The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment and ensuring access to high-quality, specialized care.
Sixty years ago, the Cystic Fibrosis Foundation was born out of the big dreams of parents who wanted their children to have the opportunity to live long, healthy lives. They paved the way for the remarkable progress our community continues to make, allowing us to dream even bigger today.

This is an exciting and transformational time in the history of cystic fibrosis. More than half of all those with the disease are now adults, a tribute to the hard work of our extraordinary team — people with CF and their families, volunteers, care teams, researchers, donors and friends.

Our community celebrated another big win with the approval of lumacaftor/ivacaftor (Orkambi®), the second drug to treat the underlying cause of the disease. The number of individuals with CF who can benefit from these important therapies is steadily increasing, and we are working aggressively to accelerate development of more disease-modifying therapies for the greatest number of people possible.

We are pursuing new opportunities to truly make a difference in the day-to-day lives of people with CF and help ensure they have access to the treatments and specialized care they need. We remain committed to working closely with individuals with CF and their families to identify the best ways to support them, now and in the future.

But our work does not stop there. Our shared dream is to put an end to this disease. We know this will not be easy, but I am confident that our amazing team has the passion, determination and spirit of collaboration to reach our ultimate goal of a cure for all people with CF.

Sincerely,

Preston W. Campbell, III, M.D.
President and Chief Executive Officer
Targeting the Underlying Cause of CF

EXPANDING TRANSFORMATIVE TREATMENTS

In July, the CF community celebrated the news of the U.S. Food and Drug Administration (FDA) approval of lumacaftor/ivacaftor (Orkambi®), the first combination drug to treat the root cause of the disease.

The FDA approved lumacaftor/ivacaftor for individuals ages 12 and older who have two copies of the most common CF gene mutation, F508del, amounting to about 8,500 people, or nearly one-third of those with CF in the United States. Clinical trials of the drug are underway in people under age 12 with two copies of F508del. If the trials are successful, close to half of all individuals with CF could eventually benefit from the treatment.

Earlier in the year, the FDA expanded the use of ivacaftor (Kalydeco®) as a single therapy to individuals with CF ages 2 and older who have one of 10 rare mutations. Ivacaftor is now available to about 8 percent of people with CF, and trials of the drug in people with other rare mutations continue.

Both ivacaftor and the combination lumacaftor/ivacaftor treatment are the result of a long-term strategy to develop small-molecule compounds that could modulate the defective CFTR protein caused by mutations in the CF gene and improve key symptoms of the disease. The drugs were developed by Vertex Pharmaceuticals Inc. with support from Cystic Fibrosis Foundation Therapeutics Inc. (CFFT), the Foundation’s nonprofit drug discovery and development affiliate.

The CFFT Laboratory moved into a larger state-of-the-art facility in Lexington, Mass., in December. The Lab is now expanding into new technologies, including gene editing, and has increased its focus on nonsense mutations of CF.
Katrina Young
Mother of a Teen with CF

“No longer a fair-haired, chubby-cheeked toddler, my son now shaves every day and is tall enough to look me straight in the eyes. In every sense, the CF Foundation has literally changed the face of this disease.”

Vertex is conducting several Phase 3 clinical trials of ivacaftor coupled with another compound, VX-661, including trials in individuals with one copy of F508del and a second copy that falls into any of three groups of other CF mutations. Results from the first of these trials are expected in 2016 and could help bring about an additional treatment to people living with CF.

DISCOVERING NEXT-GENERATION CFTR MODULATORS

To maximize the scientific knowledge gained from early CFTR modulators, CFFT has significantly expanded its support for programs designed to discover new, and potentially more powerful, compounds, and has attracted a growing number of pharmaceutical companies to the CF effort.

A top priority is advancing treatments for individuals with rare CF mutations who likely will not benefit from first-generation modulators.

As part of its new Nonsense and Rare Mutations Therapeutics Initiative, CFFT is supporting a collaboration between Southern Research and the University of Alabama at Birmingham that is using a sophisticated screening process to find therapies for people with nonsense mutations of CF. These mutations prematurely stop production of a full-length CFTR protein and require a different approach than modulating the CFTR protein.

Screening for nonsense mutation therapies is also taking place at the CFFT Laboratory, which conducts tests of promising compounds identified by other researchers as well as its own collection. The CFFT Lab has moved into a new and larger state-of-the-art facility in Lexington, Mass., allowing it to sharpen its focus on finding treatments for nonsense mutations and expand its scientific team to help refine emerging technologies for CF.
EXPLORING TECHNOLOGIES FOR A ONE-TIME CURE

Exciting scientific progress in cutting-edge technologies like gene editing, RNA therapy and stem cell biology are making it possible for the first time to repair genetic defects at their source. Some of these strategies could help lay the groundwork for the Foundation’s ultimate goal of a one-time cure for all people with CF.

