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## Updates & News

Welcome to our first newsletter! We are thrilled to share with you the latest developments in our mission to support, empower, and advocate for individuals and families living with FA. Families For Friedrich's Ataxia was founded in the spring of 2024 to improve the quality of life of those fighting FA by providing financial assistance and bringing awareness to this disease that currently has no cure.

We would like to express our gratitude to our donors and volunteers who have supported us during our first year! Your generosity and dedication allowed us to have our first fundraiser and help 3 different families with Friedrich's Ataxia.

We have been blessed that other families want to fundraise in their hometowns. In September, there will be a golf fundraiser in Fort Wayne, Indiana. We will keep you posted about this exciting new event!

We want to remind everyone that our mission relies on the kindness and support of our community. If you are able to donate your time or resources, please do not hesitate to reach out to us.

Together, we can make a real difference in the lives of those who need it most. Thank you for your continued support!

Enjoy our first newsletter!

*Rachel Menkedick*



**BILL RICHMAN**  
CO-FOUNDER

**DEREK & RACHEL  
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## How can you help?

Become a monthly donor! Even a gift of \$10 a month can make a huge difference for a family!





## Night at Revel Run

The Families for Friedreich's Ataxia Foundation is grateful for the incredible support from Chelsea and the surrounding communities.

On March 1st, Families for FA hosted its very first fundraiser at Revel Run in Chelsea, and it was an unforgettable evening! With delicious food, great music, and heartfelt generosity, the event was a huge success and raised \$33,000!

The founders and fundraising committee would like to thank all of our sponsors and everyone who contributed raffle and silent auction items. A special shout-out to Bovine, Revel Run, Ugly Dog and Wesley's Catering for their amazing support and dedication to making this event so special.

With the incredible response from the community, the Foundation will be able to continue supporting families by assisting with medical equipment and bills, home renovations for disability accessibility, and providing emotional and additional financial support.

## New from FARA



Friedreich's Ataxia Research Alliance (FARA) is a national, public, 501(c)(3), non-profit, organization dedicated to the pursuit of scientific research leading to treatments and a cure for Friedreich's ataxia.

On February 1st, 2025, the Maugee family held their 3rd Runway to the Cure in Ft. Lauderdale FL. This event raised more than \$130,000 for FARA.

PTC Therapeutic announced that the FDA has accepted the filing for the New Drug application for Vatiquinone - a treatment for children and adults. The target action date is Aug. 19, 2025.

Find much more on the website [curefa.org](https://curefa.org)

## Facts about FA



- FA is a genetic progressive neuromuscular disease -affecting the brain and muscles.
- FA is life shortening.
- FA affects an estimated **5,000** individuals in the United States and **15,000** worldwide.
- All people will experience ataxia, sensory neuropathy and progressive loss of mobility.
- **Ataxia** - loss of coordinated movement
- **Sensory Neuropathy** - loss of sensation in the arms and legs.
- Many people with FA also have heart conditions including hypertrophic cardiomyopathy - thickening of the heart muscle) and sometimes cardiac arrhythmias (irregular heart rhythm).

## Siena's Story



Siena's story begins in 2009 as a beautiful blue-eyed, perfectly healthy baby. She hit all her milestones, easily made friends, and could keep up with all fun activities. When she was 6, her parents noticed that she was having a hard time learning to ride her bike without training wheels. After seeing a neurologist, they decided to dig deeper. Four months later, after 35 blood tests, an MRI, nerve conduction study, and an echocardiogram, it was determined that she had a genetic degenerative neuromuscular disorder, Friedreich's Ataxia. Since then, she has developed fatigue, peripheral neuropathy, aggressive scoliosis requiring

a spinal fusion, hypertrophic cardiomyopathy, diabetes, minor optic nerve atrophy, and has slowly lost her ability to walk. Despite these challenges and changes, Siena finds ways to have a positive outlook and continues to do things she loves. Siena was at the point where transferring her from the wheelchair into cars became increasingly difficult. A vehicle with a wheelchair conversion was needed to allow her to stay in her chair. Families for FA, thanks to all of our generous donors, was honored to be able to provide funds to help them with their purchase. This will assist her as a passenger and allow her to drive when ready.

## Tawny's Story

Tawny turned 13 last December. She has grown into such a spunky and spicy little lady, despite all that she has been through. She hit all her milestones on time and was so full of life and determination to do everything she wanted to. When she was 5 yrs old, she showed signs of her coordination being off. After 5 years of tests, she was diagnosed with FA. Since then, her progression has been very quick. She has been diagnosed with hypertrophic cardiomyopathy, scoliosis, severe ataxia, aspiration while eating, and sleep apnea. December 27, 2025 turned into a nightmare.

Tawny spent 20 days in the hospital due to diabetic ketoacidosis and complications with her heart and lungs because of her FA. She was placed on ECMO and life support to ensure that her body would be able to fight. She was extremely weak, lost her ability to speak, and needed help with everything—even eating. She has a very long road to recovery. Tawny's mother had to take three months off work to assist with her recovery. Going from 2 incomes to 1 income is extremely challenging and Families for FA was honored to support their family to help pay the bills while they focus on Tawny's recovery and her well being.

