

2023 CORPORATE PARTNERSHIPS

Annual <u>Plunge for Elodie</u>

March 25-April 2

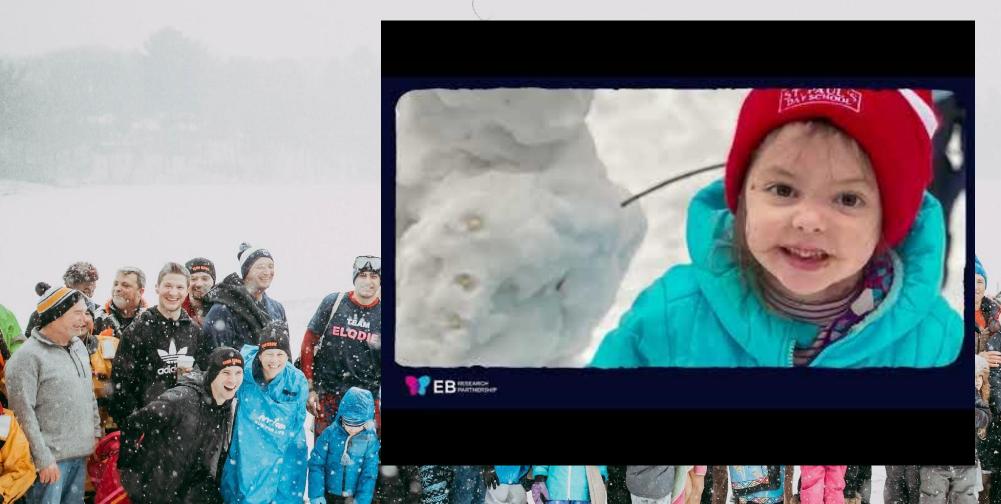
Making waves for children suffering from the rare genetic disorder Epidermolysis Bullosa (EB)

www.plungeforelodie.org





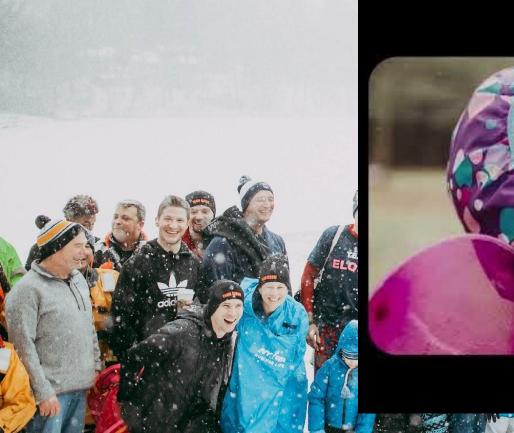
Introducing The Plunge for Elodie Watch here





More about The Plunge for Elodie, and the young girl who inspired a movement

Watch here







PLUNGE FOR ELODIE MISSION

- * RAISE AWARENESS. Raise awareness for the life-threatening rare disease Epidermolysis Bullosa (EB).
- * RAISE CRITICAL FUNDS. We have raised \$1.6 million in just 5 years' time. In 2023, hit \$2 million raised for the EB Research Partnership (EBRP) by this event.
- ♦ EFFECT CHANGE. Every dollar goes to the EBRP, which funds research and trials aimed at treating and, ultimately, curing EB. This vital work applies to many other rare diseases too, which impact over 350 million people globally, 50% of whom are children.
- * HONOR OUR CHAMPIONS. 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 2nd Annual Sophia Grace Ramsey Award, which will be presented to Steve and Joan Belkin.





PLUNGE FOR ELODIE – BACKGROUND

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.

OUR STORY

Named after 6-year-old Elodie Kubik, who lives with a severe form of EB, 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 with multiple satellite Plunges and has surpassed \$1.5 million raised for critical research aimed at curing EB and other rare diseases. Help us reach our 2023 goal of \$2,000,000 total. We are dedicated to plunging and raising awareness until a cure is reached!

JOIN US!

Join us for the 6th annual Plunge for Elodie, an event to raise awareness and funds for critical research to treat and cure Epidermolysis Bullosa (EB). Participants plunge into chilly bodies of water and create fundraising teams to help heal EB. This year's plunge events will take place in Connecticut, Massachusetts, North Carolina, California, and New York, with even more locations to be announced. Even if you're unable to attend an in-person plunge, you're still encouraged to join the fun from wherever you are with our virtual plunge!



