

Focusing and driving all of our efforts
is our mission—
to assure the development
of the means to
cure and control
cystic fibrosis
and to improve the quality of life
for those with the disease.

CYSTIC FIBROSIS FOUNDATION
STRATEGIC PLAN REPORT

What is cystic fibrosis?

Cystic fibrosis (CF) is a life-threatening genetic disease that affects the lungs and digestive system of 30,000 children and adults nationwide.

So far there is no cure for CF, but the Cystic Fibrosis Foundation is determined to change that by working to advance new treatments, improve care and further the quest for a cure.



Priscilla, 9 months

Who are we?

We are...

The leader in the quest to cure and control CF.

The **primary sponsor** of critical research that is making tremendous advances toward a cure and control of CF.

The **nexus for an extraordinary community** of people with CF, their families and friends, medical researchers and healthcare providers, donors and volunteers and more than 500 employees in 80 chapters and branch offices across the country— working together to cure and control this disease.

A nonprofit health organization (tax-exempt 501(c)(3)) based in Bethesda, Maryland and governed by a Board of Trustees whose volunteer members serve independently and without compensation.



In 1955, a small group of parents who had children with CF started one of the most effective and efficient nonprofit disease organizations in the country.

Determined to find help for their children, who were suffering from a rare disease that no one understood very well, these parents turned fear and frustration into hope and action by creating the Cystic Fibrosis Foundation.

At that time, the life expectancy for someone with CF was just beyond one year.

Today, thanks in large part to the work of the Foundation, the median predicted age of survival for those with CF is more than 37 years.

The story of the Foundation is a story of thousands of individuals working tirelessly—to lengthen and improve the lives of people with CF and to one day cure this disease.

“Since we began this work, we’ve seen care significantly improve. We’ve seen a dramatic **increase in life expectancy**. But that’s not enough...we want to put an end to this devastating disease. **And we will not rest until we find a cure.**”

ROBERT J. BEALL, PH.D., PRESIDENT AND CEO

What have we achieved?

“The Cystic Fibrosis Foundation
is the **reason I’m alive.**”

EMILY SCHALLER, 26-YEAR-OLD DRUMMER IN A ROCK-AND-ROLL BAND



Jennifer and son Casey, age 7

Since its modest beginnings in 1955, the Foundation has made incredible strides in the fight to cure CF.

WE HAVE:

“It is an exciting time in the CF medical community. We are developing more potential therapies than ever before that can make a real difference in the lives of those with CF.”

Preston W. Campbell, III, M.D.
Executive Vice President for
Medical Affairs

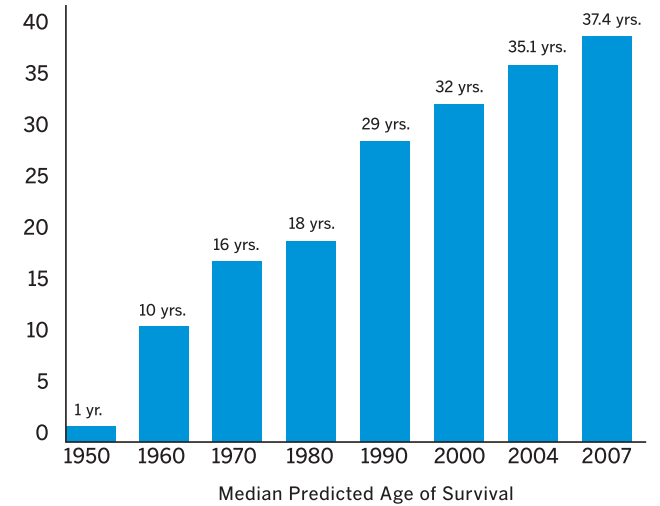
Advanced the search for a cure.

Established to attract the finest talent to our efforts, the Research Development Program (RDP) is a network of research centers of excellence throughout the U.S. Since its inception in 1980, the RDP has helped move CF research forward more quickly by encouraging collaboration among researchers from institutions across a variety of disciplines.

In 1989, Foundation-supported researchers achieved a major milestone when they identified the defective gene that causes CF. This discovery brought CF research one giant step forward in the quest for a cure.

In 1997, our Therapeutics Development Program (TDP) was established to build a robust pipeline of potential therapies for CF. Currently there are more than 30 potential drugs in the pipeline. Some are aimed at treating the symptoms of the disease, others at correcting the genetic defect that causes CF. All of these therapeutic candidates offer hope for a better future for individuals with CF.

