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WELCOME

We're so excited to welcome you to the EB Active community! EB Active is a way for you to create your own event in your community to raise money for EB Research Partnership.

EB Research Partnership is the largest nonprofit funding research aimed at treating and ultimately curing Epidermolysis Bullosa.

We will provide you with tips and materials to help you EB Active and create the most successful event possible.

Past events hosted by community members have included polar plunges, 5Ks, marathons, galas, and more. There are no fundraising minimums. We encourage you to EB Active at any level!

Why EB Active: When you donate to EBRP, your donation will go directly towards funding critical research that could change the lives of the 500,000 people around the world living with EB.
ABOUT EBRP

EBRP was founded in 2010 by a group of parents set out to save their children’s lives along with Jill and Eddie Vedder (Pearl Jam) with one bold audacious goal: cure the devastating and life-threatening genetic rare skin disease epidermolysis bullosa (EB) by 2030 and in the process pioneer an innovative business model to lead the way for 7,000 rare diseases that affect 400 million people.

EBRP utilizes an innovative business model of venture philanthropy. When making a grant to a research project we retain the added upside of generating an additional revenue stream if the therapy or product is commercially successful, and use the return on investment to fund additional EB research until a cure is found.

Since our inception, we have raised over $40 million to fund over 100 EB research projects and the number of clinical trials in EB has increased more than 20 times, from just 2 clinical trials in 2010 to nearly 40 today.
GETTING STARTED

SET YOUR GOALS

- I will raise $________ by this date __________.
- I will contact _______ people in order to reach my goal.

For example, Your goal is to raise $3,000. You estimate the average contribution will be $50. If 50% of the people you reach out to contribute, you will need to reach 120 people to meet your goal.

CREATE A FUNDRAISING PAGE

- Click HERE for more information on starting your personal fundraising page
- Be sure to include a story connecting yourself to the cause

CREATE AND IMPLEMENT A FUNDRAISING PLAN

- Maximize your success by:
  - Running an email campaign
  - Asking for gifts
  - Hosting an event
  - Involving your company
  - Asking for help

CONNECT WITH EBRP ON SOCIAL MEDIA

- Find other EB Active community members and get inspired by their stories
KEYS TO FUNDRAISING SUCCESS

Make it Personal
- Personalize your fundraising page with a picture, story and video.

Follow Up
- Most donors will not give until the third time they are asked. Send out multiple emails to friends and family and post to social media regularly.

Plan an Event
- Host a fundraising event at your favorite community establishment and invite all your friends and family.

Hold a Raffle
- Ask local businesses for a gift-in-kind, support or sponsorship and sell raffle tickets for a chance to win these prizes.
KEYS TO FUNDRAISING SUCCESS CONT.

Share EBRP’s Mission
- Use stories and pictures from EBRP in your outreach to potential donors.

Set Clear Goals and Deadlines
- If you create a plan and stick to it, you will be amazed at how quickly you can achieve your goals.

Diversify
- Use a mix of email, phone calls, personal letters, notes and social media or host an event; the more fundraising ideas you use the better your chances are for success.

Thank your Donors
- Your donors will receive a “Thank You” from EBRP, but don’t stop there. It’s important to send a personal thank you to let them know how much you appreciate their support.
EMAIL FUNDRAISING

Manage your Address Book
• Keep track of everyone you've emailed and when, so you know when to follow up with them.

Don't Hold Back!
• Email everyone, from your family and friends to neighbors and colleagues to local businesses.

Tips for a Successful Email Campaign
• Make it personal. Briefly explain why EBRP is so important to you.
• Your subject line should be simple and cause related.
• Be sure to include the link to your fundraising page, and make it stand out.
• Educate your donors on your cause and stress the benefits of contributing.
• Always ask contacts to forward your email to others.
• Ask often and ask big!
• Keep donors updated on your progress through social media, a personal blog, or emails.
ASKING FOR SUPPORT

Five Easy Steps to Request Support:
1. Identify the need you are trying to address.
2. Explain why it is important to you.
3. Share how what you are doing will help address the need.
4. Ask your potential supporter to take a specific action.
5. That's it! Don't add more than you need to and let your potential support respond.