2023 PLUNGE LOCATIONS

Come Plunge with us! Don't see a location near you? Join us virtually or start your own Plunge!

San Francisco, California

Date: Saturday, March 25, 2023

Greensboro, North Carolina

Date: Saturday, March 25, 2023

Wellesley, Massachusetts

Date: Sunday, March 26, 2023

Old Greenwich, Connecticut

Date: Sunday, April 2, 2023

Breezy Point, New York

Date: Sunday, April 2, 2023

- Additional Satellite Plunge locations to come, including Plunge for Elodie's first international Plunges!
- Virtual Plunges on social media

Visit: www.plungeforelodie.org to learn more about our satellite Plunges and out Virtual Plunges for Elodie.

EVENT HISTORY

Elodie Kubik was born with recessive dystrophic epidermolysis bullosa in 2016. As Elodie's mom's friends learned about EB and the larger rare disease community, it became clear how desperately diseases like EB need robust funding to find treatments and cures.

The 1st Plunge for Elodie was held in 2018. Now in our 6th consecutive year, the event has raised over \$1.6 million and has grown beyond our wildest dreams. The Plunge has become an opportunity to fund critical research and trials aimed at curing rare diseases, and it has united communities as we do something brave, collectively, for a worthy cause. We will continue to do all we can to make waves, and we look forward to the day when EB is cured.

With thanks for your support,

THE 2023 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



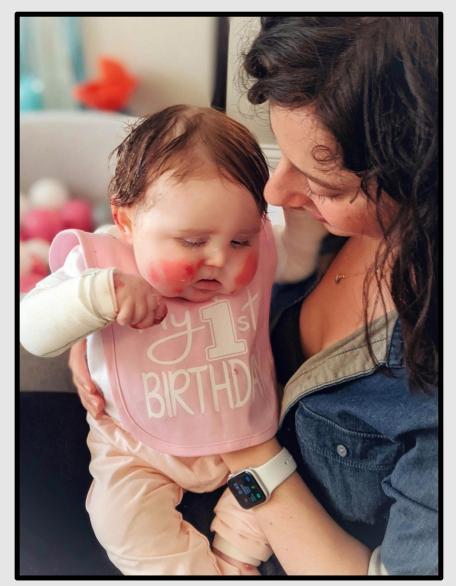


Introducing the 2nd Annual Sophia Grace Ramsey Award

This year we lovingly announce the 2nd Annual **Sophia Grace Ramsey Award.** This Award honor an integral contributor to the Plunge for Elodie mission.

Our 2022 honoree was Mike Fish, who has been devoted to the Plunge cause since 2018.

In 2023, we honor **Steve and Joan Belkin**. Together with TransNational Group and Belkin Family Outlook Farm, the Belkins have been tremendous supporters of the Plunge. It is because of people like them that this event has become so supremely impactful. Thank you Steve and Joan!



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.**= 10**

People are Affected by Rare Disease

1.=2

Rare Diseases Don't Have a Foundation or Research Support Group 157

Patients Diagnosed with a Rare Disease is a Child

3=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=10

Rare Diseases are Caused by a Faulty Gene 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.





EBRP IS FUNDING RESEARCH AND ACCELERATING A CURE FOR EB

- Over the last 12 years, EBRP has 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 2022, 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.
- These projects 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.



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 this live and viral event 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 event promotion including Plunge website, extensive local and national media coverage, wide-reaching social media coverage, 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 signage