In 1998, the Foundation established the Therapeutics Development Network as a subset of its Care Center Network. It is comprised of Foundation-accredited care centers, a central coordinating center at Children’s Hospital in Seattle and laboratories that specialize in interpreting CF outcome measures.



The median predicted age of survival for people with CF is now more than 37 years, more than double what it was just 25 years ago and more than seven times what it was in 1955.

Dramatically improved the length and quality of life for people with cystic fibrosis.

Our Care Center Network, consisting of approximately 110 care centers and 50 affiliate programs nationwide, ensures that people with CF receive the best care possible—no matter where they live. Our Quality Improvement Initiative, designed to make sure that the highest quality of care is available at all of our care centers, has become a nationally recognized model for excellence in care for a chronic disease.

More than 30 years ago, the Foundation developed a CF Patient Registry, which has become an invaluable tool for CF researchers and healthcare providers around the globe.

The Patient Registry provides critical data on clinical outcomes, which enable caregivers and researchers to identify new health trends, recognize the most effective treatments and design clinical trials for potential therapies.

Established and developed the practice of “venture philanthropy,” an innovative and highly effective business model.

Applying business concepts to the search for a cure, the Foundation has pioneered a highly effective model for quickening the pace of drug discovery and development in collaboration with the biotechnology industry.

Our innovative business approach has been recognized by the National Institutes of Health (NIH) and by publications such as *BusinessWeek*, *Harvard Business Review*, *USA Today* and *The New Yorker*. In September 2008, our leadership role in creating this model was highlighted by *Forbes* in a feature story entitled “Patient Power.”

“The Milestones campaign is focused on carrying our message, our track record and our unprecedented opportunity to people who can change the face of this disease sooner, rather than later. Those who so generously support our efforts truly have a chance to save the lives of children and adults with CF.”

Joseph J. O'Donnell

Chair

Milestones to a Cure campaign

“At the heart of our organization is the energy, dedication and generosity of an extraordinary group of people—families, friends, volunteers and donors. They are behind every step we take and every milestone we have achieved in the fight against CF.”

C. Richard Mattingly
Executive Vice President and COO

Developed a reputation as one of the most effective, innovative and efficient nonprofit healthcare organizations devoted to fighting a chronic disease.

As custodians of public investment, it is our responsibility to carry out our work as efficiently as possible, while maintaining the highest standards of excellence.

Year after year, the Foundation has been recognized as one of the most effective and efficient organizations of its kind.

We have invested more money in drug discovery and development with for-profit companies than any other disease foundation in the country.

The Foundation is an accredited charity of the Better Business Bureau’s Wise Giving Alliance, meeting or exceeding all of its Standards for Charity Accountability.

In 2008, we achieved the coveted four-star rating for sound fiscal management from Charity Navigator, the largest independent charity evaluator in the United States.

Expanded the reach and accelerated the pace of our major giving effort in support of a robust therapeutics development pipeline.

In 2004, the Foundation recognized the need for more dollars to keep pace with rapidly accelerating CF research. Under the leadership of Joe O’Donnell, we launched the *Milestones to a Cure* major gifts campaign to raise \$175 million by the end of 2010 to help fund the Foundation’s successful Therapeutics Development Program.

The campaign relies on major gifts from individuals, private foundations and corporations and is on target for reaching its goal.

Fueled by these funds, the Foundation has created its “pipeline of promise” with more than 30 potential CF therapies in development; discovered innovative ways to address the underlying cause of CF; and fostered quality improvement at CF care centers across the nation, resulting in the steady improvement of lung function and weight gain for CF patients.

Enhanced and expanded our volunteer base, engaging 250,000 volunteers and participants in our annual fundraising efforts and recruiting new leaders through our Volunteer Leadership Initiative (VLI).

Each year the Foundation sponsors thousands of fundraising events and efforts across the country. From GREAT STRIDES walks and elegant dinner dances to golf tournaments and silent auctions, from celebrity-sponsored events to spare-change campaigns run by school children, there are numerous ways for people to raise the critical funds needed to search for a cure.

Over the past 20 years, our fundraising from special events has grown by six to 10 percent annually. The Foundation's fundraising activities bring in more than \$150 million in public support revenue every year.

The Foundation's VLI is our primary volunteer recruitment program and is essential to growing and replenishing our vast network of volunteers and keeping the "people pipeline" full. VLI members devote their time and energy to reaching out to the community and recruiting the next generation of volunteer leaders.

Each spring, volunteer leaders and CF staff from across the country attend a two-day meeting at which they discuss proven techniques to recruit new volunteers; talk about ways to make fundraising events more successful; confer about methods to increase donations; exchange first-hand experience on recruiting event chairs; and plan ways to garner more community and business support.

