



Partner with Us Program

Stacy Pike-Langenfeld
President

Do you want to help #curekrabbe?

- Facebook Fundraisers
- In-person fundraisers such as a lemonade stand, marathon, bingo night, etc.
- **Family Advised Fund** -The opportunity for a family or an individual to establish a fund, utilizing KrabbeConnect's non-profit platform and resources, to strengthen groundbreaking research, contribute towards a special project, or simply to aid other impactful efforts in the Krabbe disease space.



Purpose of Program?



TO GIVE FAMILIES A STRONGER VOICE AND
SENSE OF OWNERSHIP IN THE JOURNEY
TOWARDS ADVANCING CURATIVE WORK IN
KRABBE



STRENGTHEN COLLABORATION AND
TEAMWORK WITHIN THE KRABBE
COMMUNITY



ALLOW FAMILIES A POWERFUL VEHICLE
TO AID EFFORTS WITHOUT
ESTABLISHING A FOUNDATION.

Fund vs. Foundation Comparison

Category	Family Advised Fund	Foundation
Start-up Time	Immediate ability to fund projects upon availability of funds	Can take several weeks or months to begin funding projects because all legal and administrative documents need to be filed/IRS approved
Start-Up Costs	None	Legal and other startup fees are typically substantial and can cost thousands of dollars to create a foundation.
Ongoing Admin, Legal, and Accounting Fees	Average is 5%-10%, KrabbeConnect currently administers a nominal fee.	\$3,000-\$5,000/year or more
Privacy	Names of individual donors can be kept confidential if desired, and grants can be made anonymously	Must file detailed and public tax returns on grants, investment fees, staff salaries, and more
Reporting	None	Required annual state and federal tax returns-time consuming and requires an expert accountant in the non-profit space
Governance	None	For incorporation purposes, must develop by-laws and board documents, overseen by a formal board

The Steps:

1. Reach out to KrabbeConnect at info@krabbeconnect.org
2. Stacy and/or Anne set up a meeting to review the program with the family.
3. Family decides to move forward.
4. Family petitions to board of director a name for their fund.
5. KrabbeConnect and family complete contractual agreement.
6. The family acts as advisors and successors to the fund in perpetuity.



COLLIN'S CREW FOR KRABBE

Join Collin's Crew in working towards a cure for Krabbe! The Cushman family utilized KrabbeConnect's "Partner with Us" program



QUINTON'S QUEST FOR A CURE

Join Quinton's family in the fight! The Nitahara family utilized KrabbeConnect's "Partner with Us" program to help aid developments in the Krabbe disease space.



BRAVERY FOR AVERY

Join the Coupe family working towards a cure! The Coupe family utilized KrabbeConnect's "Partner with Us" program to help aid developments in the Krabbe



Quinton's Quest for a Cure

Ryan and Laura Nitahara

The importance of the fund to you:

- a. It gave us purpose in the Krabbe world.
- b. We have a huge network of loving family, and friends, and we were being asked all the time how they could help-creating QQCF gave us an answer for our network to pour their support into.
- c. We have made a difference by starting QQCF; we know that our efforts are moving this disease space towards a cure.





Bravery for Avery

Kevin and Lindsey Coupe

The importance of the fund to you:

- a. An opportunity for our friends and families to come together to raise money and awareness for Krabbe disease in Avery's name.
- b. Raise funds to help advance research for Krabbe disease.
- c. Support families to access this research, clinical trials, and future treatments.



QQC & BFA Funds

Benefits of the Fund	Hope for the Fund
KrabbeConnect guided us through our entire fundraiser	To utilize funds to advance research to #curekrabbe
Did all the marketing, flyers, invites, social media, etc.	To conduct a fundraiser every 1-2 years to raise funds for QQCF so we can make a difference.
Provided down payment and/or covered necessary costs required in advance	Provides an avenue for us and our network of supporters to pour our grief and energy into
Provided full financial breakdown of	Quinton's Quest for a Cure Fund

Benefits of the Fund	Hope for the Fund
KrabbConnect has the connections and partnership with those working to cure Krabbe, ensuring our funds will be used in the best way possible	We hope that for years to come, our family, friends, and our community will come together to remember our Avery Girl and raise money in her honor.
The partnership allows us the opportunity to plan and host events for the BrAvery for Avery Fund, with added support from the foundation	We hope, year after year, our fund will help advance research for Krabbe disease and help find a cure so that no child suffers from this awful disease
KrabbeConnect manages and keeps records of all donations made to the fund and shares all the information with us throughout the year.	Bravery for Avery Fund



QQC & BFA Experience Statements

QQCF: "Working with KrabbeConnect is a dream come true. We knew as soon as Quinton was diagnosed with KD, that we were going to need to pour our grief and energy into something; a way to raise money and fundraise for a cure. When we found the Partner With Us program, we knew it was a perfect fit for us. Their passion for finding a cure is responsive, understanding, and encouraging."



BFA: KrabbeConnect has been so supportive and encouraging in the past year since Avery's death, helping us to develop a fund in our sweet girls' name that we can use to help advance research to cure Krabbe disease. We've been able to connect with families affected by Krabbe disease and stay on top of the current scientific developments. Joining the efforts of such a well-established foundation has helped to ease the process of determining how we can keep Avery's name alive, spread awareness, and raise funds that will be used to help #curekrabbe.

Current Family Advised Funds



***NEW* Collin's Crew for Krabbe**



These 3 Family Advised Funds (together) have raised nearly \$48,000, further aiding those impacted with Krabbe disease!!! Congrats to the Nitahara, Cushman, and Coupe family.



Thank you!

Questions: info@krabbeconnect.org

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