CFFT funded nearly 50 new basic science projects, many in laboratories not previously working in CF, with a focus on optimizing tools that could be applied to CF research and cultivating future drug discovery programs. Some of these technologies could address the early cellular processes that generate the malfunctioning CFTR protein in people with CF, regardless of an individual’s mutations. These new technologies will be further explored at a research conference that will bring together top scientists in the summer of 2016.

Tackling CF From All Angles

NEW TREATMENT FOR NUTRITION

People with CF who rely on tube feeding have another tool to help them improve their nutrition. In December, the FDA approved Relizorb™, a cartridge containing digestive enzymes that help break down beneficial fats in supplemental nutrition. Developed by Alcresta Inc. with funding from CFFT, Relizorb simplifies the use of enzyme supplements for people with CF who have overnight tube feedings or are in intensive care units.

PRESERVING AND IMPROVING HEALTH

Despite tremendous progress in combating lung infection and damage, respiratory problems remain the most serious and persistent complication for people with CF. Clinical trials to prevent or slow damage to the lungs include potential new treatments for infections caused by bacteria that are resistant to multiple antibiotics.

The Foundation is supporting several clinical trials that may help improve treatment of difficult lung infections. One Phase 2 trial is studying the effectiveness of the chemical element gallium in treating people with CF who are chronically infected with antibiotic-resistant strains of the bacteria *Pseudomonas aeruginosa*.

FDA Approves Orkambi to Treat Root Cause of CF

The approval of lumacaftor/ivacaftor (Orkambi) is an important advance for the cystic fibrosis community. This step has the potential to affect the lives of nearly one-third of individuals with CF in the United States.
In a planned Phase 3 study, researchers will investigate whether aggressive treatment with an inhaled version of the antibiotic vancomycin (AeroVanc™) can address persistent lung infections caused by methicillin-resistant Staphylococcus aureus (MRSA). Other studies are looking at the roles of azithromycin and tobramycin in treating new and existing Pseudomonas infections.

Lung inflammation is another serious problem for people with CF. White blood cells damage the tissue in the airways and can be just as destructive as infections. Because of this, CFFT is supporting a targeted effort to develop more anti-inflammatories, including two ongoing Phase 2 trials evaluating potential drugs to reduce the production of molecules that lead to or increase inflammation. Another two anti-inflammatory trials are scheduled to start in 2016.

New strategies to thin the mucus that builds up in the lungs of people with CF remain a priority. A Phase 3 clinical trial is testing an inhaled form of mannitol (Bronchitol™), which works by drawing water into the airways. Another Phase 2 trial is evaluating the potential drug VX-371 (formerly P-1037), designed to block the sodium channel in airway cells, which might help the lungs retain fluid after hypertonic saline treatment.

In addition to these clinical research programs, the Foundation has initiated a large effort to improve outcomes for individuals with CF who have had lung transplants. It is also working with leading scientists and physicians to expand research in multiple areas that cause significant health problems in individuals with CF, including nontuberculous mycobacteria infections, fungal infections and pulmonary exacerbations.

Supporting CF Clinical Research

Boosting Capacity and Participation

CFFT’s Therapeutics Development Network (TDN) oversaw nearly 40 clinical trials across the CF therapeutic spectrum, including 23 new trials — more than triple the number of new trials in any single year.

To enhance the network’s capacity to carry out the high volume of trials, CFFT provided funding to hire and help train an additional 75 research coordinators. In April, the TDN held its annual spring research meeting, bringing together staff from all of the network’s 82 research centers to discuss priorities, provide training and troubleshoot common challenges.

The Foundation is also working harder to foster a culture of clinical trial participation among people with CF and their families, and to improve referrals between centers to ensure all trials are fully enrolled and successfully completed. With direct input from the CF community, CFFT is creating powerful online tools to help people with CF find information about clinical trials on CFF.org and more easily identify opportunities that interest them.

The annual North American Cystic Fibrosis Conference is the world’s largest cystic fibrosis medical conference. The 2015 conference brought more than 4,000 scientists, clinicians and caregivers from 42 countries to Phoenix, with an additional 950 people viewing sessions through online streaming.
To advance drug development and a search for a cure, Cystic Fibrosis Foundation Therapeutics (CFIT) has contractual agreements with several companies to receive royalties related to drugs that are developed as a result of CFIT funding. Any royalties we receive are used in support of our mission.
Twenty-first century businesses will rely on American science and technology, research and development. I want the country that eliminated polio and mapped the human genome to lead a new era of medicine—one that delivers the right treatment at the right time.

In some patients with cystic fibrosis, this approach has reversed a disease once thought unstoppable. So tonight, I’m launching a new Precision Medicine Initiative to bring us closer to curing diseases like cancer and diabetes, and to give all of us access to the personalized information we need to keep ourselves and our families healthier. We can do this.”

