

SUMMER 2023

CREATE YOUR LEGACY

PLAN TODAY FOR DREAMS OF TOMORROW



Lisa (right) celebrates being the first person with CF to complete Xtreme Hike Sedona with her siblings Kelly (left) and Mitchell (center)

“We can continue to keep the torch lit until there is a cure — to do our very best for people with CF even after we are gone.”
– Tim Lenihan (see page 3)

ALSO INSIDE
NEW METHODS TO
DELIVER GENETIC
THERAPIES
AND MORE



LEGACY GIVING

BY HER SISTER'S SIDE

MEET KELLY

On a sunny day in October, Kelly Amsler looked on as her younger sister, Lisa, walked down the aisle arm-in-arm with their father, Lee. It was Lisa's wedding day — a moment the entire Amsler family had been looking forward to and one made more poignant by the fact that Lisa, diagnosed with cystic fibrosis at age two, was about to reach a significant life milestone.

"Growing up, our family treated Lisa's CF as 'normal,'" recalls Kelly. "We integrated her treatments into family activities, the getting-ready-for-school routine, and made CF events something to look forward to. Of course, CF is anything but normal, and our family readily acknowledged the serious nature of CF and the impact it had on my sister, making it our ongoing mission to find a cure."

From the moment the Amslers learned that Lisa had cystic fibrosis, they became actively involved with the CF Foundation. Lisa's mother, Penny, and her father formed the Great Strides team, "Amsler's Army," a tradition the entire family has continued for almost three decades.

"We were there for Lisa from the start," said Kelly. "When she would do her daily treatments — often two to three hours — Mitchell and I would join her and turn this into an opportunity to play board games, video games, or sneak in an extra episode of *Power Rangers*."

Beyond offering moral support, Kelly does all she can to advance the Foundation's mission. She participates in annual events such as Great Strides and Xtreme Hike



Lisa Amsler celebrates her wedding day surrounded by her loving family.

and most recently attended the Volunteer Leadership Conference with her family in Denver. Last year, Kelly joined the Legacy Society by naming the CF Foundation as a beneficiary of her retirement plan.

"Legacy giving is an easy way for young professionals like me who are just starting their financial planning to get involved," she said. "I'm 36 years old and take comfort in knowing that while I may not have a large sum of money now, I can make an impactful gift in the future."

Today, the now grown Amsler siblings make it a point to get together each year and Kelly is planning a wedding of her own this summer. Whether they are meeting up for a CF event, joining a family vacation, or taking yoga classes together — the sibling trio remains close. "Last spring, we hiked Sedona. Lisa was the first person with CF to finish the Xtreme Hike in all of Arizona," said Kelly. "Crossing that finish line was an amazing moment for all of us."

Kelly Amsler is the Assistant Director for C.A.T.S Academics at the University of Arizona where she provides academic support to student athletes. She looks forward to getting married in June, with Lisa, Mitchell and her parents by her side.

PLANNING WITH A PURPOSE: GIFTS THROUGH BENEFICIARY DESIGNATIONS

Did you know that naming the Cystic Fibrosis Foundation a beneficiary of your life insurance policy, retirement plan or donor advised fund is one of the easiest ways to leave an extraordinary gift tomorrow at no cost today?

How you benefit:

- A beneficiary designation is easy to set up with your financial institution, often online.
- You can adjust beneficiary designations at any time in your career journey and at any age, giving you maximum flexibility with your plans.
- You can divide your retirement assets between charities

and loved ones, and neither you nor your heirs will pay income taxes on the distribution of the assets.

- Unlike a will, assets from a life insurance policy or retirement plan are immediately distributed directly to your beneficiaries without going through probate.
- You can still take regular withdrawals from your pre-tax invested dollars during your lifetime.

Consult your financial advisor today as you consider whether this type of gift makes sense for you. Please let us know that you have left a gift by using the enclosed form or visiting cff.org/LegacyGiving.

KEEPING THE TORCH LIT

MEET THE LENIHANS

In 1996, Deb and Tim Lenihan welcomed their first child, Jason, into the world. While he seemed healthy, the CF Care Center located at the Connecticut Children's Hospital in Hartford called Deb and said they wanted to conduct a sweat test for Jason after reviewing results from a newborn screening test conducted at the hospital.

No sooner did they learn the sobering news: Jason had cystic fibrosis. The Lenihans were not familiar with CF and began learning all they could about the disease. Two years later, they had their second child, Amy, who was also diagnosed with CF.

"There was a great deal of fear during those years. We spent a lot of time sleeping on the couch in the hospital and juggling our many priorities," remembers Tim.

