

Hope In Our Hands

CYSTIC FIBROSIS FOUNDATION • 2010 ANNUAL REPORT



| Adding *tomorrows* every day.

OUR MISSION

The Cystic Fibrosis Foundation is dedicated to assuring the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease. Every day, countless families, scientists, caregivers, donors and volunteers contribute time, energy and passion to reach our shared goal.

Hope for the future is in our hands.



Dear Friends,

This is a historic time in the fight against cystic fibrosis. Promising therapies that treat the underlying cause of cystic fibrosis are now in late-stage clinical trials. As this annual report went to press, the Foundation announced remarkable results of two Phase 3 clinical trials of VX-770, a potential therapy that addresses the basic defect in CF. In studies of VX-770 in adults and young children with the G551D mutation, those taking the drug showed profound improvements, especially in lung function and weight gain.

These results demonstrate that our drug development strategy is on the right track and represent a major step toward potentially controlling this disease for a segment of the CF population.

With this important data in hand, we remain committed to accelerating the discovery and development of additional drugs targeting the underlying cause of the disease—for *all* people with CF. To that end, we recently announced a major expansion of our collaboration with the maker of VX-770, Vertex Pharmaceuticals, Inc., to help bring new therapies to the CF community as quickly as possible. We are also continuing our efforts to advance much-needed drugs to treat CF symptoms and foster excellence in CF care.

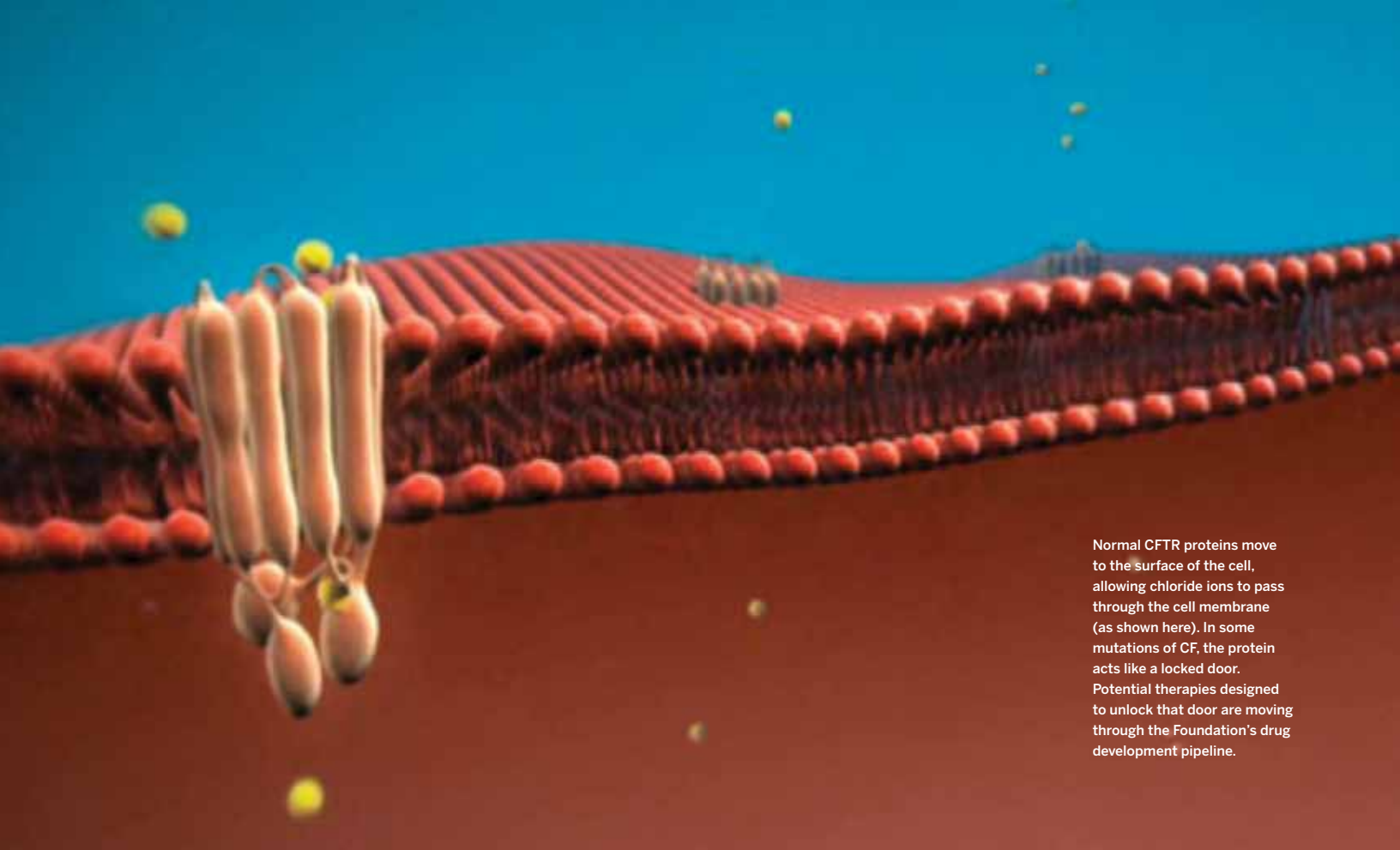
Because of the work of an extraordinary team of researchers, caregivers, families, people with CF and devoted volunteers and donors around the country, there are now nearly 30 potential drugs in the Foundation's CF therapeutics pipeline. In 2010, a major milestone was reached with the FDA approval of Cayston®, the first new antibiotic for CF in more than a decade. Developed by Gilead Sciences, Inc., Cayston® received support from the Foundation at every stage of the discovery and development process.