Advocated for better funding and access to insurance and treatments for people with CF.

In 1988, the Foundation opened CF Services, Inc., a full-service pharmacy, to provide nationwide access to the latest CF medications. The CF Services Pharmacy also promotes access by helping CF patients maximize the use of their insurance benefits, by furnishing emergency supplies of medications and by providing hardship assistance on a case-by-case basis.

Although the Foundation receives no funding from the federal government, it maintains a presence on Capitol Hill to ensure that critical research toward a cure for CF progresses. The Foundation educates members of Congress about CF and supports legislation that sustains drug discovery and development efforts.

Launched with the support of the Foundation in 2006, the Congressional CF Caucus has more than 125 members, making it one of the largest caucuses in Congress. The CF Caucus supports funding for CF research through the NIH and other federal agencies; encourages collaboration between the public sector and private organizations; advocates for state-based newborn screening laws; and promotes public policies that address the research and healthcare needs of the CF community.

Other key Foundation initiatives—including a CF Legal Information Hotline and the CF Patient Assistance Foundation—address issues of access and underinsurance to ensure that all CF patients can get the help they need.

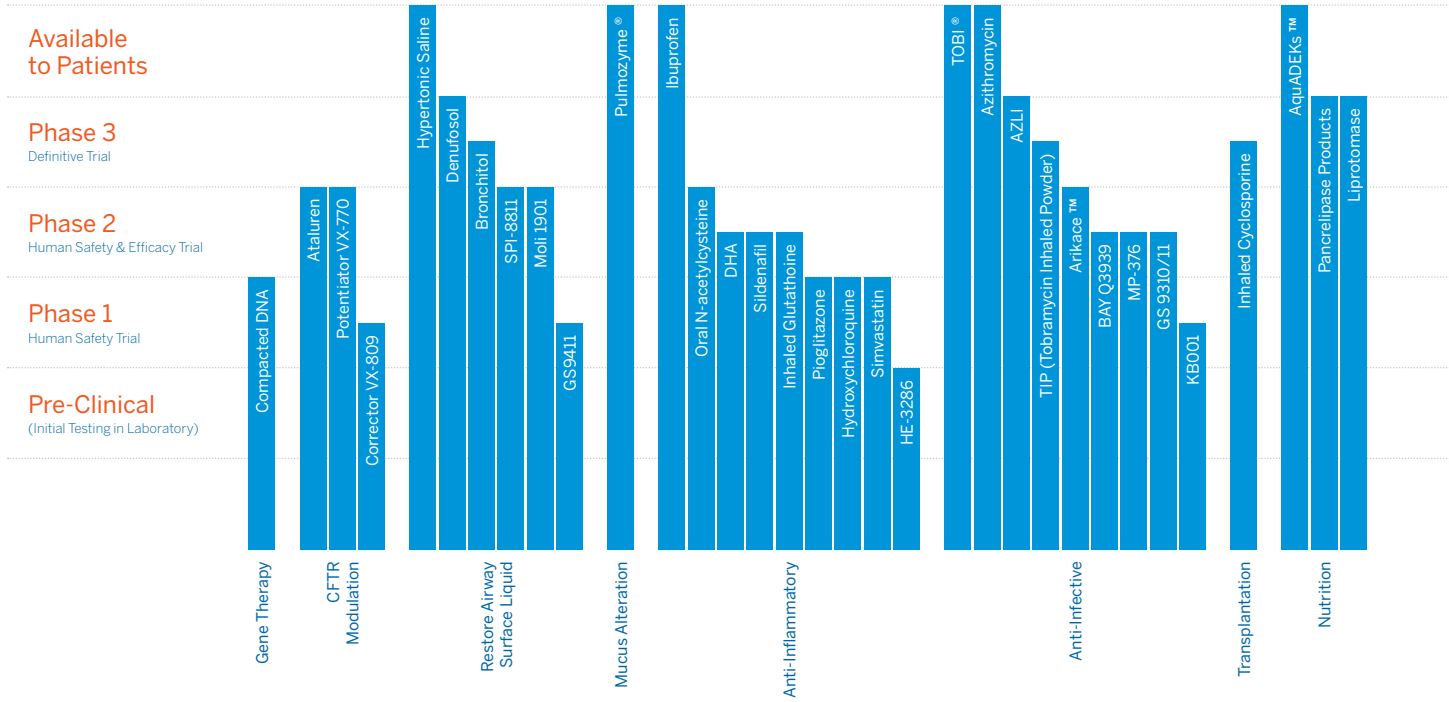
"Bringing our mission to Capitol Hill and getting our congressmen and women and senators to support us can translate into increased awareness about the disease, the cost of treatments and the need for extra funds for research."