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 signage



SPONSORSHIP LEVELS

GOLD SPONSOR - \$2,500

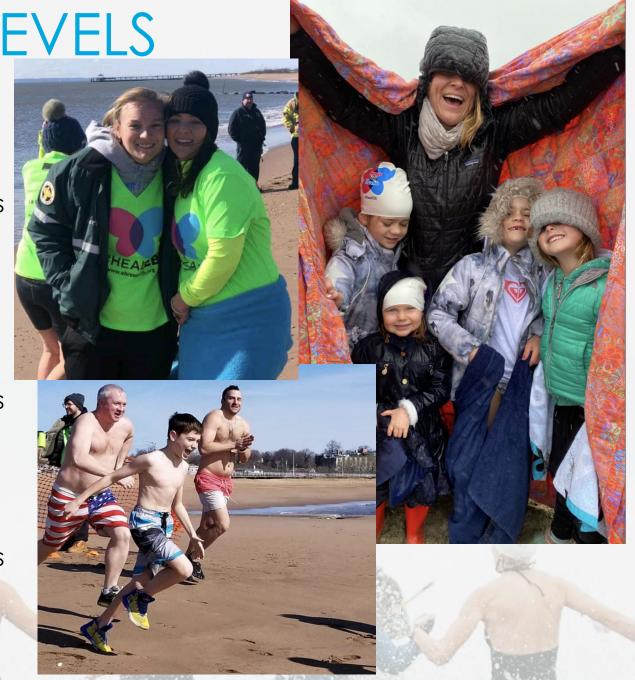
- Listing on the website and in all marketing materials
- Recognition on social media
- Recognition during live Plunge event

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 (2022)

DELLBROOK JKS



UNIBANK











RENNER CONSULTING LLC



2022 SPONSOR LIST:

TITLE SPONSORS

Dellbrook JKS Belkin Family Lookout Farm

PLATINUM SPONSORS

Amryt Pharma UNIBANK **Premier Dermatology**

GOLD SPONSORS

allways Health Partners **CIBC**

Castle Creek Biosciences

SILVER SPONSORS

CBIZ D&M Civil Renner Consulting LLC



PRESS HITS

PLUNGE FOR ELODIE 2022





Plunge for Elodie held at Morses Pond Beach in Wellesley The fifth annual Plunge for Elodie was held in Wellesley on March 27, 2022. Tommy Cassell, Wochit

WELLESLEY - Elodie doesn't like bath time.

Normally a fun activity for children, Elodie thinks bathing is scary. That's because the 5-year-old from Connecticut has a rare skin disease that makes it painful to soak in the tub.





Products

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Announcing the 5th Annual Virtual Plunge for Elodie March 26 - 27, 2022

A Small Hometown Fundraiser Evolves Into a Global Movement that Will Surpass \$1 M Raised for the Life-Threatening Rare Disease Epidermolysis Bullosa (EB)

NEWS PROVIDED BY EB Research Partnership → Mar 10, 2022, 11:21 ET

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WICKEDLOCAL.com

Wellesley football, track and field teams take the Plunge for Elodie at Morses Pond Beach

6 PHOTOS

4:10 p.m. EDT Mar. 27, 2022









\$1 for 6 months



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Plunge for Elodie held at Morses Pond Beach in Wellesley

The fifth annual Plunge for Elodie was held in Wellesley on March 27, 2022.

Tommy Cassell Tommy Cassell, Wochit

Published 4:58 p.m. ET March 27, 2022



PRESS HITS PLUNGE FOR ELODIE 2022





For Immediate Release

GAC to host 'Plunge for Elodie' fundraiser on Saturday

(Greensboro, NC) - The Greensboro Aquatic Center (GAC) will serve as one of several locations across the country as a site for the 5th annual 'Plunge for Elodie' fundraising event on Saturday, March 26.

This now-global movement invites participants to plunge into waters to fundraise for the lifethreatening rare genetic disorder Epidermolysis Bullosa (EB). Called "Butterfly Children" because their skin is as fragile as the wings of a butterfly, children with EB face severe pain, open external and internal wounds, and a grueling daily bandaging process. Elodie is 1 of 500,000 people in the world suffering from EB, and she faces a life expectancy of just 30 years old.

The plunge at the GAC is being held in honor of Brooks Kendrick, a two-year-old Greensboro boy, who also has this skin disorder. Brooks has a milder subtype of EB but there is no "good EB". The disease affects his life on a daily basis. The GAC is hosting this event to help find/fund a cure for all children with EB - "the worst disease you have never heard of".

Individuals can participate in the plunge from 12 - 2 p.m. on Saturday at the GAC. The event is free and open to all ages. A group jump is planned for 12:45 p.m. Donations are encouraged and can be made in person or online prior to or following the event.