These and other advances in CF research and care could not have happened without the steadfast support and passion of our donors, friends and volunteers, who continue to give selflessly to end this disease. This year the *Milestones to a Cure* campaign achieved its ambitious goal, with major donors raising \$175 million to support essential research opportunities.

Our community has continually ventured into new terrain, worked collaboratively and taken strategic risks, without ever losing sight of our central mission: to cure and control cystic fibrosis. We can take pride in these hard-earned achievements and draw strength from our shared hope and determination as we work together to reach our ultimate goal.

Sincerely,

Robert J. Beall, Ph.D.
President and Chief Executive Officer
Cystic Fibrosis Foundation



Normal CFTR proteins move to the surface of the cell, allowing chloride ions to pass through the cell membrane (as shown here). In some mutations of CF, the protein acts like a locked door. Potential therapies designed to unlock that door are moving through the Foundation's drug development pipeline.

DRUG DISCOVERY AND DEVELOPMENT

Major Breakthroughs on Multiple Fronts

The Cystic Fibrosis Foundation saw remarkable achievements in 2010, many resulting from its longtime support of cutting-edge technologies and innovative treatment strategies to control and cure cystic fibrosis. New therapies targeting the disease from different angles are now in patients' hands, while other promising candidates continue to advance through the Foundation's drug development pipeline.

Most notably, Foundation investments made through the CF Foundation's drug discovery and development affiliate, Cystic Fibrosis Foundation Therapeutics, Inc., (CFFT) to accelerate the progress of compounds that address the basic defect in CF are reaping significant rewards. Later-stage clinical trials have further validated the "proof of concept" achieved in earlier studies—that small molecules can repair the faulty CFTR protein made by the CF gene and affect key indicators of the disease. To help move the most promising potential therapies more quickly to market, the Foundation has magnified its efforts to improve the clinical research process and boost the participation of people with CF in clinical trials.

