

FALL 2021

CREATE YOUR LEGACY

MAKE CF STAND FOR CURE FOUND



Ashvani and his wife of 36 years, Sangeeta, along with his three grown children Ambika, Amrit, and Arunav along with bride Leesa.

Photo courtesy of www.justicephoto.com

“As long as I’m alive I want to do all I can to help those living with this disease, and when I’m not here, I want my support to continue.”

Read Ashvani’s story on page 2

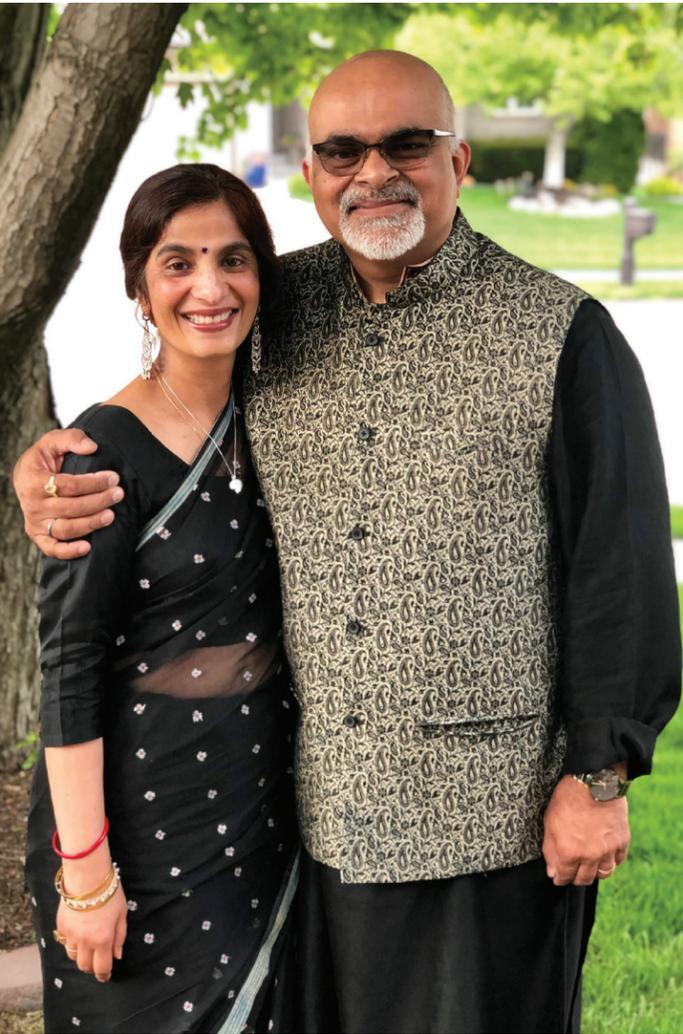
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RESEARCHER
PAYING IT FORWARD
AND MORE



LEGACY GIVING

A DEDICATED RESEARCHER

MEET ASHVANI SINGH



Sangeeta and Ashvani Singh.

“As long as I’m alive I want to do all I can to help those living with this disease, and when I’m not here, I want my support to continue.”

—Ashvani Singh

On January 28, 1989, Ashvani Singh stepped off a plane from India and onto U.S. soil for the first time as he formally began his career in CF research.

“The very next day, I got a call from my wife who told me, ‘You have a son.’ It still brings tears to my eyes. Because I didn’t want to lose my fellowship, I had to travel while my son, Amrit, was being born. My arrival marked an important moment in my journey, professionally and personally.”

That fall pioneering scientists discovered the CFTR gene, putting the CF research trajectory on an entirely new plane. “We researchers had our work cut out for us,” recalls Ashvani. “Many scientists at the time said we were crazy, that we would not achieve anything. But we stayed focused.”

Ashvani has spent more than three decades working tirelessly on scientific research that provides new therapies - and hope - for the cystic fibrosis community. Today, he spends his free time cooking and listening to his wife Sangeeta, who is a classically trained singer. This past summer they watched their son, Amrit, walk down the aisle and celebrate a big milestone when he married the love of his life, Leesa.

Together, Ashvani and Sangeeta have pledged their long-term commitment to the Cystic Fibrosis Foundation by leaving a gift in their will.

“I’ve given everything I have in terms of the science. As long as I’m alive I want to do all I can to help those living with this disease, and when I’m not here, I want my support to continue. My car’s license plate is registered as ‘CF Cure’ – I want to put a ‘d’ at the end.”

Ashvani Singh is a Senior Principal Research Scientist at AbbVie. He received his Doctor of Philosophy (Ph. D.) in Medical Chemistry from Central Drug Research Institute, Lucknow in India and has over thirty years of experience in the pharmaceutical industry in the field of cystic fibrosis drug development.

