

Sutton's story

When Sutton Burnett was just 5 days old, her parents learned she had CF. Just an hour after her diagnosis, a team from the Emory+Children's Cystic Fibrosis Center of Excellence care program called to help the Burnetts deal with the overwhelming news that their precious daughter would face a lifetime of health challenges. The couple traveled to the CF clinic at Children's Healthcare of Atlanta that day and met with the entire team—a physician, nutritionist, social worker, therapist, and nurses—who would serve as their support system.



Along with the pressures of having a newborn, the Burnetts have had to learn how to help their daughter grow stronger each day. They make sure Sutton stays healthy by working closely with her interdisciplinary care team and relying on her many medications, breathing treatments, and respiratory therapy vest. As she gets older, she will learn to manage the disease on her own. While there is no cure for CF yet, the Burnetts remain hopeful, and the Emory+Children's Cystic Fibrosis Center of Excellence will support them every step of the way.

Imagine a day when cystic fibrosis is cured.



EMORY+CHILDREN'S
CYSTIC FIBROSIS CENTER OF EXCELLENCE

CASE FOR SUPPORT



“What are you doing to save my life?”

a 10-year-old patient asks. The answer from our physicians and researchers is:

“A lot, but we need to do more.”

EACH YEAR
1,000
NEW PATIENTS
ARE DIAGNOSED

We are providing hope and a healthier future for people living with cystic fibrosis.

Combining the power of a comprehensive pediatric health care system and a leading research university, Emory University and Children’s Healthcare of Atlanta are working together to bring an end to cystic fibrosis (CF). Philanthropic support for this partnership, known as the Emory+Children’s Cystic Fibrosis Center of Excellence, will bring us closer to the day we can tell every patient and family: “No need to worry. We have a cure.”

Emory and Children’s care for nearly 700 patients with CF, which places our CF care program among the country’s largest. One of only a handful of such collaborations nationally, the center is transforming patient care, research, and education throughout the Southeast. From the best and brightest research investigators to world-renowned physicians and treatment professionals, our team provides hope and a healthier future for children and adults living with CF.

Because of these strengths, there has never been a better time for philanthropic investment in our CF program. With financial support, the center quickly can become the nation’s premier comprehensive CF resource, providing the highest-quality care and creating breakthroughs in research that will improve patients’ lives.

MORE THAN
75%
OF PATIENTS ARE
DIAGNOSED BY
AGE 2

NEARLY
50%
OF PATIENTS ARE
OVER 18
YEARS OF AGE

NEARLY
40
IS THE MEDIAN
PREDICTED
AGE OF SURVIVAL

SOURCE: CFF.ORG

Cystic fibrosis is an inherited disease in which a defective gene causes intense inflammation, chronic infection, and a buildup of mucus in the lungs. CF also keeps the pancreas from aiding digestion and food absorption. As a result, patients suffer from life-threatening lung infections and malnutrition. Quality of life declines drastically over time, and many patients die during early adulthood. Although treatment advances have been made, CF remains the most common life-shortening genetic disease among Caucasians.

Our Mission

The Emory+Children’s Cystic Fibrosis Center of Excellence is committed to developing a cure for CF. Along the way, we are working to improve patient care so substantially that CF becomes a manageable condition rather than a life-shortening disease.

We will succeed by building our strengths in each of three areas.

1. CLINICAL CARE

GOAL

- Provide the highest quality of care, earning recognition as the CF program with the nation’s best outcome measures. We want our patients to grow old and be healthy.

ACTIONS

- Build our clinical program until it creates the best outcomes for pulmonary function, nutritional status, quality of life, and age of survival.
- Provide patients with the full program of interdisciplinary care they need to maintain wellness.
- Identify and quickly implement best-practice guidelines that improve outcomes.
- Become full partners with patients and families in designing personalized, family-centered health maintenance plans.
- Recruit outstanding clinicians to join our health care team to help patients live longer, healthier lives.

2. RESEARCH

GOAL

- Become the nation’s leading center for research that develops new therapies, drugs, and devices to improve the lives of patients with CF.

ACTIONS

- Foster the growth of an internationally recognized, interdisciplinary program in CF basic and translational research.
- Make new breakthroughs, creating a deeper understanding of CF and identifying new areas for clinical intervention so that no more patients die from this disease.
- Harness the power of partnerships by working with other Atlanta institutions to cure and control CF.

3. EDUCATION AND OUTREACH

GOALS

- Train the next generation of top clinicians, researchers, and other health care workers in interdisciplinary CF care.
- Develop programs that support and educate CF patients and their families.

ACTIONS

- Focus training on the use of modern approaches to characterize this complex disease.
- Provide a program for continued learning, team building, and leadership development.
- Educate the health care community about the center’s clinical and research programs.
- Organize conferences for professionals with different levels of expertise.
- Further strengthen our education and outreach programs for patients and families.



Make a Difference

Developing a world-class Cystic Fibrosis Center of Excellence requires a significant investment of resources from Emory, Children’s, and the philanthropic community. When you become our partner by making a gift, you fuel the center’s work in clinical care, research, and education and outreach. With your help, Atlanta will become the home of the nation’s best comprehensive CF program.

Your gifts can help the center recruit and retain clinical and research leaders, for example. You can support training programs for students and fellows working in center laboratories, preparing new generations of CF researchers. You can help build the infrastructure required for advanced, team-based CF research. And you can help us create a new support team, including a child life specialist and social worker, to assist patients and families with non-medical needs. Throughout the center, your philanthropic support will make a significant difference for patients with CF and their families.

Thank you.