TARGETING THE BASIC DEFECT

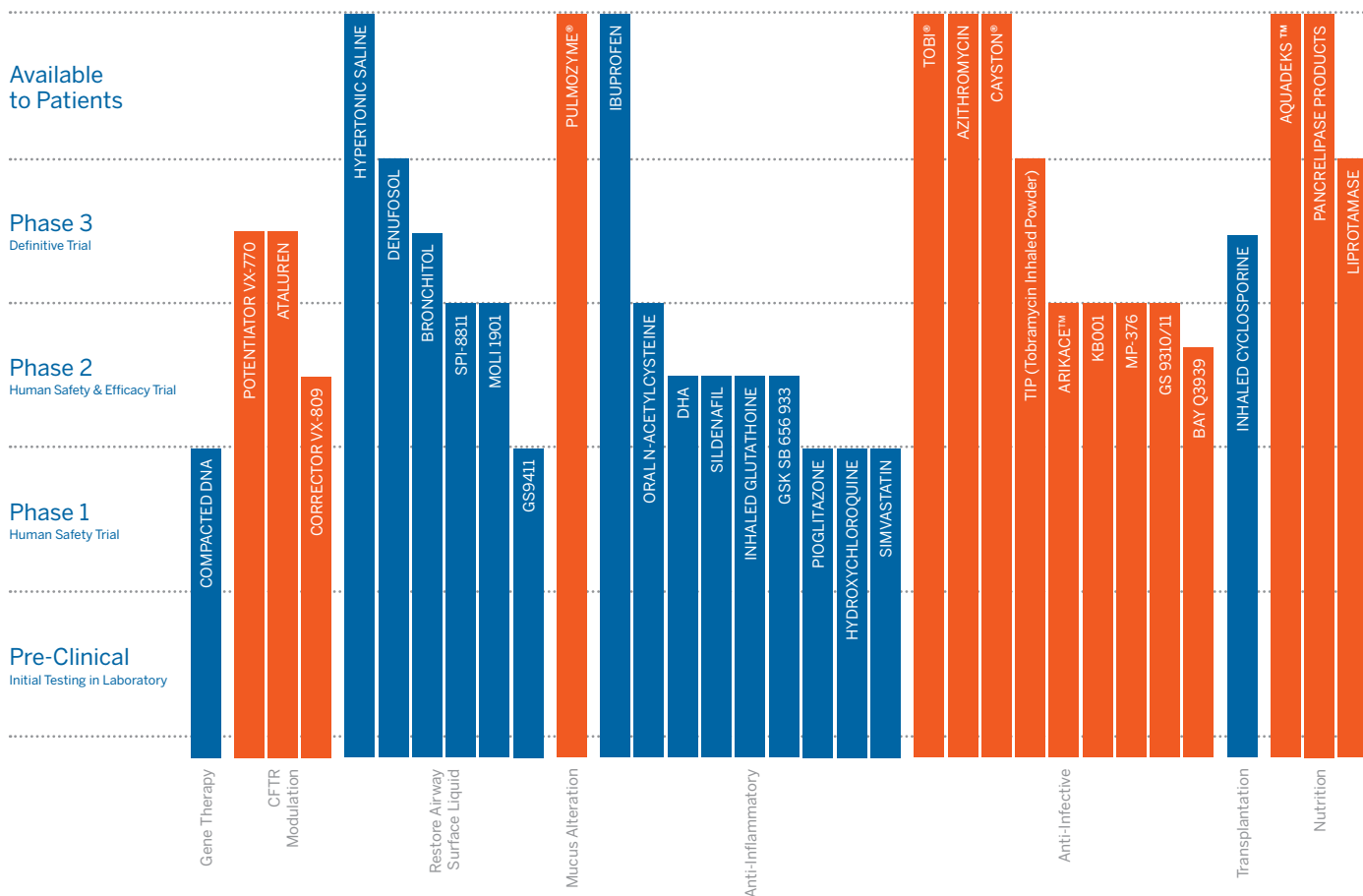
CFFT-supported programs to treat the underlying cause of CF made tremendous progress this year.

As this annual report went to press, the Foundation announced that a Phase 3 clinical trial of VX-770 had shown profound results. VX-770 is one of two potential therapies being developed by Vertex Pharmaceuticals, Inc., to improve the function of the defective CFTR protein in people with CF.

In the study, those receiving the drug demonstrated a marked improvement in lung function—the best result seen in any clinical trial of a CF drug. They also showed significant improvements in sweat chloride levels, weight gain and other key measures of the disease, compared with those on the placebo.

The trial examined VX-770 in CF patients who carry at least one copy of the G551D mutation. In CF mutations like G551D, the defective protein doesn't function properly once it is at the cell surface but instead acts like a locked door. VX-770 helps unlock that door, allowing chloride to pass through and restore the proper flow of salt and fluids into the airways.

CYSTIC FIBROSIS FOUNDATION THERAPEUTICS PIPELINE



VX-770 was discovered through an ongoing collaboration between Vertex and CFFT that dates back to 1999 and is the largest in the Foundation’s history. Vertex anticipates it will submit a New Drug Application to the U.S. Food and Drug Administration (FDA) in the second half of 2011, with the hope of drug approval in 2012.

In October, Vertex launched a Phase 2a clinical trial of VX-770 in combination with another CFTR modulator, VX-809, in people with the most common CF mutation, Delta F508.

In this mutation, CFTR does not fold correctly and cannot move to its proper place on the surface of the cell. VX-809 aims to help move the protein to the cell surface. VX-770 is designed to increase the activity of the defective protein once it is there.

Initial results are expected in the middle of 2011 and could pave the way for future studies using combinations of compounds to treat the underlying cause of CF.