President Barack Obama
2015 State of the Union Address
Robert J. Beall, Ph.D., stepped down as president and chief executive officer of the Cystic Fibrosis Foundation. Preston W. Campbell, III, M.D., previously the Foundation’s executive vice president for medical affairs, succeeded Dr. Beall as president and CEO.

During his 35 years with the Cystic Fibrosis Foundation — 21 years as its president and CEO — Beall had a profound impact on the lives of people with CF. Under his leadership, the Foundation achieved unprecedented gains in research, treatment and care, and as a result people with CF are living longer, healthier lives than ever before. When Beall joined the Foundation in 1980, the median predicted age of survival for a person with the disease was 18 years of age — today it is more than 40 years. For the first time ever, more than 50 percent of people with CF are over 18 years of age. CF is no longer a pediatric disease.

“We are profoundly grateful for Dr. Beall’s leadership and in awe of his many accomplishments. During his more than three decades with the Foundation, he has had a transformative impact on the CF community,” said Catherine C. McLoud, chair of the CF Foundation Board of Trustees. “A CF trailblazer in his own right, Dr. Campbell joined the CF Foundation 17 years ago and has the expertise and vision to propel the organization forward in the years to come. I am confident that Dr. Campbell will continue to further the Foundation’s mission in both research and patient care in the coming years.”
Cystic fibrosis care has long been a collaboration between people with CF and the multidisciplinary teams at the Cystic Fibrosis Foundation’s network of 120 accredited care centers and 55 affiliate programs. Specialized, comprehensive care helps individuals with CF — who already have expert knowledge of living with their disease — become more involved in managing their own care and treatments to improve their health.

**Patient Registry**

**SHARING HEALTH INFORMATION TO IMPROVE CARE**

The Foundation’s Patient Registry captures a broad range of data on the health of those living with CF, providing critical information to help advance many important initiatives, from improvements in the quality of CF care and the development of care guidelines to the design of clinical trials to test new CF therapies.

For the first time, more than half of the 28,000 people who share their health information in the Registry are age 18 or older — an important milestone in the history of CF. Highlights of the most recent data suggest steady gains in key health measures among adults with CF, including pulmonary function and nutrition, as well as a near doubling in the number of college graduates.

The data also continue to shine light on areas for further improvement. Many individuals with CF still require hospitalization for treatment of pulmonary exacerbations and, as more are living into adulthood, many now face other health problems such as CF-related diabetes and depression.

**Partnerships for Sustaining Daily Care**

**HARNESSING THE POWER OF RELATIONSHIPS**

People with CF and their family caregivers can face many barriers to managing their CF — a demanding regimen that includes daily airway clearance, medication, nutrition therapies and fitness, making it one of the most challenging burdens of living with the disease.

Acknowledging these complex barriers, the Foundation brought together a committee of adults with CF, parents, members of multidisciplinary care teams and representatives from specialty pharmacies and pharmaceutical manufacturers to form Partnerships for Sustaining Daily Care, a multipronged initiative to discover and develop effective ways for people with CF to routinely manage their prescribed therapies successfully.

Although the CF care model has improved health outcomes for people with CF, much work is underway to continue building on our progress and harness the community’s collective power to coproduce high quality care over the long-term.
The initiative's early activities include a pilot study to gain insights into patient and clinician perspectives on conversations about managing daily care, and projects to identify objective measures to track adherence, including barrier screening tools and the reporting of prescription refill data. In addition, a team of clinical researchers is working with individuals with CF and their families to better understand how technology can be used to support them in maintaining complex treatment regimens.

**CF Care Model of the Future**

**INNOVATIVE IDEAS AND TECHNOLOGY**

In an ongoing initiative with the Dartmouth Institute and Cincinnati Children's Hospital Medical Center, the Foundation completed the first phase of a formal design process to develop a system of care that is based on collaborative learning and supported by Registry data to deliver even better care.

Project teams representing stakeholders from the CF community have identified components of a future model that hold the most promise. One component is a digital dashboard where individuals with CF and their clinicians can track health information and changes in the care routine, and review health priorities and potential barriers to sustaining daily care between care center visits.

A Pilot Learning Network will test and refine these components at 10 to 15 pediatric and adult CF programs in 2016, using monthly virtual meetings and semiannual conferences.

**Guidelines for Screening and Treatment of Anxiety and Depression**

**BROADENING CARE TO SUPPORT MENTAL HEALTH**

People with cystic fibrosis and parents of children with CF are two to three times more likely than the general population to experience depression, anxiety or both. When left untreated, these conditions can interfere with the successful management of daily therapies, which in turn can affect both quality of life and health outcomes for those living with the disease. In collaboration with the European Cystic Fibrosis Society, the Foundation developed clinical care practice guidelines with recommendations for prevention, screening, clinical assessment and treatment for those receiving care at CF care centers.

