SPRING 2021

CREATE YOUR LEGACY

MAKE CF STAND FOR CURE FOUND

Jenna Baier (age 36) and her family.

"It's important to have plans in life, and my dream is to watch Azalea and Jersey grow up and to grow old with my husband."

Read Jenna's story on page 2.

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CYSTIC FIBROSIS FOUNDATION®

LEGACY GIVING

A FAMILY'S INVESTMENT IN THE FUTURE

JENNA BAIER'S STORY

Jenna's parents, Jim and Diana Brown

"It takes a great deal of time to bring new treatments to market, so it was an easy decision for our entire family to become legacy donors," reflects Jeremy. "We want to be sure there is enough funding for the long term."

On December 18, 2017, Jenna and Jeremy Baier received a phone call that would change their lives forever. It was their adoption caseworker who had exciting news to share – two little girls, Azalea and Jersey, were ready for adoption.

"The call came on Jeremy's birthday," Jenna recalls. "Three days after Christmas, they were home with us, and we have been going full force ever since."

Going full force is not something Jenna has ever shied away from since being diagnosed with cystic fibrosis at 17 months. As a child, Jenna swam and did gymnastics, and in college, she became an avid golfer while pursuing a degree in business.

Today the 36-year-old busy mother of two enjoys not only golfing – but crafting, gardening, and caring for their Labrador, Phoenix, all while working as an associate financial representative alongside her parents at Northwestern Mutual.

Jenna initially became involved in fundraising for the CF Foundation through the annual golf and cycle events and now is the Annual Fund Chair for her local chapter and a monthly donor. "We know the impact of fundraising firsthand," says Jenna. "Once I began taking the therapy Trikafta®, I saw my lung function increase by 15 percent."

Jenna and Jeremy, along with her parents, Jim and Diana Brown, recently made the decision to join the Legacy Society by leaving gifts to the CF Foundation in their wills.

Jenna, too is focused on the future. "It's important to have plans in life, and my dream is to watch Azalea and Jersey grow up and to grow old with my husband. I want to be part of that story when a cure is found."

CONSIDER YOUR LEGACY

We are entering a new era in cystic fibrosis, with life-changing new therapies and promising treatments on the horizon. With your support, we are confident that one day, not one person will lose a loved one to cystic fibrosis. We are committed to funding world-class research that will produce innovative, new treatments and a cure. **If you, like many others, leave a gift, please use the enclosed form to let us know and start your free Legacy Society membership today.**

Your gift, left to the CF Foundation in your will or trust or by beneficiary designation, can be a lasting reflection of your values. Thank you for considering this way of deepening your support.

HOW YOU BENEFIT

- Leaving a gift to the CF Foundation costs you nothing now.
- No minimum donation required. Every gift makes an impact.
- You can provide for your loved ones and for the CF Foundation.
- You can honor or memorialize a loved one with your gift.
- You can remain anonymous if you choose, but we hope you will let us know so we can thank you privately for your generosity.

Visit www.cff.org/LegacyGiving

FDA APPROVES KALYDECO FOR INFANTS AS YOUNG AS 4 MONTHS

Research shows that starting treatment with a CFTR modulator at a young age could help slow or even prevent the irreversible progression of cystic fibrosis, dramatically altering the course of the disease over time. Consequently, many in the CF community are pleased that the U.S. Food and Drug Administration (FDA) has approved the use of Kalydeco® (ivacaftor) for infants with cystic fibrosis as young as four months who have certain mutations.

Highly effective CFTR modulators, including Kalydeco, are known to have a transformative effect on the health and wellbeing of people with CF. Kalydeco was initially approved in 2012 for the treatment of people ages six and older with the gating mutation G551D, who make up 4 percent of the 30,000 people with CF in the U.S. Last year, approval was expanded to babies ages six months and older with one of 38 mutations.

"Our hope is that those who start on modulators as infants may never experience many of the classic symptoms of CF, and we are committed to supporting ongoing research to better understand the impact of early treatment," said JP Clancy, Vice President of Clinical Research of the Cystic Fibrosis Foundation.

During a 24-week study in six children between four and six months, the safety profile of Kalydeco was similar to that observed in older children and adults. It was developed by Vertex Pharmaceuticals Inc. with significant clinical, scientific, and financial support from the Cystic Fibrosis Foundation.

While the Foundation has made great scientific progress, not everyone with CF can benefit from existing modulator therapies. Through its Path to a Cure initiative, the Foundation is working to advance more therapies for more people and ultimately a cure for CF. For more, visit: **cff.org**.

CYSTIC FIBROSIS FOUNDATION ANNOUNCES NINE RESEARCH AGREEMENTS TO ADVANCE ITS PATH TO A CURE

The Cystic Fibrosis Foundation announced $1.7 million in new research funding to drive progress on its Path to a Cure. The awards to seven academic institutions and two companies will support focused research into key scientific challenges associated with developing therapies to address the underlying cause of disease for all people with CF, regardless of their underlying mutation.

"There has been an explosion of scientific progress in novel technologies with the potential to benefit all people with CF, yet significant additional research will be required to move these advances out of the lab and safely to patients," said William Skach, MD, executive vice president and the chief scientific officer of the Cystic Fibrosis Foundation. "These awards reflect important investments into the foundational research that is needed to advance curative therapies for all people with cystic fibrosis."

Learn more: **cff.org/PathtoaCure**.

A FATHER'S DETERMINATION

MEET CLAY SNELLINGS

Clay Snellings has been involved in the fight against cystic fibrosis for over 20 years. The proud father of three remembers the day his daughter and youngest child, Emily, was diagnosed.

"We became very internally focused as a family after that diagnosis," he recalls. "We did our best to help Emily live the most normal life possible. Despite her challenges, we always shared a sense of optimism."

At age 12, Emily's lung function started to decline, which resulted in more frequent hospitalizations. Clay and his wife, Lori, soon got involved with the CF Foundation, participating in bowling and golf events and eventually helping start Insure the Cure, an alliance with the insurance industry of Atlanta, which has raised more than $2 million since its inception.

The Snellings tenacious support, alongside that of the CF community, has helped lead to several breakthrough treatments over the past decade. When Emily began taking the first triple-combination modulator therapy, Trikafta®, her lung function climbed to the 40s, and her health improved.

Clay's personal involvement has grown in his role as Board Chair for his local chapter, which enables him to connect and learn from other CF families while sharing new fundraising ideas. Recently, Clay and Lori also became Legacy Society members by including a gift to the Foundation in their will.

Today Emily is about to graduate from the University of Georgia with a master's degree in accounting and has a job lined up at Deloitte. While she is living a full life, her father hopes for the next breakthrough for his daughter.

"Scientific research is incredibly expensive. With legacy giving, you are putting a stake in the ground for the future by perpetuating the Foundation's mission for a very long time. That's important for Emily and for all those living with CF."

Clay Snellings (middle) with his wife Lori (bottom left), daughter Emily (bottom right) and sons Walker (top left) and Blake (top right).

I'M HERE TO HELP

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For our financial information visit; **www.cff.org/About-Us/Reports-and-Financials/Annual-Reports-and-Financials/**

ARE YOU READY FOR TAX SEASON?

To learn more about the tax advantages of your charitable giving and to download your complimentary estate planning tools, visit:

www.cff.org/LegacyGiving