Another CFTR modulator, ataluren (formerly known as PTC124), is now being tested in a Phase 3 trial that is fully enrolled

SPOTLIGHT ON VX-770 RESEARCH

The *New England Journal of Medicine*, the country’s most widely read and influential medical journal, featured a study in November of the promising results of a Phase 2 trial of VX-770. The article was accompanied by an independent editorial by Michael Welsh, M.D., who wrote, “This research represents a milestone along the pathway of discovery to better preventions, treatments and cures.”

at sites in North America, Europe and Israel. The study is examining whether ataluren can improve lung function in CF patients and will determine if the drug can be given safely for a longer period of time.

Developed by PTC Therapeutics, Inc., with support from CFFT, ataluren aims to address nonsense mutations, which interrupt production of the CFTR protein and cause it to be too short and not function. An earlier study showed that CF patients who took ataluren had improved CFTR function and the drug was also associated with improved lung function.



TURNING THE HOPE OF NEW THERAPIES INTO REAL RESULTS

A May 20 U.S. Senate briefing co-hosted by the Foundation, FasterCures/The Center for Accelerating Medical Solutions and Sens. Richard Shelby (R-Ala.) and Richard Durbin (D-Ill.) focused on how federal funding for medical research can be leveraged to more quickly create new therapies and save lives.

At the briefing, National Institutes of Health (NIH) Director Francis S. Collins, M.D., Ph.D., highlighted the Foundation's success at quickening the pace of research to create new therapies for CF. "There is great progress being made in cystic fibrosis," said Collins, a co-discoverer of the CF gene. The Foundation's venture philanthropy model, he said, is "proof of principle of what we ought to be doing for many other diseases."

Collins joined Margaret Anderson, executive director of FasterCures, and Foundation President and CEO Robert J. Beall, Ph.D., who also took part in the Senate briefing.

TREATING THE SYMPTOMS OF CF

Lung health

Respiratory problems remain the most serious complication for CF patients, among them lung infections caused by the bacterium *Pseudomonas aeruginosa*, which occurs in up to 80 percent of adults with CF.

In February, the first new inhaled antibiotic for CF developed in more than a decade was approved by the U.S. Food and Drug Administration (FDA). Cayston®, an inhaled form of aztreonam lysine, was developed by Gilead Sciences, Inc., with vital support from CFFT and the CF Foundation every step of the way. It offers a much-needed and highly effective alternative for those who battle persistent *P. aeruginosa* lung infections and often develop resistance to existing antibiotics.

Cayston® is administered with the Altera® Nebulizer System. This new electronic nebulizer delivers the drug more efficiently than existing jet nebulizers do, allowing patients to take the medicine in less than five minutes.

Other therapies designed to stop or slow damage to the lungs are also moving forward in later-stage clinical trials. These include a Phase 2 study of hypertonic saline in children under 5 years old and as young as 4 months. Earlier CFFT-supported trials revealed that inhaling the aerosolized saltwater solution had a powerful effect on rehydrating the lining of the lungs of CF patients, reducing the number of exacerbations. Many CF patients around the world now use hypertonic saline every day.

The Infant Study of Inhaled Saline (ISIS) seeks to determine if hypertonic saline is as safe and effective in young children as it is in older CF patients. Research has shown that infants with CF, even those with no symptoms of the disease, often already have lung damage. If successful, ISIS could pave the way for doctors to prescribe hypertonic saline early in life and considerably slow the cycle of lung infection and inflammation that leads to severe lung damage. ISIS is now fully enrolled and being carried out at 30 sites across the United States and in Canada.

The second of two long-term Phase 3 clinical trials of Bronchitol was completed this year. Developed by Pharmaxis, Bronchitol is an inhaled dry powder formulation of mannitol—an alcohol sugar solution—designed to restore normal airway clearance and reduce the buildup of mucus. In previous trials, CF patients receiving the drug showed significant improvement in lung function and fewer respiratory symptoms. Pharmaxis has been awarded

FOUNDATION HELPS BRING NEW ANTIBIOTIC TO MARKET

The Foundation provided ongoing support to Gilead Sciences, Inc., as Cayston® advanced through the Foundation's pipeline—from an initial \$1 million CFFT therapeutics development award, to making its CFFT clinical trials network available to test Cayston® in patients, to explaining the scientific benefits of the drug to the FDA before approval. The Foundation also helped develop a Cayston® call center on behalf of Gilead to assist people with CF and members of their care teams with insurance verification, co-pay assistance and claims support. In addition, the CF Services Pharmacy is one of only four Cayston® distributors in the country.

fast-track status for Bronchitol by the FDA and is preparing a New Drug Application.