The Foundation uses Registry data to continuously improve the quality of care that is delivered. At the heart of the Foundation’s care model are the long-term relationships people with CF develop with their care teams.
To support the implementation of the guidelines, a Foundation-sponsored task force recommended adding the role of a mental health coordinator to care teams. Following a request for applications, the Foundation issued awards to help support the addition of a mental health coordinator at 84 of the 154 programs that applied. Given the overwhelming response, a second round of awards is planned for 2016.

Patient and Family Experience of Care Survey

ENHANCING QUALITY FROM THE PATIENT PERSPECTIVE

Just as health outcomes are important measures of quality care, so too are the experiences of individuals with CF and their families during care center visits. Launched nationally in January, the Patient and Family Experience of Care Survey offers care teams an important look at how people with CF and their families perceive the quality of care provided.

The survey was developed with input from adults with CF, parents of children with CF and care team members. Responses are collected anonymously online, by phone or on tablets provided during a clinic visit, and the data are then aggregated and reported to the care center to review how it is doing and how it compares with others. More than 130 pediatric and adult care programs are enrolled in this important initiative, with more in the process of enrolling as care teams realize how helpful the feedback is for informing their quality improvement work.

“We know that your lives are hectic and that adding another daily CF treatment can make it even more so. It’s part of our job to help you with this by sharing what we know from our experience and what we have learned from other people with CF.”

Mary Lester, R.T.
Respiratory Therapist
Keck Medical Center of USC
A core component of the Cystic Fibrosis Foundation’s mission is to ensure that people with CF have access to high-quality, specialized care and treatments. Members of the cystic fibrosis community play an instrumental role in helping the Foundation engage policymakers at all levels of government on issues vital to the care and well-being of those living with CF, including initiatives and legislation aimed at advancing CF research, drug discovery and development.

Access to and Coverage of CF Care

Lack of adequate insurance coverage for CF medications has been a consistent concern for those living with the disease and their families. To better address these needs, Cystic Fibrosis Foundation Compass was launched in early 2016. Formerly known as the Patient Assistance Resource Center (PARC), Compass is a highly personalized service tailored to an individual’s circumstances related to complex insurance, financial, legal and other issues that can prevent access to much-needed CF therapies and care.

In 2015, skilled case managers helped more than 1,700 people with CF and their families understand and maximize their insurance coverage and benefits. Case managers also assisted many others with finding resources for issues related to life with CF that can affect access, including basic living and food expenses.

As a result of new government regulations, the Foundation closed the Cystic Fibrosis Patient Assistance Foundation program (CFPAF). Foundation staff helped more than 1,200 people successfully transition to a new service provider, HealthWell Foundation®, to ensure that those individuals maintained access to financial assistance to help with medication co-pays.

PROTECTING ACCESS AND COVERAGE IN THE STATES

Across the country, CF advocates met with elected officials to educate policymakers about CF and the unique needs of people living with the disease and their families. The Foundation worked with volunteer advocates and care center providers in more than 35 states to ensure access to vital CF care and treatments.
“The greatest thing about CF Foundation Compass was that they called me to follow up and make sure that their assistance actually did help me and, if not, how they could work on finding other options for me. It felt like someone was finally on my side and understood how much trouble it is to figure this all out on your own. I thank them immensely.”

Sarina Sandstrom
Adult with CF

These efforts included protecting funding for critical health programs like Medicaid and Children with Special Health Care Needs, attending Medicaid committee hearings to safeguard access to CF therapies and hosting two state advocacy days in New York and Massachusetts to raise CF awareness among state legislators.

Following the approval of lumacaftor/ivacaftor, the Foundation worked with care center providers, individuals with CF and their families to educate Medicaid programs and other insurers about this new CF therapy, engaging with officials in 26 states. Ultimately, every state with individuals who were eligible for lumacaftor/ivacaftor established an avenue for coverage for the therapy.

ENGAGING WITH INSURERS
In February, the Foundation hosted state Medicaid officials, private insurance representatives, care center providers, health experts and a person with CF at a forum to discuss innovative ways to improve access to quality CF care. Participants identified opportunities for the Foundation to work with payers to make informed coverage decisions, improve standardization of care and reduce the administrative burden on people with CF, their families and health care providers — with the ultimate goal of improving the health and well-being of those with the disease.
Advocating to Advance CF Research and Drug Discovery

CF community volunteers successfully advocated for more funding for the National Institutes of Health (NIH) to support basic and translational research that directly benefits people with cystic fibrosis. The NIH’s budget included full funding for President Barack Obama’s Precision Medicine Initiative, aimed at enabling health care providers to customize treatment and prevention strategies to the individual.

