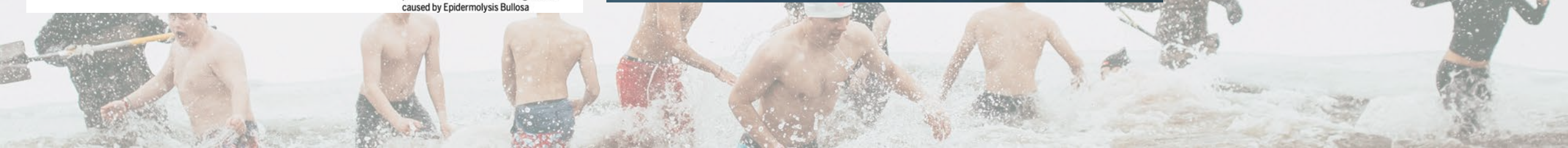
Soon after Elodie Kubik was born in July 2016, she was diagnosed with recessive dystrophic epidermolysis bullosa. EB is a family of rare connective tissue disorders that affects one out of every 20,000 births in the United States.



Elodie Kubik is wrapped up in bandages to protect her skin from the damage that is caused by Epidermolysis Bullosa

Wellesley taking to Morses Pond again for the sake of Elodie

WICKEDLOCAL.com





PRESS HITS

PLUNGE FOR ELODIE 2020



The Swellesley Report

More than you really want to know about Wellesley, Mass.

3rd annual Polar Plunge at Morses Pond in Wellesley to benefit Elodie

March 2, 2020 by [Deborah Brown](#) — [Leave a Comment](#)

WELLESLEY PUBLIC MEDIA

Take The Plunge!

MARCH 7, 2020

WELLESLEY, MA

PLUNGE

8:30am | Morses Pond Beach

CELEBRATION

9:00am | Wellesley College Club

No registration required to plunge; plungers must sign a waiver at the event site

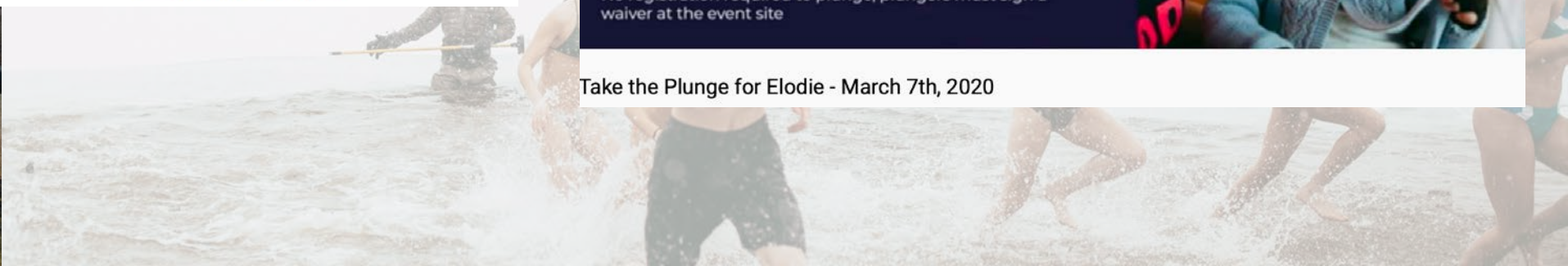
3-year-old Elodie suffers from the life-threatening genetic disorder Epidermolysis Bullosa (EB), which makes the skin extremely fragile and leads to severe pain and wounds. Today there are no treatments or cure, and children's lives are cut devastatingly short. Join us as we make waves to Heal EB, for Elodie and all those who suffer from this disorder.



Take the Plunge for Elodie - March 7th, 2020

Wellesley's Morse's Pond Plunge -- private version -- goes on

WICKEDLOCAL.com





PAST PRESS hits for the Annual Plunge for Elodie

OVER 6 MILLION IMPRESSIONS IN JUST 4 YEARS...AND MORE TO COME

The Boston Globe

BRIT + CO

WCVB 5 abc
BOSTON'S NEWS LEADER

Mom.me

NEWS

'Butterfly' Toddler Has One of the Worst Diseases You've Never Heard Of

By Angelica Lai | Mar 21, 2018

People

FOX 8

Life & Style WEEKLY

WICKED LOCAL HINGHAM
NEWS FROM THE HINGHAM JOURNAL

Harbor Media

Macaroni Kid

Wellesley Weston MAGAZINE



the Improper Bostonian



MEDIA HIGHLIGHTS

OVER 6 MILLION IMPRESSIONS IN JUST 4 YEARS, INCLUDING...