An Example of a Specific Request for Support:

Children with Epidermolysis Bullosa (EB) are often called "Butterfly Children," because their skin is as fragile as the wings of a butterfly. They lack critical proteins that bind the skin's two layers together causing their skin to tear, blister, and shear off, leading to severe pain and internal and external wounds that may never heal.

I'm running 13.1 miles in the NYC Half Marathon this March to help EBRP fund critical research that could forever change the lives of the 500,000 people around the world living with EB.

Will you help me reach my goal of $1,500 by making a donation today?
HOSTING AN EVENT

Define the Cause
• Share EBRP's mission but also share what you are doing to help and why: “I’m hosting a lemonade to support EBRP because I believe that the science they fund can and will cure EB by 2030 and save the lives of countless children.”

Set the Date and Time
• Check the availability of your friends and family and ensure there are no conflicts with other local events.

Know your Budget
• Make a robust list of all your potential costs, look at what you expect to raise, and how, and understand what your net will be (net = funds raised – expenses). Look for donations and sponsorships to help bring down costs.

Understand your Network and Community
• What do your friends and family like to do? Will your community be more likely to come out to an event at your local school, a 5K run, a bowling alley, a black tie gala, a golf tournament, etc.?
HOSTING AN EVENT CONT.

Choose the Venue

- Pick a place that is fun, fits your capacity requirements and is willing to work with you on pricing and promotion.

Get your Community Involved

- Ask local businesses for sponsorships or grants. Work with community groups to get volunteers and ask friends and local business to donate raffle items.

Promote

- Send out a save-the-date, put up flyers around town, craft a press release for local newspapers, send out emails and promote the event on social media.

Make it Educational

- Spread awareness of EB by putting up pictures from EBRP at your event and give a brief speech to the crowd to share the who, what, and why of the mission.

Have fun!
IN Volving Your Company

Matching Gifts
- Employee matching gifts (also known as matching funds) are grants an employer makes to match its employees’ charitable contributions. Check with your company on their matching gifts policy.

Start a Corporate Team
- Engage your fellow employees by creating a fundraising team together for one of our events, or for your own event. You can also create multiple teams within your company hold a fundraising competition!

Additional Opportunities
- EBRP's CEO would love to discuss further options for company involvement including:
  - Exclusive volunteer opportunities
  - Branding and presence marketing at EBRP events.
  - Recognition at EBRP events.
  - Spotlight articles in EBRP's newsletter updates.
HOW EBRP CAN HELP

We are happy to provide the following resources for use in your fundraising efforts:

- EBRP logo and photos
- A personal fundraising page
- A letter of support to be used to validate the authenticity and intention of your event and fundraising efforts.
- Example Donation Request and Thank You letters.
- Fundraising tips and advice

Please contact the EBRP Team at info@ebresearch.org for the above resources.

Important Note on Event Promotion:

- Event promotions should reflect EBRP as a beneficiary and not sponsor of the event. For example, proceeds from XYZ Event will benefit EBRP as opposed to EBRP's XYZ Event.
WAYS TO EB ACTIVE

PLUNGE
• Join an existing Plunge for Elodie event or start your own Plunge!
• For more information on Plunge for Elodie, visit: http://www.plungeforelodie.org/

RUN
• EBRP participates in the NYC Full and Half Marathons each year. Request one of charity spots for these events or create your own race to fundraise around!
• Email info@ebresearch.org for EBRP sponsored running events.

CREATE YOUR OWN COMMUNITY EVENT
• From lemonade stands and bake sales to golf outings and galas, there are endless ways to EB active! Use your skills and talents to create a unique event to benefit EBRP, spread EB awareness, and engage your local community.
• Click HERE for more information on starting your own event.