



Rachel Hill, Development Manager, Cystic Fibrosis Foundation

Nominated by Allison Watson, PharmD, CSP, AcariaHealth Specialty Pharmacy

Patient Support and Care

Being a mother is challenging, especially when two of your four children are diagnosed with cystic fibrosis (CF). Rachel Hill's daughter, Lucie, was diagnosed at birth, followed by her oldest son, Xavier. As their primary caregiver, she has dedicated her life to ensuring they receive the best care and live life to the fullest.

Rachel tirelessly manages their medical needs, taking them to doctors and specialists, administering medications, and overcoming obstacles so her children don't have to. When Lucie was 3 years old, she was hospitalized for 14 days with a severe respiratory infection. Rachel advocated with the specialty pharmacy and insurance to get her necessary inhaled therapy medication approved and on time for discharge.

Despite lacking a medical background, she educates herself to know and understand what is best for Lucie and Xavier. When a job change led to a new insurance company refusing to cover a specialty medication proven to help patients with CF live longer, Rachel spent hours on the phone with the insurance, the pharmacy benefits manager, the specialty pharmacy, lawyers, and foundations that offer grants. Rachel persisted until she got the medication covered by insurance for both children. Her relentless advocacy and dedication make her an exceptional candidate for the Caregiver of the Year Award.

Advocacy

Rachel is not only an advocate for her two children who have cystic fibrosis (CF), but also for the broader CF community. Despite raising four kids, being a full-time caregiver, and working a full-time job, Rachel prioritizes giving back. Since Lucie's diagnosis in 2014, Rachel has led a team for the Cystic Fibrosis Foundation (CFF) Great Strides Walk, raising money and awareness. She has been team captain every year for the last 11 years.

In her second year on the national CFF Education Committee as the only parent representative, she took her son Jordan to CFF Teen Advocacy Day in Washington, DC. They participated in nine congressional meetings advocating for the HELP Copays Act, which would ban "copay accumulator" schemes and the PASTEUR Act, which aims to enhance antibiotic development and address resistance. These acts would benefit all specialty patients.

In September 2023, she became the Development Manager for her local CFF Gateway Chapter, leading the Great Stride Walks in Missouri. She works closely with six local CF care center teams collaborating on a local and national platform for CF advocacy.

Rachel's selfless efforts and advocacy impact current and future CF patients and other specialty patients. She understands the challenges of disease burden, medical expenses, and health concerns, and remains composed and continues to move forward, inspiring others with her quiet strength and resilience.



Additional Information

Despite caring for two children with CF, Rachel acknowledges the impact on her other children. Many holidays and birthdays have been spent in the hospital, yet her other children without CF choose to be there, reflecting the loving and compassionate example Rachel sets.

The financial burden of CF is immense, but Rachel takes on with stride. She maintains a career to help with medical expenses. Rachel has always kept Lucie and Xavier at the forefront when making career decisions. Leading up to the pandemic, she found a job she could work at from home. This allowed her kids to complete school from home for over two years. This selfless career move allowed Lucie and Xavier the best opportunity to avoid COVID, which could have resulted in serious complications with their disorder.

Lucie and Xavier have been hospital free for four years now. Xavier is a sophomore in high school and pitches for the varsity baseball team, achieved academic all-state honors for cross country, and was inducted into the National Honor Society. He started his first job a year ago as a caddie at a country club. Lucie is a bright and outgoing 10-year-old who loves all things arts and crafts, reading graphic novels, swimming, playing basketball, and above all else, her cats. As a result of Rachel's compassion for caring for Lucie and Xavier, she has given them the opportunity to live their lives to the fullest.