Nutrition

In CF, thick secretions build up in the pancreas, preventing the release of important enzymes that help with digestion. About 90 percent of people with CF take pancreatic enzyme replacements, which help the body absorb essential vitamins and nutrients. Although these therapies have been in use for decades, in 2004 the FDA required that all pancreatic enzymes on the market be reformulated and undergo clinical testing to receive FDA approval.

In April, the pancreatic enzyme replacement therapy Pancreaze™ by Ortho-McNeil-Janssen Pharmaceuticals, Inc., was approved under the more rigorous FDA testing and review procedures. The Foundation had encouraged the FDA to require these new processes to help ensure that CF patients receive only those products documented to be safe and effective. Pancreaze™ joins CREON® and ZENPEP™ as the only FDA-approved pancreatic enzyme products available to CF patients. Other companies still completing the FDA review process are Axcan Pharma, Inc., for its product ULTRASE® and Digestive Care, Inc., for PANCRECARB®.



In October, nearly 4,000 researchers, physicians and other caregivers gathered at the 24th annual North American Cystic Fibrosis Conference in Baltimore to exchange ideas and discuss the latest developments in CF research and care.

CLINICAL TRIALS INITIATIVE

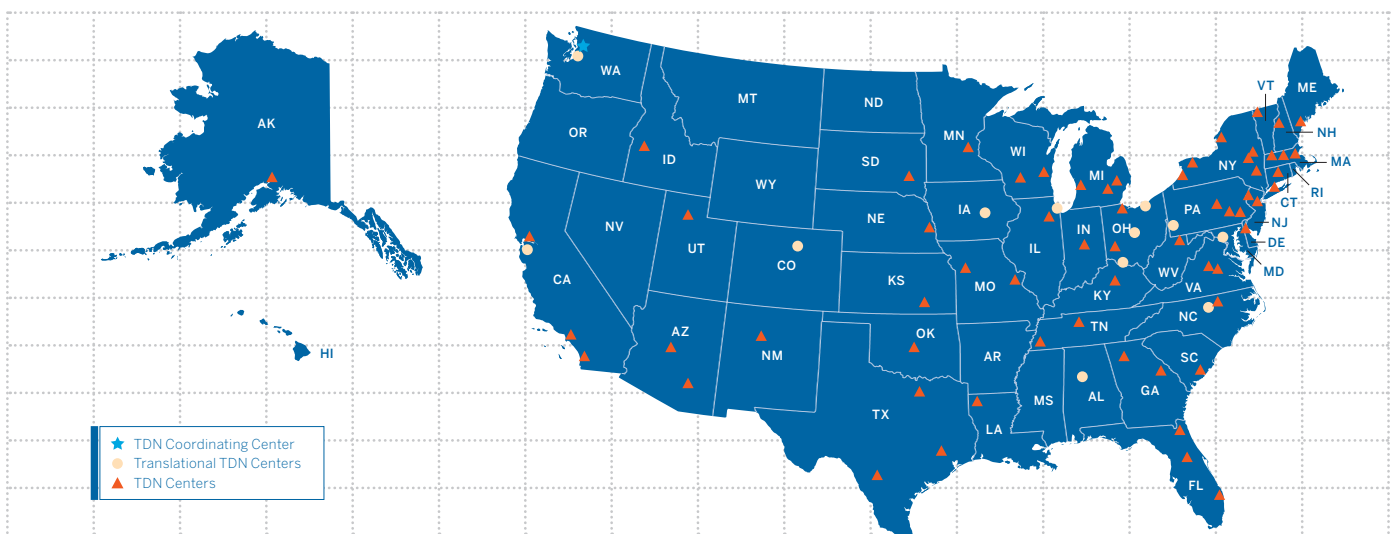
The Foundation continues to initiate and lead a broad array of efforts to increase participation in CF clinical trials and accelerate the progress of potential therapies in its drug development pipeline. These steps include applying lessons from the CF care centers' quality improvement initiative to the clinical research enterprise.

In December, the CF Clinical Research Quality Improvement Project conducted the last of nine benchmarking site visits to centers in the Therapeutics Development Network. The goal of the project is to identify and disseminate best practices across the network to improve clinical research processes. An "Action Guide" is being created for other centers to perform self-assessments and help them become high-performing clinical research teams.

The Foundation also piloted its Clinical Trials Ambassador program to more fully engage CF patients and their families in clinical research. The program grew out of the successful "I Am The Key" initiative, launched in 2007 to enhance awareness of clinical trials among CF patients and their families.

