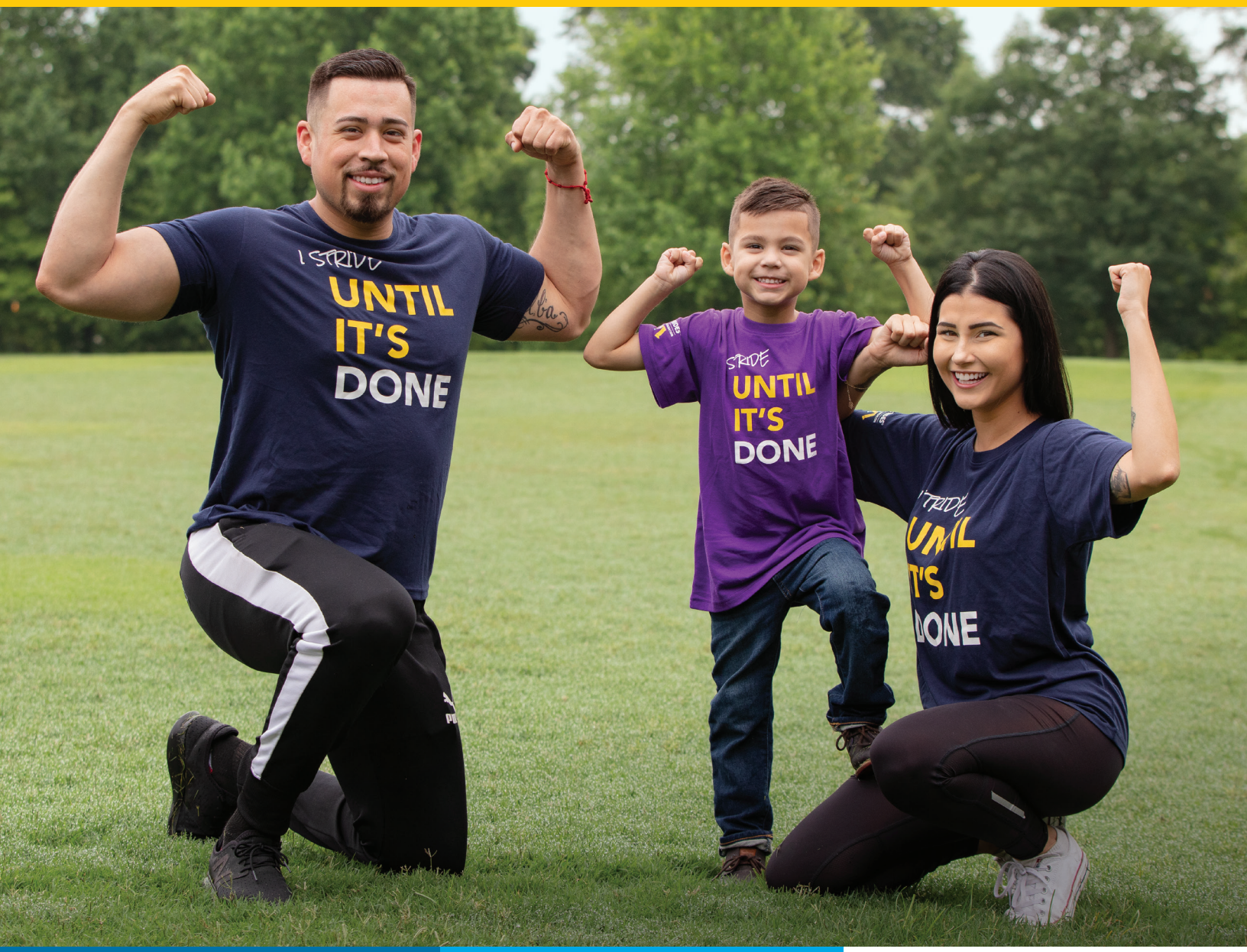
FALL 2019

CREATE YOUR LEGACY

MAKE CF STAND FOR CURE FOUND



"We've made so much progress, but there is still much more to do."