The president’s initiative has put CF and the work of the Foundation at the forefront of this cutting-edge approach to treating illnesses. The progress in treating CF was held up as a model of excellence in medicine by the president during the 2015 State of the Union address, at the official launch of the initiative and at a White House Champions of Change ceremony.

To educate policymakers on how they can support and advance the initiative, the Foundation hosted a congressional briefing, Precision Medicine & Cystic Fibrosis: Using Genetics to Treat Disease, in collaboration with the Congressional Cystic Fibrosis Caucus and its co-chairs, U.S. Reps. James McGovern and Tom Marino.

SUPPORTING PARTICIPATION IN CF CLINICAL TRIALS

The Foundation supports policies to ensure that the drug development process is efficient and that new drugs for people with CF are safe and effective. Through these efforts, the CF community supported the need for reliable, robust funding for the U.S. Food and Drug Administration and spearheaded legislation to remove barriers to clinical trial participation.

In September, the U.S. Congress passed the Ensuring Access to Clinical Trials Act (EACT), which permanently removed a barrier to clinical trial participation. The legislation makes the Improving Access to Clinical Trials Act (IACT) of 2009 permanent, allowing individuals living with rare diseases like CF to receive compensation for participating in clinical trials without losing access to Supplemental Security Income and Medicaid benefits. The Foundation provided expert testimony to the House Energy and Commerce Committee’s Subcommittee on Health in support of EACT, and also formed a broad-based coalition in support of the bill, collecting signatures from more than 75 organizations.

CF community volunteers sent nearly 30,000 messages and held more than 450 meetings with members of Congress to advocate for the passage of EACT. With more clinical trials underway for potentially life-changing CF treatments than ever before, it is critical that as many people as possible have the opportunity to participate in these trials.
With the creation of a new Community Partnerships department, the Cystic Fibrosis Foundation has significantly broadened its ongoing efforts to partner with — listen to and learn from — people with CF and their families in all of its activities. Under a new vice president, the department is spearheading efforts to increase connectivity between the Foundation and people with CF and ensure that its programs are relevant to the day-to-day lives of those living with the disease.

**Adult Advisory Council and Adult and Family Advisors**

**LISTENING TO COMMUNITY VOICES**

To formalize the involvement of the CF community in its initiatives, the Foundation partners with two advisory groups to inform ongoing and new projects that could help improve the everyday quality of life of individuals with CF.

CF Adult and Family Advisors (AFA) was launched in 2014 to serve as a consultative body and partner to the Foundation on various activities. The group is composed of nearly 300 parents, caregivers, spouses, siblings and people with CF. The Adult Advisory Council (AAC), which was adopted into the Foundation’s bylaws, consists of 12 adults with CF who are charged with conveying the hopes, needs and aspirations of adults living with CF.

Both the AFA and the AAC contribute ideas and feedback on the Foundation’s work through surveys, focus groups, individual interviews, studies and targeted committees. Plans for 2016
“The vision of Community Partnerships, the Foundation’s newest department, is to bring the perspective of people with CF and their families into all Foundation activities, and to support and partner with people touched by CF every day.”

Drucy Borowitz
Vice President of Community Partnerships at the CF Foundation

include efforts to make these groups more representative of the community’s demographic diversity and to find new ways to incorporate the AFA and the AAC across Foundation programs.

Peer-to-Peer Mentoring Program

**SHARING LIFE EXPERIENCES**

The Foundation took significant steps toward developing a peer-to-peer mentoring program, which will match adults with CF on specific topics related to life management. The program will draw on the knowledge of trained members of the CF adult community who will provide a safe, comfortable outlet for individuals with CF to receive support from someone with expertise in living with the disease.

The mentoring program has completed its second phase, in which five people with CF, six clinicians, one parent and three Foundation staff members developed a pilot road map and program, with a planned launch at 12 adult care centers in May 2016. The peer-to-peer mentoring program exemplifies the Foundation’s growing efforts to partner with people with CF and their families and provide high-quality resources to those living with the disease.
The unflagging persistence of those who dare to dream big has fueled remarkable progress for people living with cystic fibrosis. The Cystic Fibrosis Foundation had a banner year, thanks to many individuals — generous donors, volunteers, families and friends — who remain deeply committed to finding a cure for CF.

SUPPORTING PROGRESS TO FIND A CURE
The Foundation’s chapters hosted more than 1,000 events from coast to coast. Every person who gave their support made an impact in the ongoing quest for a cure and in helping those with CF live healthier lives today. As one team, with one dream, the Foundation relies on many generous individuals to help accelerate progress and make life for those with CF better today.