Marc Cassalina

National Advocacy Co-Chair

Father of Eric, age 17

CYSTIC FIBROSIS THERAPEUTICS PIPELINE



Virtually every approved CF therapy available today was made possible because of the Foundation and its supporters.

Where are we going?

Our **strategic plan** for the next five years is based on the **solid progress** we have made in the past, and is **fueled** by our unrelenting determination to **reach our goals**.



⊕ Aaron, age 23

Throughout our history one of our greatest strengths—and the key to our success—is the fact that we have never lost sight of our central mission, and we have always maintained a clear sense of our priorities.

Keeping these priorities at the forefront, we have identified four primary **strategic objectives** for the next five years.

WE WILL:

Develop new medical treatments for people with CF.

Our pipeline of potential therapies has been critical to our past success—and it is the key to meeting our future goals.

As we continue to oversee development of the numerous drugs in our pipeline, we built a strategic plan flexible enough to respond to changes brought about by new and emerging knowledge and technology, and addresses the challenges of both success and disappointment in our drug discovery efforts.

Going forward, our priorities will continue to be to:

- Collaborate with both academia and industry, making sure to keep a close watch on novel scientific developments and keep our research efforts on the cutting edge.
- Increase our focus on knowledge management, developing systems that will help us effectively and efficiently assimilate the countless new data emerging from both our biopharmaceutical and academic collaborators.

- Encourage greater participation in our clinical trials program to ensure that new treatments are made available to those with CF as quickly and safely as possible.
- Maintain a detailed and up-to-date risk mitigation plan that proactively identifies risks and provides strategies for managing the consequences of our successes in drug discovery and development, as well as those projects that do not yield anticipated results.

“I want everyone to know that there are people here to help. They are not alone... there should never be a reason why someone doesn't have the necessary medication to treat cystic fibrosis.”

Beth Sufian, J.D.
Director
CF Legal Information Hotline

Deliver high-quality, compassionate patient and family-centered care through our Care Center Network.

In 2002, the Foundation launched a Quality Improvement Initiative to help people with CF live longer, healthier lives. This initiative allows individual care centers to evaluate their own practices and determine how they can improve. To continue to deliver the best care possible, the Foundation will:

- Recruit more pediatric and adult care providers who are well-trained in providing state-of-the-art, high-quality care for those with CF.
- Ensure that all of our care centers fully incorporate the Foundation's quality improvement methodology so that those with CF will receive a consistently high-level quality of care no matter where they live.
- Expand the scope of data provided in the Patient Registry and the ways we mine that data to foster greater progress in the development of new treatments.
- Work with our industry and academic collaborators to select and implement a quality-of-life instrument to monitor the impact and assess the practicality of novel therapies.
- Work with healthcare practitioners to monitor "burden of care" issues for CF patients as new therapies become available.
- Find ways to reduce the burden of treatment for people with CF.

Help patients and their families find new ways to improve their self-management skills.

We believe that people with CF and their families understand their needs best and are the greatest advocates for their own healthcare requirements.

We will continue to:

- Listen to what people with CF and their families tell us they need in order to improve their daily care.
- Develop and implement new resources for collaborative self-management.
- Find more ways to support and encourage people with CF and their families to practice collaborative self-management with their healthcare providers.
- Involve people with CF and their families in the development of clinical research trials.

Expand access to quality CF care.

The development of new CF therapies is vital to our success; so is ensuring that once these therapies reach the marketplace, the people who need them are able to obtain them. In keeping with our mission, we will continue to ensure that people with CF have access to the highest quality care and to the treatments that emerge from our pipeline.

Never losing sight of whom we serve and why, we will:

- Conduct surveys and other research to measure and understand the challenges of accessing CF care and treatment.
- Design and execute communications plans that will educate both the CF community and others about the challenges that can arise in gaining access to care and provide potential solutions to these challenges.
- Provide information, tools and resources to help people with CF and their families obtain access to the healthcare and CF medications they need.

How will we get there?

In support of our strategic objectives,

WE WILL CONTINUE TO:

“Just as we strive to keep our drug development pipeline stocked with potential new treatments, we are dedicated to keeping our ‘people pipeline’ full, energized and moving forward.”

Ann Palmer
Senior Vice President of
Field Management

Explore and develop new ways to fund our mission.