—Astrid, Nico's mom

ALSO INSIDE

THE POWER OF VOLUNTEER LEADERSHIP

REACHING LIFE'S GREATEST MILESTONES IN SPITE OF CF

AND MORE

CYSTIC FIBROSIS FOUNDATION®

LEGACY GIVING

THE POWER OF VOLUNTEER LEADERSHIP

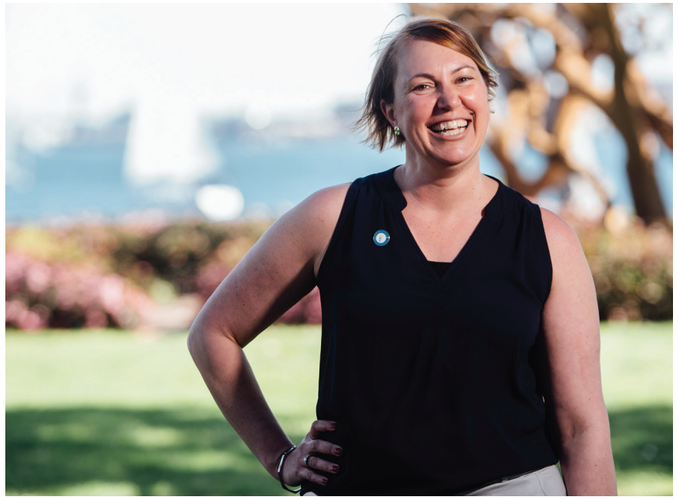
MEET JESSICA COX

Why did Jessica Cox start to volunteer with the CF Foundation? "Well," she said, "because my dad told me to," she laughed. "Even though I was 8 years old, my dad would put my siblings and me to work. Whether I was blowing up balloons, picking-up pizza boxes, or handing out beads, you could bet I'd be there."

Her family's involvement with the CF Foundation began when her father, John Cox, learned that his close friend in college had cystic fibrosis. He quickly became a dedicated volunteer of the CF Foundation's Massachusetts Chapter, got his whole family involved, and later became a Foundation leader in various roles.

I hope others get to experience how powerful it feels to have your legacy intertwined with what is truly today's greatest story in medicine.

VISIT CFF.ORG/GET-INVOLVED TO EXPLORE THE VARIOUS WAYS YOU CAN GET INVOLVED WITH YOUR LOCAL CHAPTER!



Because of her father, volunteering with the Foundation wasn't just a checkbox on Jessica's annual to-do list; "it was really a part of my everyday life," she explained. "I'm so grateful that my father instilled in me that sense of service and giving back. It's brought me to where I am today."

Jessica now has over 35 years of involvement with the Foundation, is chair of the Northern New England Board of Directors, makes annual donations, and most recently, joined the Legacy Society by designating the CF Foundation as a partial beneficiary of her retirement plan.

She joined the Northern New England Board in unanimously agreeing to each leave a gift to the CF Foundation in their will, trust, or by beneficiary designation. They are the first Chapter Board to ever make such a deep commitment that clearly communicates their values and hopes for future generations of people with CF!

"We hope our actions will inspire other volunteers, leaders, walkers, friends, and family to follow in our footsteps," Jessica said. "I hope others get to experience how powerful it feels to have your legacy intertwined with what is truly today's greatest story in medicine."

REACHING LIFE'S GREATEST MILESTONES

WITH A RARE FORM OF CYSTIC FIBROSIS

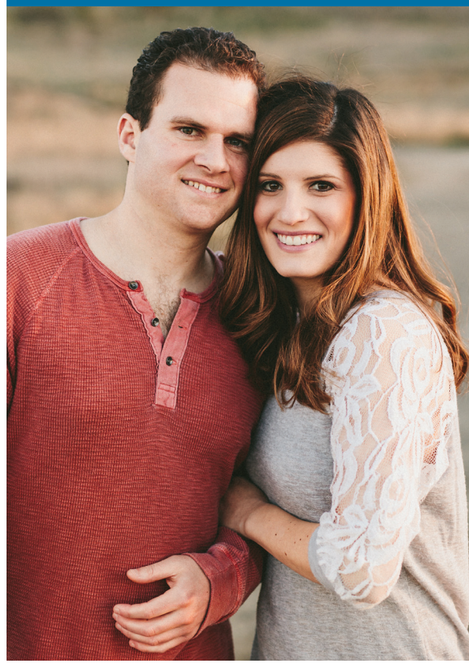
When Stacy Carmona was diagnosed with cystic fibrosis at birth, her parents were told she would not live to see her 18th birthday. Further complicating her prognosis, Stacy has two rare CF gene mutations that prevent her from being able to benefit from current therapies that treat the underlying cause of the disease. Recounting her childhood, Stacy said, "My family and I were scared. We never thought that I would experience any major life milestones."

Despite the diagnosis and expectations set for her, Stacy never let CF limit or define her. She went on to graduate high school and celebrate turning 18. "After high school," she says, "I was making plans for my future -- a future that I didn't think I was going to have. When I had outlived my life expectancy, I wanted more. I wanted to go away to college, to live in a foreign country, and to get married."

And so, Stacy did exactly that. She went on to graduate from the University of California, Santa Barbara, study abroad in Sydney, Australia, and marry her now husband, Danny.

Now at age 32, Stacy says, "I am grateful every single day to all of the people who have helped get me to this point in my life. And, I am beyond excited to see what my future holds."

DID YOU KNOW THERE ARE MORE THAN 1,700 DIFFERENT GENETIC MUTATIONS KNOWN TO CAUSE CYSTIC FIBROSIS?