VOLUNTEER ENGAGEMENT
Throughout the year, nearly 16,000 dedicated volunteers made incredible strides by supporting events, raising awareness and giving their time and talent. At the Community and Collaboration Volunteer Leadership Conference, 535 volunteers and donors gathered to share personal stories, network and learn about fundraising best practices and scientific breakthroughs that are advancing the Foundation’s mission.

In October, attendees enjoyed a new Volunteer Engagement Conference, held in conjunction with the North American Cystic Fibrosis Conference in Phoenix. The event provided a great opportunity for the volunteer leaders of the Foundation’s West Coast chapters, family members, advocates and individual giving program participants to engage with others who seek to make a difference in the fight against CF.

In September, the Foundation was thrilled to launch the teamMATE (Make Adding Tomorrows Easier) initiative to further recruit, engage and retain volunteers. The goal of the campaign is to inspire action, recognize volunteer contributions, train volunteers on services and build connections between people living with CF and volunteers.

SPECIAL EVENTS
Together, impassioned supporters throughout the CF community held an array of festive events to raise funds and attract first-time donors, as well as new volunteers. Across the nation, individuals participated in Great Strides walks, CF Cycle for Life, Xtreme Hike and golf events to make a difference. They also donned their finest attire and danced the night away at hundreds of dinner dances, black-tie galas, wine tastings and CF Foundation’s Finest events, many of which featured premier live and silent auctions, high-energy entertainment and gourmet food. Collectively, the Foundation netted $91 million from its special events.

More than 125,000 Great Strides walkers gathered in nearly 500 locations across the United States to show their support for those with CF. Together, they raised nearly $42 million.
“Keeping a person with CF healthy takes a lot of teamwork. My son Will was diagnosed with CF when he was two years old. When someone you love is diagnosed with CF, your world changes. You welcome into your life entire teams of doctors, nurses, CF Foundation volunteers, chapter staff and, by extension, researchers and scientists around the world. Today, because of that powerful teamwork, Will is 34.”

Catherine C. McLoud
Chair, Board of Trustees
“I am so proud that I was able to finish the hike — it was a great accomplishment for me — but I have to give credit to my cousin, Ilene. She has battled CF her entire life and she is fearless. This hike was no exception. The hike was 20 miles long, and the last 4–5 were in the rain. Yet, she still had such a positive attitude. She was singing and so cheery… it really helped me get through the hike.”
**MILESTONES II, ACCELERATING THE SEARCH FOR A CURE**

For the past decade, the Foundation has aggressively raised funds to move CF research and other mission-driven programs forward, beginning with the *Milestones to a Cure* campaign in 2005. Thanks to the generosity of many donors, the Foundation completed *Milestones II, Accelerating the Search for a Cure*.

Led by visionary *Milestones II* Chair Joe O’Donnell, the campaign resulted in $80 million, which will help support the development of the next generation of therapies targeting the underlying cause of CF and the Foundation’s mission. Together, these major gift campaigns raised a total of $257 million.

**LEGACY GIVING**

The Foundation has renewed its focus on legacy giving to further engage donors who are considering or have made plans to leave a gift in their will or trust or by beneficiary designation. In addition, thanks to those members of the Paul di Sant’Agnese Legacy Giving Society, the Foundation saw more than $4 million in bequest revenue. This society honors Paul di Sant’Agnese, M.D., who developed the sweat test, which revolutionized CF diagnosis. It recognizes donors who make a lasting commitment to the CF Foundation through their estate plans.

**PARTNERS IN PROGRESS ANNUAL FUND CAMPAIGN**

Thanks to the leadership of Peter Hodge, national chair of the Annual Fund, and long-time volunteer Mark Harvey, M.D., the Annual Fund became a significant revenue generator. Dr. Harvey and the Marlin Oil Corporation offered a matching gift opportunity of up to $500,000 nationally. As a result, the Foundation raised $4 million, the largest amount in the campaign’s five-year history.

**DORIS F. TULCIN MAJOR GIVING SOCIETY**

The Doris F. Tulcin Major Giving Society continues to grow, with more than 2,500 members. This society honors Doris F. Tulcin, one of the founding parents of the CF Foundation and a pillar of the CF community, by recognizing members who have made total commitments of $100,000 or more, allowing the Foundation to continue to advance CF research and drug development.

“Who would have ever thought that we would have come so far when we began the *Milestones* campaign a decade ago? These are great days at the Foundation, but that doesn’t mean we are done by any stretch. We need to continue coming together, digging deep and giving until a cure is found for all.”

Joe O’Donnell Chair, *Milestones II*
Corporate Support

Corporate friends generously showed their dedication to the Foundation’s quest for a cure. We thank all organizations that have helped raise awareness of this disease by engaging their employees, sponsoring events and making contributions. Following are members of the Corporate Leadership Council, which represents direct corporate support of $250,000 and above in 2015.

