

SUMMER 2022

# CREATE YOUR LEGACY

PLAN TODAY FOR DREAMS OF TOMORROW



Anton and Kelli Newman with their daughters Regan (2) and Bailey (5)

“Legacy giving enables you to make a big impact in the future without having to make a large payment now.”

– Anton Newman

## ALSO INSIDE

PLANNING WITH  
A PURPOSE

A BREATH OF FRESH AIR  
AND MORE



**LEGACY GIVING**

# A TRADITION OF GIVING

MEET THE NEWMANS



Deb and Scott Newman with granddaughter Bailey.

Like many little girls, Bailey Newman loves unicorns, playing soccer, and donning her princess crown. But it is Bailey's courage and adaptability in the face of cystic fibrosis that is admirable. According to her father, Anton, in her first year of life, Bailey took over 8,000 pills as part of her CF therapeutic regimen.

"She is typical of many 5-year-old girls – she just happens to go to the doctor a lot. We never have to persuade Bailey to take her medicines," he says. "She is driven to do whatever it takes for her health."

Being driven is second nature to the Newman family. Bailey's grandmother, Deb, is an entrepreneur who founded a successful long-term care insurance agency 30 years ago. Anton studied architecture and interior design in college, and today leads one of the largest furniture businesses in Minneapolis.

The Newman family first got involved with the Cystic Fibrosis Foundation not long after Bailey's diagnosis, attending their local chapter's Gala and eventually hosting their own fundraiser "Bailey's Bash," which now draws over 250 people annually and has raised more than \$200,000 dollars. Deb also serves on board of the Minnesota Chapter and, most recently, she and her husband Scott joined the Legacy Society by naming the CF Foundation in their will and have pledged a significant 10-year gift through their IRAs as a Qualified Charitable Distribution (QCD).

"I was particularly inspired by the book *Breath from Salt* which tells the CF Foundation's story," Deb said. "Learning about longstanding supporter and CF father, Joe O'Donnell, and his tenacity further motivated me to give back."

Anton also gives back. He currently serves as the Board Chair for the Minnesota chapter and is also a Legacy Society member alongside his wife, Kelli. "There are many young people who want to be philanthropic," he says. "Legacy giving enables you to make a big impact in the future without having to make a large payment now."

Today, Bailey is thriving. "She's a natural caretaker," says her dad. "She takes care of her little sister, Regan, and her friends. She would also take care of you. That's just who Bailey is."

## PLANNING WITH A PURPOSE: GIFTS THROUGH YOUR IRA

### As part of an Estate Plan

Join us in the commitment to finding a cure by naming the Cystic Fibrosis Foundation as a beneficiary of your IRA. You can divide your retirement assets between charities and loved ones as part of your legacy, and neither you nor your heirs will pay income taxes on the distribution of the assets.

# CF FOUNDATION INVESTS \$3.5 MILLION IN PULMOCIDE FOR DEVELOPMENT OF NOVEL ANTIFUNGAL TREATMENT FOR LUNG TRANSPLANT RECIPIENTS

Although anyone who has received a lung transplant may be susceptible to an Aspergillus fungal infection, people with CF who get a lung transplant are at an even higher risk. They are more likely to have fungus present in their airways because of their cystic fibrosis, even before transplant, which can lead to an invasive fungal infection after transplant.

To help address this challenge, the Cystic Fibrosis Foundation announced its investment of \$3.5 million in Pulmocide Limited, a U.K.-based biotech company, to develop an inhaled drug (opelconazole) to prevent Aspergillus fungal infections in lung transplant recipients. The investment is part of the CF Foundation's Lung Transplant Initiative, a commitment to improve outcomes and support people with CF throughout the transplant journey. It also marks the CF Foundation's first funding of a potential treatment specifically for people who have received a lung transplant.

The CF Foundation's funding will support a multicenter Phase 2 study of opelconazole. The objective of the study is to assess the treatment's safety and tolerability and the patient's ability to complete the course of treatment when being used to prevent invasive pulmonary fungal infections in lung transplant recipients.



## LUNG TRANSPLANT INITIATIVE

As part of the CF Foundation's commitment to helping people with CF wherever they are on their journey, the Foundation established the Lung Transplant Initiative in 2016 with the goal of maximizing the opportunity for transplant as a life-sustaining therapy and extending post-transplant survival. Since the initiative began, the Foundation has made significant progress. The agreement with Pulmocide is the first clinical-stage lung transplant trial for the initiative.

Pictured above: Lung transplant recipient, Don Gouchie.

### Who benefits from making a QCD?

- If you are retired
  - If you rely on a fixed income
  - If you are unable to itemize and/or would like to lower your adjusted gross income
- Consult your financial advisor if this kind of gift makes sense for you. And let us know if you plan to leave a planned gift by using the enclosed form or visiting [www.cff.org/LegacyGiving](http://www.cff.org/LegacyGiving) so you can join our Legacy Society today!

# A BREATH OF FRESH AIR

## MEET DON

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Don Gouchie is active. He likes to bike, golf, and travel alongside his wife of 29 years, Linda. Diagnosed with cystic fibrosis at three years old, Don has worked hard his whole life to stay as fit as possible. For many years his health was relatively stable but in 2011, he began experiencing infections and his lung function declined. In 2016, the doctor advised him to consider getting a lung transplant.

Two and half months after being listed in August 2017, Don received a call that would change his life – a lung match had been found.

“It was kind of a shock when I got the call,” he remembers. “I thought, am I really ready to do this? I still felt like I was healthy, but I knew it was time.”

The complex operation went smoothly and within 24 hours, Don was walking. By the end of the first week post-transplant, he was climbing up flights of stairs. One month later and Don felt he had a new lease on life, which he credits to his active lifestyle.

“It was around that time that Linda and I decided to give back to the CF Foundation.” Influenced by his mother, who began fundraising when Don was a young boy, he followed suit and made a financial contribution in support of the Lung Transplant Initiative – which seeks to improve pre-transplant care and long-term outcomes and survival for those living with CF who have advanced lung disease.



Don and Linda Gouchie during a Cycle for Life

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“We ride so that someday there will no longer be a reason to ride.”

—Don Gouchie

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When Don and his wife Linda retired last year after selling his engineering business, they decided to set up a generous trust to benefit the Cystic Fibrosis Foundation. In addition to being legacy donors, Don and Linda are active participants in their Massachusetts CF Cycle for Life as well as other CF fundraising efforts.

“We ride for all families currently impacted by cystic fibrosis and for families who will be impacted in the future. We ride so that someday there will no longer be a reason to ride.”

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## I'M HERE TO HELP

Amanda Zar, Planned Giving Director  
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### CYSTIC FIBROSIS FOUNDATION

4550 Montgomery Ave., Suite 1100 N  
Bethesda, MD 20814

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](http://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 \$\_\_\_\_\_.”