A FOCUS ON WELLNESS

The psychological challenges of CF on children, their parents, and adults with cystic fibrosis are well known. According to one study, depression and anxiety are two to three times greater among people with CF and family caregivers than the general population.

To help combat this reality and support overall wellness in those with CF, the CF Foundation announced in the spring an extension of its collaboration with Beam, an online exercise, education, and wellbeing platform, to offer adults living with CF in the United States free and unlimited access to the platform’s exercise and well-being content throughout 2021.

“Wellness plays a critical role in an individual’s quality of life no matter what challenges they are facing, and our goal is to help all people with CF

to not simply survive but thrive,” said Sue Sullivan, senior director, head of community partnerships at the CF Foundation.

The benefits of regular exercise for overall health and disease management are well documented. Research shows that regular physical activity provides benefits well beyond better lung function -- keeping fit also helps strengthen bones, manage diabetes and heart disease, and improves mental health.

Beam offers users access to on-demand workouts, live classes, community groups, and special events. Classes are led by specialized physical therapists and trainers who are experts in CF. Beam also offers educational content and emotional support to users. The collaboration began as a pilot program in 2019 and will be evaluated later this year. To learn how to sign up visit cff.org/BEAM.

JOIN THE LEGACY SOCIETY

We are driven by a dream that one day every person with cystic fibrosis will have the chance to live a long, healthy life. Working alongside the CF community, the Foundation has achieved unparalleled advances in the treatment and care of cystic fibrosis.

Today, we are pursuing a new frontier, exploring research that holds promise for a cure, while helping those with CF live their healthiest lives through comprehensive care and support. You can help drive this momentum forward.

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 TO JOIN

- Leave a dollar amount, percentage, or specific assets such as real estate to the Foundation in your will or living trust.
- Designate the Foundation as a beneficiary of your IRA, 401(k), life insurance policy or Donor-Advised Fund. Simply log in to your account or request a Change of Beneficiary Form from your custodian.
- You can mix these no-cost ways together.

Let us know that you have left a gift by using the enclosed form or visiting cff.org/LegacyGiving.

PAYING IT FORWARD

MEET THE BARRY FAMILY

In 1996, Amy Barry was up in the middle of the night comforting her sick newborn son, Jamie, when she caught a news segment on television about two young parents who had established their own medical research foundation to help their sons afflicted with a rare fatal disease. Just ten days later Jamie was diagnosed with cystic fibrosis.

"I immediately reached out to these parents seeking their guidance on how to create our own research effort," recalls Amy. "I soon received a reassuring letter back from them, telling me that we were fortunate to already have the gold standard of rare disease organizations on our side: the Cystic Fibrosis Foundation."

Amy and her husband, Peter, dedicated themselves to helping the Foundation in any way possible. Shortly after meeting with then CEO, Bob Beall, whose visionary leadership would change the course of CF, Amy joined the national board of trustees. There, she had an early peek into the promising developments underway. "Peter and I began to imagine what was possible," Amy said. "We told ourselves that if this succeeded, we would commit ourselves to helping other parents of children with rare diseases fight for their futures."

In 2019, the Barrys watched Jamie take his first dose of the newly released therapy Trikafta®. "Within hours, Jamie began to experience the benefits," said Peter. "We were so grateful, but we understood that Jamie's solution would not work for everyone with CF. It became clear that our job was to pay it forward within our own CF community, and fight for other CF families still looking for an effective therapy."

Over the years, the Barrys have been major donors, active board members, public policy advocates and ardent fundraisers for the Foundation. Last year, they



From left to right: Peter, Julia, Will, Jamie and Amy Barry

turned their focus to legacy giving and joined the Paul di Sant'Agnesse Legacy Society after learning about a national matching gift opportunity offered by CF community member, avid supporter and CF grandmother, Bonnee Binker and her family.

"It was an easy decision. Legacy donations are future monies that will help end CF," reflects Peter. "We were lucky to get a therapy that has worked so far for Jamie – we've had a taste of normalcy. The entire CF community deserves to feel this way."

SPECIAL MATCHING GIFT ANNOUNCEMENT



Every new Legacy Society donor that joins between July 15 - December 28, 2021, or when the match is completed whichever comes first, will be matched with a \$500 contribution to the Cystic Fibrosis Foundation by the Delaney Binker Family Cure Cystic Fibrosis Miami Foundation, up to \$50,000.

Join today by contacting your local chapter or by visiting cff.org/LegacyGiving

I'M HERE TO HELP

Amanda Zar, Planned Giving Director
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CYSTIC FIBROSIS FOUNDATION LEGACY GIVING

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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 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 \$_____."