Kim Mroczkowski accepted the 2015 Leadership Council Award on behalf of Wells Fargo at the 2016 Volunteer Leadership Conference.

Corporate Leadership Council
In line with our expanded mission — adding tomorrows and helping people with CF live better lives today — the Foundation launched an enhanced website and our first-ever CF Community Blog. The new site includes improved content for people living with cystic fibrosis, including sections on emotional wellness, traveling with CF and lung transplantation. The blog, highlighting voices from across the CF community, touches on all aspects of living with cystic fibrosis. The new site and blog have received rave reviews from the CF community — and the amount of time visitors are spending on CFF.org increased by more than 50 percent.
“It means so much to have your organization hear our story... really hear our story, then do so much to give us a voice. Not only that, but names and faces too. Publishing this on your blog might well be one of the best gifts I have ever received in life. In a truly tangible way, you have softened that word ‘isolation.’ There is no price tag for that.”

Michelle Patrovani
Mother of Two Young Adults with CF
Media Coverage

TELLING THE FOUNDATION’S STORY IN HEADLINES

The CF Foundation continues to be prominently featured in top print and broadcast outlets as it strategically communicates announcements and proactively works with the media to shape important stories. When the FDA approved lumacaftor/ivacaftor (Orkambi®), the Foundation’s pivotal support of the development of breakthrough CF drugs was highlighted in leading national media outlets as a result of targeted media relations efforts. Throughout the year, the Foundation secured key opportunities to spotlight its progress toward a cure.

The Washington Post

‘Groundbreaking’ cystic fibrosis treatment could improve quality of life for thousands

May 18, 2015

The New York Times

Orkambi, a New Cystic Fibrosis Drug, Wins F.D.A. Approval

July 2, 2015

Forbes

Kalydeco, For Cystic Fibrosis, Wins First Annual Forbes Breakthrough Drug Award

December 3, 2015

CF Foundation Social Media

Instagram is the Foundation’s most rapidly growing social channel. It grew more than 400% in 2015, allowing us to reach millennials, who are the Foundation’s volunteers and donors of the future.

Facebook is the Foundation’s most established community, with more than 200,000 members.

The Foundation shared highlights from the Patient Registry reports on social media. This post, showcasing that nearly 50 percent of all people living with CF are age 18 or older, is the Foundation’s most popular Facebook post of all time.

The Washington Post

‘Groundbreaking’ cystic fibrosis treatment could improve quality of life for thousands

May 18, 2015

The New York Times

Orkambi, a New Cystic Fibrosis Drug, Wins F.D.A. Approval

July 2, 2015

Forbes

Kalydeco, For Cystic Fibrosis, Wins First Annual Forbes Breakthrough Drug Award

December 3, 2015
Hundreds of photos of people living with CF were featured in the Foundation’s seasonal photo albums on Facebook.
## ASSETS

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<td>Due from investment manager</td>
<td>—</td>
<td>41,093,843</td>
</tr>
<tr>
<td>Receivables, net</td>
<td>50,472,210</td>
<td>19,612,390</td>
</tr>
<tr>
<td>Other assets</td>
<td>8,808,007</td>
<td>8,638,294</td>
</tr>
<tr>
<td>Fixed assets, net</td>
<td>4,550,154</td>
<td>3,821,848</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td><strong>$3,830,884,870</strong></td>
<td><strong>$3,926,314,760</strong></td>
</tr>
</tbody>
</table>

## LIABILITIES AND NET ASSETS

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and other liabilities</td>
<td>$24,589,948</td>
<td>$21,286,892</td>
</tr>
<tr>
<td>Awards payable</td>
<td>126,870,394</td>
<td>90,664,922</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>151,460,342</strong></td>
<td><strong>111,951,814</strong></td>
</tr>
</tbody>
</table>

### UNRESTRICTED NET ASSETS

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undesignated net assets</td>
<td>364,492,149</td>
<td>496,361,145</td>
</tr>
<tr>
<td>Board-designated net assets</td>
<td>3,300,000,000</td>
<td>3,300,000,000</td>
</tr>
<tr>
<td><strong>Total unrestricted net assets</strong></td>
<td><strong>3,664,492,149</strong></td>
<td><strong>3,796,361,145</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Temporarily restricted net assets</td>
<td>11,255,303</td>
<td>14,083,576</td>
</tr>
<tr>
<td>Permanently restricted net assets</td>
<td>3,677,076</td>
<td>3,918,225</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td><strong>3,679,424,528</strong></td>
<td><strong>3,814,362,946</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL LIABILITIES AND NET ASSETS</strong></td>
<td><strong>$3,830,884,870</strong></td>
<td><strong>$3,926,314,760</strong></td>
</tr>
</tbody>
</table>