LEAVING NO ONE BEHIND

THE NONSENSE AND RARE MUTATIONS INITIATIVE

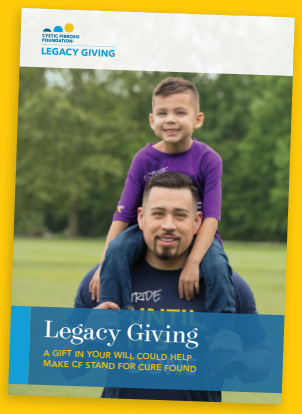
There is currently an unprecedented number of CFTR modulators (drugs that treat the underlying defect of CF) that are being tested in clinical trials. We believe in the next few years more than 90 percent of people with CF could benefit from these drugs. However, we will not rest until we are able to restore CFTR function for everyone. That is why we launched the Nonsense and Rare Research and Therapeutics Initiative.

This multifaceted initiative has funded more than 60 projects over the past several years at both academic institutions and pharmaceutical companies around the world. The CF Foundation awarded $63 million for these projects between 2015 and 2018 and has committed over $70 million for 2019 and beyond.

The long-term goal is to replace or correct the defective CF gene by developing a one-time cure for every person with CF. This would be a major step towards replacing a lifetime of daily medications with a simpler, healthier life.

LET'S GET STARTED

GET A **FREE** PLANNING GUIDE



We can help make sure your plan reflects what matters most to you, and that you have all the necessary protections in place for your future.

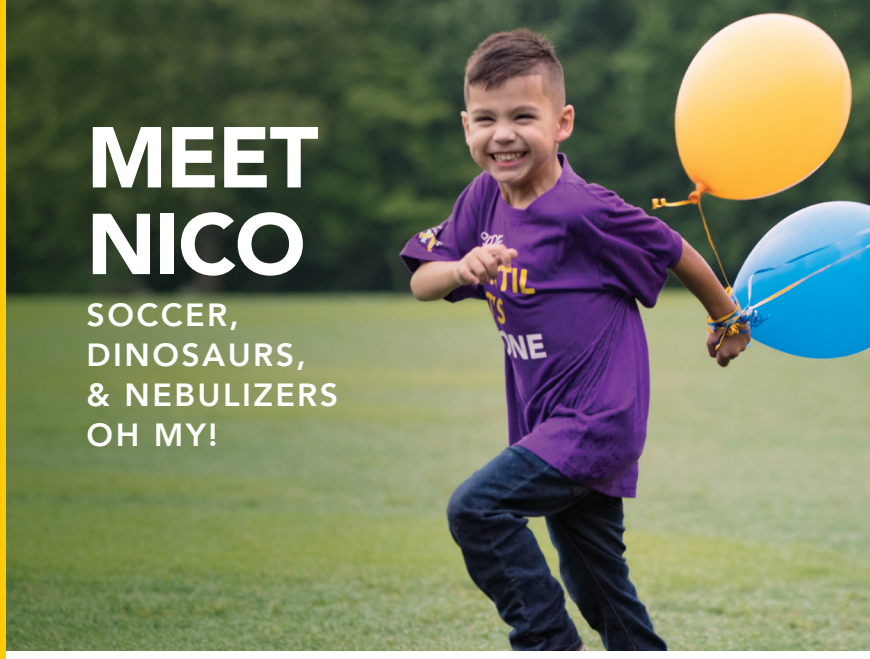
Use the enclosed form to request a complimentary copy of our newest planning guide. For additional valuable tools, visit: **cff.org/legacygiving**.

OR USE A SIMPLE SENTENCE IN YOUR WILL…

I bequeath to the Cystic Fibrosis Foundation (chapter name if applicable), located in Bethesda, MD, Federal Tax ID 13-1930701, the sum of $_____ (or ____ percent of the remainder of my estate).

TO JOIN THE PAUL DI SANT'AGNESE LEGACY SOCIETY.

If you, like many others, leave a gift in your will, trust, or by beneficiary designation to the CF Foundation, I hope you will use the enclosed form to let us know!



MEET NICO

SOCCER, DINOSAURS, & NEBULIZERS OH MY!

Five-year-old Nicolas ("Nico") is happiest running around playing tag outside, going to soccer games, and naming facts about dinosaurs to anyone who will listen. In between typical childhood activities, Nico vigilantly takes his enzymes and keeps up with his airway clearance and nebulizer schedule. "He is a fighter and never complains," said Nico's mom, Astrid. "He's not scared of anything, but at the same time is really sensitive and caring."

Astrid and her family remain excited about the progression of medical developments and dream of the day when there will be a cure for CF. "We have hope not only for Nico, but all those living with CF. We've made so much progress, but there is still much more to do."

Leaving a gift in your will, trust, or by beneficiary designation can help make CF stand for Cure Found for young fighters like Nico. Doing so clearly communicates your dreams for future generations and your desire to help all those living with CF have full, productive lives.

I'M HERE TO HELP

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