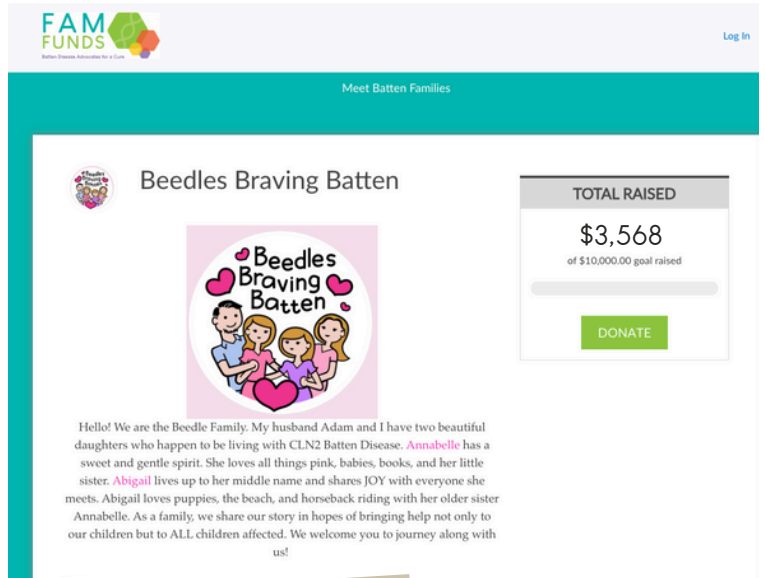




Batten Disease Advocates for a Cure

We all have the same **mission**: To be able to effectively **advocate, support, and find treatments and cures** for our loved ones with Batten disease. To do this, we must raise awareness and money. We are most **powerful** when we all **come together** as one voice, under one mission. FamFunds allows your family to **share your story** within your communities and effectively **raise awareness and funds** to support the same mission.



Personalized

You pick your own FamFund Name to represent your child or family. A personalized web page with a unique URL hosted by the BDSRA Foundation for you to share your story with a way for those in your community and give the opportunity to make a life changing donation in honor of your affected child(ren).



Directed Funds

Families can direct thier FamFund Donations to the mission areas that mean the most to them within the BDSRA Foundation:

- The Greatest Need
- Family Support
- Scientific Research
- Advocacy



Event Support

Host fundraising events with the full support of the BDSRA Foundation. BDSRA has the technology and database to help with ticketing, auctions, donor management, accounting, expenses, and advertising to make your event run smoothly.



High Advocacy - Low Administration

The BDSRA Foundation handles all of the administration of your Family Fund (Non-profit filing, tax filing, accounting, donor management, EOY tax statements, etc), so you can focus on your family, advocating, and raising money to help other affected families.

FAQ's



Can we still raise money for our family, in addition to FamFunds through BDSRA?

- Yes. Only funds raised directly through your BDSRA FamFund will go to the BDSRA Foundation. You can still accept donations from anyone who donates directly to you (GoFundMe, etc.) without compromise to your FamFund.

Are FamFunds for both families with Batten children/adults who are living and bereaved families?

- Yes. Your FamFund is for you to share your story and journey with your community, no matter where you are on that journey. Memorial FamFunds are a wonderful way to honor your child and your journey.

Can we have our own creative name and logo?

- Yes! In fact, we encourage you to adopt your own FamFund name to make your story more personal to you and for your supporters to identify and relate to you. This logo is yours to use on your FamFund page and on anything else you want to brand. If you have a logo, we are happy to add that to your FamFund web page as well, or we can help you design a logo to fit your FamFund name.

Can we change our FamFund name or story in the future?

- For the purpose of tracking your FamFund donations, we do not recommend changing your name after it has been established. As your story changes, you can update your web page to reflect your story and message at any time.

Can we direct where the funds we raise are used at the BDSRA Foundation?

- Yes. Families can direct their FamFund donations to the mission areas that mean the most to them within the BDSRA Foundation. Any funds generated through your FamFunds go directly to BDSRA. Seven percent of all funds donated will go to the Greatest Needs Mission to support the administration of BDSRA. Families can direct the remaining 93% of their FamFund donations to the mission areas that mean the most to them within BDSRA:
 - Greatest Need: These funds will be used at the discretion of BDSRA where the greatest need at the time is. This means that the funds could be used for administrative purposes, or for any of the other mission areas.
 - Family Support: These funds are used to support our families with grants for emergency travel, bills, unexpected costs, safety hazards, funeral expenses, and more. This fund also supports the SIBS and Life Goes On programs, as well as maintaining the memorial. Ideally, this fund will be healthy enough to also fund grants for accessible vehicles, medical equipment, home modifications, and other large requests.
 - Research: This fund supports scientific research for Batten Disease. You can direct your research funds to a specific CLN Type or to the general research fund.
 - Advocacy: This fund will help individuals and families in the Batten community attend advocacy events such as Rare Disease Week on Capitol Hill, and other conferences related to Batten disease. It also provides stipends for families that want to attend our Annual Family Conference.

Do we have to raise a certain amount as a FamFund?

- Not at all. The primary goal is to have a place for you to share your story and advocate for your child and all Batten families. Donations are a bonus, and we are grateful for any funds you raise through your advocacy. When you set up your page, a default goal will be set for \$10,000. Potential donors like to see a goal and feel good when they can move that needle. If this number feels too high or too low for you, you can change it.

What do we need to do to set up a BDSRA FamFund?

- We are excited that you want to partner with us to achieve the mission of the BDSRA Foundation. First, you will need to complete the Fam Fund interest form on the BDSRA Website. We will review your information and get back to you personally in the next few days. You will be sent a link to complete a form with the content for your FamFunds Page. This is where you will indicate your FamFund name, tell your story, upload any photos you would like to have featured, and indicate where you would like your Fam Fund donations to be directed within BDSRA. Once you have submitted this form, your personalized web page and URL will be published and ready for you to edit and share with in 5-7 business days.

What kind of fundraising events can we host with the help of BDSRA?

- Events can be anything from a simple spaghetti dinner fundraiser to an online auction, a 5k, a fishing tournament, a golf tournament, a raffle, or a gala. Let us know what you have in mind! Get creative. Events can be a lot of work, but we hope to alleviate some of the back end set up and administration. We have the expertise and platforms to help with planning, ticketing, donations, raffles, auctions, and so much more.

Do we have to host a fundraising event?

- Absolutely not. Just by sharing your story through a BDSRA FamFund page you are advocating and giving your community an opportunity to donate. We understand that executing fundraising events is not for everyone.

What does Low Administration mean?

- Starting and running a non-profit comes with many administrative tasks that most are unaware of: non-profit tax filing and documentation, accounting, acknowledgment letters, database management, board members and meetings, grant management, etc. With FamFunds, you get to support the mission area that means the most to you without worrying about the administration of a non-profit. You get a seat at the table in a quarterly FamFund Voices call and opportunities to help direct the funds raised within BDSRA.

What other benefits are there to having a FamFund with the BDSRA Foundation?

- We are grateful to have you as a partner and we want you to have a seat at the table. We plan to provide a graphics suite for you with personalized graphics to help share your FamFunds page throughout the year for Rare Disease Day, International Batten Disease Awareness Day, your child's birthday, and more. We plan to host a quarterly call with all our FamFunds partners to receive your feedback, ideas, and see how else we can support you, along with sharing current happenings within the Batten community. We also plan to celebrate and honor our FamFund Families at the Annual Family Conference in a special way.