*The independently audited financial statements of the Cystic Fibrosis Foundation are available online at the Foundation’s website, cff.org, or by contacting Cystic Fibrosis Foundation, 6931 Arlington Road, Suite 200, Bethesda, MD 20814.*
Cystic Fibrosis Foundation Condensed Financial Information

CONSOLIDATED STATEMENTS OF ACTIVITIES
For the years ended December 31, 2015 and 2014

REVENUE

SUPPORT RECEIVED FROM THE PUBLIC

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special event revenue</td>
<td>$105,489,279</td>
<td>$110,482,695</td>
</tr>
<tr>
<td>Direct benefit expenses</td>
<td>(14,091,052)</td>
<td>(14,236,354)</td>
</tr>
<tr>
<td><strong>Net special event revenue</strong></td>
<td><strong>91,398,227</strong></td>
<td><strong>96,246,341</strong></td>
</tr>
<tr>
<td>General contributions</td>
<td>31,821,862</td>
<td>36,544,484</td>
</tr>
<tr>
<td><strong>Total support received from the public</strong></td>
<td><strong>123,220,089</strong></td>
<td><strong>132,790,825</strong></td>
</tr>
</tbody>
</table>

Proceeds of sale of intangible rights under drug discovery agreement — 3,274,431,963
Royalty revenue 32,038,457 197,146
Other 17,799,687 10,186,270

**TOTAL REVENUE** $173,058,233 $3,417,606,204

EXPENSES

PROGRAM SERVICES

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical programs</td>
<td>193,877,491</td>
<td>145,709,774</td>
</tr>
<tr>
<td>Public and professional information and education</td>
<td>20,922,456</td>
<td>19,278,391</td>
</tr>
<tr>
<td>Community services</td>
<td>8,368,074</td>
<td>8,080,186</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
<td><strong>223,168,021</strong></td>
<td><strong>173,068,351</strong></td>
</tr>
</tbody>
</table>

SUPPORTING SERVICES

<table>
<thead>
<tr>
<th></th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management and general</td>
<td>12,393,843</td>
<td>12,798,986</td>
</tr>
<tr>
<td>Fundraising</td>
<td>17,041,113</td>
<td>17,477,338</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td><strong>29,434,956</strong></td>
<td><strong>30,276,324</strong></td>
</tr>
</tbody>
</table>

**Total expenses** 252,602,977 203,344,675

(Decrease) increase in net assets from operations (79,544,744) 3,214,261,529

OTHER CHANGES IN NET ASSETS

Net nonoperating investment (loss) income (55,393,674) 2,335,571

(DECLEARCE) INCREASE IN NET ASSETS $ (134,938,418) $ 3,216,597,100

Measure of operations

The Foundation includes in its measure of operations all support received from the public, income on investments designated for operations including interest and dividends and realized and unrealized gains and losses, royalty revenue, other revenue and all costs of program and supporting services. The measure of operations excludes gains or losses on discontinued operations and nonoperating investments. Nonoperating investments are amounts identified by the Investment Committee of the Board of Trustees for investment over the intermediate to long term.

Revenue recognition

Support received directly or indirectly from the public is recorded as revenue when received or when the donor has made an unconditional promise to give. Conditional promises to give are not recognized until the conditions on which they depend are substantially met. Contributions of assets other than cash, including gifts-in-kind, are recorded at their estimated fair value at the date of the gift. Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence or nature of any donor restrictions. All donor-restricted support, including related investment income and realized and unrealized gains and losses, is reported as an increase in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), temporarily restricted net assets are reclassified to unrestricted net assets and reported in the consolidated statement of activities as net assets released from restrictions.

CFF and CFFT retain legal and beneficial rights to intellectual property developed under certain grant agreements and drug discovery agreements. Revenues received under these agreements are recorded when earned. In addition, at times CFFT may sell its intangible rights under certain agreements in exchange for a lump sum. Amounts received under these agreements are recorded when rights are forfeited and proceeds are receivable. In November 2014, CFFT entered into an agreement to sell its intangible rights to future revenues under a drug discovery agreement. Net revenue from the November 2014 transaction was $3,274,431,963, which consists of gross proceeds of $3,300,000,000 net of $25,568,037 of transaction costs. In 2015, under the same drug discovery agreement, CFFT earned additional one-time royalties of $27,792,000. This amount was earned upon achievement of certain milestones, as defined in the agreement. This amount is included in royalty revenue and accounts receivable as of December 31, 2015.
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AS OF DECEMBER 31, 2015

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Bethesda, Maryland

Executive Vice President and Chief Financial Officer
Vera H. Twigg
Bethesda, Maryland

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Brian and Kay Hill
Richard Marx
Rosie O’Donnell
Jim Palmer
Mike Schmidt
Mike Scioscia
Thanks to the wonderful community that makes our efforts possible. Because of your support, we will continue to add more tomorrows and help all people with CF live better today.