We will continue to use the best practices that have served us so well in the past, while embracing fresh strategies to create an even more successful and dynamic future.

Critical to this effort is our ability to attract and retain volunteers. We will draw on new data and fundraising techniques as they evolve to enhance our current abilities and to develop innovative new strategies for reaching both current and prospective donors.

Through it all we will count on the ongoing spirit, loyalty and commitment of our “people power”—our volunteers, donors and staff—the engines that fuel our search for a cure.

Specifically, we will:

- Continue to build and grow our most successful fundraising programs, such as GREAT STRIDES, *Milestones to a Cure* and special events.
- Establish a Corporate Leadership Council to help open new doors and garner increased commitment from the corporate community.
- Enhance and expand our Volunteer Leadership Initiative, with a special focus on recruitment and retention of volunteers.
- Broaden our focus on major gifts and planned giving through *Milestones to a Cure*.

- Increase special events aimed at up-and-coming young professionals through our Young Professionals Leadership Committee.
- Continue to develop, support and grow our successful fundraising programs such as *CureFinders*®.
- Embrace new communications tools and technology, such as Web 2.0, and use them to build, retain and expand our volunteer base.

“The Foundation has an extraordinary business mentality. Using strong technological platforms, we must continuously seek to build tools for our leadership team, ensuring that we get better and better at understanding challenges before us and, most important, how to efficiently and effectively address them.”

Vera Twigg
Senior Vice President and CFO

“The economic situation continues to change, but the disease—and its impact on the lives of those who have it—remains constant. We know that with the abundant energy, enthusiasm and dedication of our community, we can and will accomplish our goals.”

CATHERINE C. McLOUD, CHAIR, CF FOUNDATION BOARD OF TRUSTEES
AND MOTHER OF WILL, AGE 27



Mary-Leigh, age 26

Nourish and maintain our “people pipeline.”

People are our greatest resource.

To ensure that we are able to attract and retain high-caliber, high-performance employees who are committed to the Foundation as an employer, we will:

- Position the Foundation as an organization with a reputation for hiring only the best employees, and expecting high performance from them.
- Provide our employees with a positive work environment, as well as the training and resources they need to be successful in their jobs.
- Implement a nationwide college internship program as a source of employee talent.
- Provide opportunities for career advancement internally.
- Attain and maintain high levels of employee satisfaction.

Evaluate and improve the effectiveness of our communications, taking full advantage of new means of and strategies for reaching our various audiences.

The Foundation educates a wide and diverse audience about its mission through print and electronic publications. To expand public awareness of our quest to cure and control CF, and to provide those with CF with the information they need to live better, healthier lives, we will:

- Modernize and maximize the effectiveness of our Web site, providing a platform for video and Web 2.0 applications to attract a larger and more diverse user base.
- Expand the use of e-marketing and other new marketing tools.
- Develop additional materials to inform both our community and external audiences about the challenges and potential solutions of gaining access to care for those with CF.
- Create new information tools and educational resources for CF patients to promote collaborative self-management.
- Apply the Foundation’s brand—using our empowerment theme and new visual identity—to VLI materials to better articulate the key message of the VLI and to aid in recruiting and retaining qualified leadership volunteers.

Enhance our organizational structure so that all departments optimally align with our science and medical programs.

Our science and medical programs and our fundraising operations are intricately intertwined in pursuit of one common goal: simply stated, money buys science and science saves lives. The more seamless and efficient our operation, the more money we have available to pursue our goals effectively. To this end, we will:

- Leverage the power of cff.org to accelerate the advancement and communication of new developments in CF science.
- Enhance our information technology infrastructure to optimally support medical and scientific programs.
- Encourage greater community involvement in our programs by streamlining our communications pathways and making them more user-friendly.
- Improve patient and family access to information that will help them practice effective collaborative self-management healthcare.
- Cultivate and sustain synergies between our medical and fundraising team efforts.

What Can You Do?

Join Us...



Keith, 11, and sister Kennedy, 4

Twenty-five years ago, the hope for children with CF to grow up, have successful careers and start families of their own seemed a distant dream. Today, with the help of our extraordinary community of patients, families, volunteers and donors, that dream is becoming a reality. By building on our past success and dedicating ourselves to finding new ways to address the challenges ahead, we know the future for those with CF will be brighter still. We need you now—more than ever before—to sustain critical momentum in research and drug development, and to advance our quest to find a cure for CF. Help us make CF stand for “Cure Found.” You can make a difference.

Visit www.cff.org to learn how you can support the CF Foundation’s life-saving mission.



| Adding *tomorrows* every day.

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