Please visit the Plunge for Elodie website for more information and to make a donation.

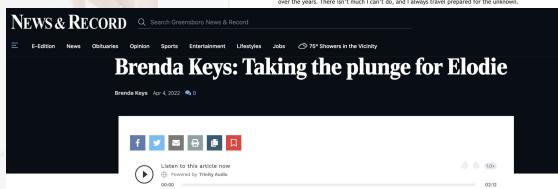
What began as a small hometown fundraiser now includes four national Plunge locations: a main Plunge in Massachusetts plus satellite Plunges in North Carolina (including the Greensboro Aquatic Center), New York, and Connecticut, and a far-reaching Virtual Plunge campaign on social media.





3. What are some challenges, if any, that you've faced as an individual with EB? How do you learn to

I have always been aware that there were certain activities I could not participate in and shoes that would rub blisters on my feet. I have also learned that's OK. I used to get upset when it would take a lot of care. soaking, and time to heal from large wounds. Eventually, I learned to enjoy that time as "me time" while watching my favorite shows on TV. Cute shoes are my biggest adversary, but that has changed quite a bit over the years. There isn't much I can't do, and I always travel prepared for the unknown.



he Plunge for Elodie, in honor of our grandson, Brooks Kendrick, was held March 26 at the Greensboro Aquatic Center. This event, started in Wellesley, Mass., and now becoming a global phenomenon, encourages participants to plunge into bodies of water to raise awareness and funds for critical research to treat and cure epidermolysis bullosa (EB).

Two-year-old Brooks has this rare genetic skin disease, as does Elodie Kubik. This vear the fifth annual Plunge for Elodie will surpass \$1 million raised for research. We are excited to be a part of this!

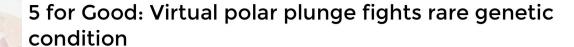


Despite the pandemic and the cold, **Elodie's champions plunge into Morses Pond**

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







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











Updated: 5:00 PM EDT Mar 15, 2021



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 tightknit group of friends from the Class of

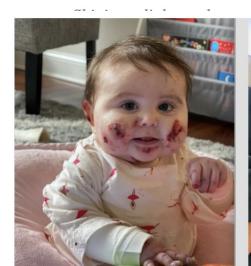




By **Bill B**



The Monroe Sun













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



click to join

MARCH 28, 2021



Make waves with us for this worthy cause at



news12

NEWS

WEATHER

INVESTIGATIVE

CORONAVIRU

Monroe family spreads awareness about rare genetic skin disorder

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

By: News 12 Staff





The Newtown Bee Since 1877 – Best for Local News and Advertising

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 talls us



PRESS HITS

PLUNGE FOR ELODIE 2020



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





















Rare skin disease won't stop Greenwich toddler



Tatiana Flowers

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

















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













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

WICKEDLOCAL.com





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Parents Fight to Find Cure for Toddler Suffering From Rare Skin Disease: She's Covered in 'Wounds'

Emily and David Kubik are doing all they can to cure their daughter Elodie of a rare skin condition that leaves her covered in wounds and blisters

By Char Adams | Published on March 15, 2018 05:04 PM





PAST PRESS hits for the Annual Plunge for Elodie

OVER 6 MILLION IMPRESSIONS IN JUST 5 YEARS...AND MORE TO COME

The Boston Globe BRIT+CO



Mom.me

NEW!

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

By Angelica Lai | Mar 21, 2018





















MEDIA HIGHLIGHTS

OVER 20 MILLION IMPRESSIONS IN JUST 6 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

READ MORE

People Health covered this story on Elodie Kubik, a two-year old with RDEB, and her family's exeperience 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.

223,000 + SUBSCRIBERS



READ MORE

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-monthold 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.

2 Million + SUBSCRIBERS

JESSICA BIEL JUST INTRODUCED US TO **BRIT+CO** THE NEXT ICE BUCKET CHALLENGE

MARCH 4, 2018

READ MORE

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.

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 <u>Facebook</u> and <u>Instagram</u> @PlungeforElodie. Also follow the EBRP on Instagram <u>@EBResearch</u>.

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