Deb and Tim got connected with the CF Foundation and formed the Great Strides team, "Team AJ," which has raised more than \$1 million over the past 25 years. Tim has also served as a Board Member for the Foundation's Connecticut Chapter for more than two decades, and Deb Co-Chairs the Rose Ball, an annual gala that has raised hundreds of thousands of dollars to advance the Foundation's mission.

"We know the funds raised lead to real results as we have watched the median survival age more than double over the past 27 years," said Tim. "Trikafta has been a game changer for Jason and Amy, but not everyone can benefit from existing therapies."

Recently, the Lenihans joined the Legacy Society at the Breakthrough Level of the Milestones III campaign through a disclosure of their will in honor of their children. "The late Mary Weiss, mother to three sons with CF, helped lay the groundwork for the Foundation's fundraising efforts, but of course, we still need a lot more money to get it done," said Deb. "We can continue to keep the torch lit until there is a cure — to do our very best for people with CF even after we are gone."

Today, Jason and Amy are thriving. Jason (age 27) is earning a PhD in organic chemistry from Boston University and Amy (age 25) is a human resources professional for an insurance agency based in England. She is also a doting mom to her dog, Jameson.



From left to right: Jason, Tim, Deb, and Amy Lenihan celebrate the holidays together.

CF FOUNDATION TO EXPLORE A NEW METHOD TO DELIVER GENETIC THERAPIES TO THE LUNG

Delivery of genetic therapies to affected tissues is a key challenge to developing new treatments for people with cystic fibrosis. The Cystic Fibrosis Foundation announced in March that it is investing up to \$2 million in Nanite Inc. to explore a new way to deliver genetic therapies into the lung. In addition to investing in viral delivery and lipid nanoparticles, the CF Foundation is looking at the potential of a relatively new approach to delivery using an exceptionally small synthetic molecule called a polymer nanoparticle.

Nanite will be using artificial intelligence to narrow down the best polymer nanoparticle candidates. Nanite researchers believe they can program polymer nanoparticles to more accurately target lung cells and potentially better resist the thick, sticky mucus that clogs the lungs of people with CF.

At first, Nanite will work on developing polymer nanoparticles that can deliver messenger RNA therapy into the lungs. Eventually, Nanite hopes these nanoparticles can be used to deliver any type of genetic therapy and target other organs affected by CF, such as the pancreas.

The Foundation believes this early-stage research will help determine the feasibility of using polymer nanoparticles for CF. This investment is part of the Foundation's \$500 million Path to a Cure, an ambitious research initiative to accelerate treatments for everyone with CF and ultimately deliver a cure.

ADVANCING ENZYME THERAPY

The CF Foundation is focused on advancing the next generation of transformative therapies to address complications, treat the underlying cause of CF in every individual with CF, and find a cure. One such complication is pancreatic insufficiency, which nearly 90% of people with CF suffer from, preventing the body from easily breaking down food for digestion. With no enzymes to break down food, much of the protein, fat, and carbohydrates in food are not absorbed. This can result in poor growth, gastrointestinal symptoms such as gas and bloating, and malnutrition.

The Foundation recently agreed to provide up to \$15.5 million to Anagram Therapeutics (formerly known as Synspira Therapeutics) to conduct early-stage clinical trials of a novel enzyme replacement therapy. If the therapy is successful, people with CF would be able to decrease the number of enzyme pills they must take to digest food properly from a handful of pills to only one per meal. In addition, the therapy would be available as either a tablet that can be dissolved in water, or granules that could be mixed with soft food. The drug is non-porcine, which means it contains non-animal derived enzymes, and is designed to break down fats, proteins, and carbohydrates.

This potential therapy would be more convenient and provide another option to current therapies for people with CF who struggle with digestion.

“This potential therapy would be more convenient and provide another option to current therapies for people with CF who struggle with digestion,” said JP Clancy, MD, senior vice president of clinical research for the Foundation. “We are striving to develop better therapies for CF complications, such as poor digestion, to improve the everyday lives of people with CF.”

Anagram is planning to start a Phase 1 clinical trial of the enzyme therapy over the summer.



Use this QR code to view our current list of Legacy Society members or visit cff.org/legacygiving/members

I'M HERE TO HELP

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CYSTIC FIBROSIS FOUNDATION

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This information is not intended as legal, accounting or other professional advice. For assistance in charitable planning, consider engaging the services of a qualified professional.

For our financial information, visit cff.org/Finances.



USEFUL LEGAL INFORMATION

Legal Name: Cystic Fibrosis Foundation
Address: 4550 Montgomery Ave, Suite 1100N
Bethesda, MD 20814
Federal Tax ID Number: 13-1930701

SAMPLE BEQUEST LANGUAGE:

"I give and bequeath to the Cystic Fibrosis Foundation (chapter name if applicable) located in Bethesda, Maryland, the sum of \$_____."