3.4 Million +SUBSCRIBERS



PARENTS FIGHT TO FIND CURE FOR TODDLER SUFFERING FROM RARE SKIN DISEASE: SHE'S COVERED IN 'WOUNDS'

MARCH 15, 2018

People Health covered this story on Elodie Kubik, a two-year old with RDEB, and her family's experience with EB. Friends of the Kubiks started the Plunge for Elodie, a polar plunge, to raise awareness for EB and funds for EB Research Partnership. Actress Jessica Biel joined in on the action by plunging into her own swimming pool and posting a video on social media. Read more about the Kubiks and the Plunge for Elodie [here](#).

READ MORE

2 Million + SUBSCRIBERS



JESSICA BIEL JUST INTRODUCED US TO THE NEXT ICE BUCKET CHALLENGE

MARCH 4, 2018

Actress Jessica Biel took the Plunge For Elodie into her swimming pool and posted the video on social media to show her support for Elodie, a baby girl with RDEB. The Plunge for Elodie was started by lifelong friends of EBRP Board Member and Elodie's mother, Emily Kubik.

Read Brit + Co's article and watch Biel's plunge [here](#).

READ MORE

223,000 + SUBSCRIBERS



IN HINGHAM, FRIENDS PLAN TO 'PLUNGE FOR ELODIE'

FEBRUARY 23, 2018

The Boston Globe covered [this](#) heartwarming story of Board Member Emily Kubik and her lifelong friends who came together to find a cure for Kubik's daughter Elodie, a 19-month-old with RDEB. The friends planned to 'Plunge for Elodie' and have raised over \$108,000 and counting. They will take a polar plunge into the chilly waters of Hingham Bathing Beach in Hingham, MA on Saturday, March 3rd.

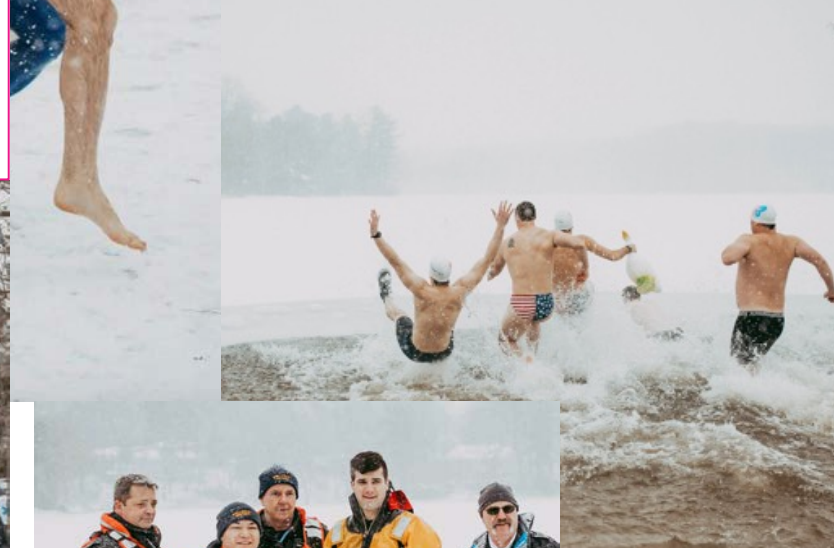
READ MORE

10.4 Million + SOCIAL MEDIA FOLLOWERS





**MAKE WAVES WITH US!
TOGETHER WE CAN HEAL EB**





CONTACT INFORMATION

Visit the **Plunge for Elodie** website: www.plungeforelodie.org

Follow the **Plunge for Elodie** on [Facebook](#) and [Instagram](#)
@PlungeforElodie. Also follow the EBRP on Instagram
[@EBResearch](#).

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Emily Kubik (Elodie's mom)
emilystt@gmail.com
415/595-4776