Using the model of the Foundation's patient and family advisory boards in place throughout the care center network, the Ambassador program pairs CF patients and families with their local research teams to share their clinical trial experiences and educate others about participating. The pilot program is under way at three sites and is available to other interested care centers.

THERAPEUTICS DEVELOPMENT NETWORK



The Therapeutics Development Network (TDN) is a nationwide network of research centers that conduct clinical trials of potential new CF therapies. Following a major expansion in 2009, the network now has 77 centers, including 13 translational centers focusing on early-phase clinical trials and identifying potential therapies. The TDN is funded primarily by Cystic Fibrosis Foundation Therapeutics, Inc., the CF Foundation's nonprofit drug discovery and development affiliate.



Capri, a second-grader who proudly took part in a clinical trial this year, goes to the CF care center at East Tennessee Children's Hospital in Knoxville, Tennessee.

CYSTIC FIBROSIS CARE

Sharing Knowledge and Experience to Advance Care

The CF Foundation's leadership in supporting specialized care continues to help improve health outcomes for people with CF. In 2010, the latest data available showed that children and adults with CF enjoyed better overall lung function and increased body mass index, both important predictors of better survival.

Early diagnosis through newborn screening also began to produce a healthier population of infants with CF. In response to a nationwide newborn screening initiative led by the Foundation and its volunteer advocates, as of 2010 all 50 states and the District of Columbia actively screen every newborn for CF, and nearly half of CF diagnoses are now made through newborn screening.

Specialized CF care also supports a growing number of adults: 47 percent of the CF population is now age 18 and older. Central to all of these gains is the shared spirit of partnership among people with CF, their families and health care professionals throughout the Foundation's care center network.

QUALITY IMPROVEMENT

The Foundation's quality improvement (QI) efforts in 2010 included the new adult QI collaborative to help accelerate improvements in care. One focus of this collaborative was patient- and family-centered care. Participating centers are implementing QI tools and ideas, developed by adults with CF and families, which aims to strengthen communication and staff understanding of the goals and priorities of adults with CF.

Discipline-specific mentorship programs are also flourishing, with a pilot program for physical therapists added in 2010. One-on-one mentoring has proved to be an effective way to maintain and build on the QI gains already having a significant impact on patient care.

To ensure that QI measures continue to enhance patient care, in 2010 the Foundation conducted a comprehensive assessment of its QI initiative, with input from national QI leaders, care center staff, adults with CF and parents of children with CF. With results showing that the majority of care centers are now engaged in QI, the Care Center Committee has incorporated a review of QI activities into its accreditation process.

PATIENT REGISTRY

The Patient Registry supports the Foundation's mission by capturing trends and practices that are helping to improve the quality of life for people with CF. Keeping pace with ever-evolving technology, in 2010 the registry underwent substantial upgrades, which have strengthened its ability to gather data and made it a more effective tool. The Patient Registry now meets FDA requirements, allowing the Foundation and the pharmaceutical industry to chronicle the long-term safety of recently approved drugs.

The Foundation's annual registry has set international standards for tracking and gathering patient data with informed consent and transparency. With the help and guidance of the Foundation, the Cystic Fibrosis Trust in the United Kingdom has successfully deployed the Foundation registry, and the Cystic Fibrosis Association of New Zealand is planning to deploy the registry over the coming year.

MEDICATIONS AND COVERAGE

Two Foundation surveys conducted in the past year have yielded new information about the cost of care for people with CF and how rising health care costs may affect treatment. The results indicate that, while the cost of CF care has risen at about the same rate as medical inflation, CF care remains significantly more expensive than care for the general population and the burden of cost sharing is shifting considerably onto the CF patient.

The Foundation took the following steps in 2010 to protect the ability of CF patients to receive the therapies they need:

- Supported critical provisions in the health care reform law to assist people with CF.
- Maintained funding for state-level CF care programs in multiple states, ensuring access to needed health benefits.
- Preserved access to critical CF therapies for Medicaid beneficiaries in 14 states, turning back proposals to limit automatic coverage of pancreatic enzymes.
- Helped reduce red tape and ensure faster enrollment of CF patients into vital benefit programs such as Supplemental Security Income (SSI).

CYSTIC FIBROSIS SERVICES PHARMACY

The CF Services Pharmacy is committed to providing access to high-quality prescription medications, regardless of an individual's health insurance coverage or financial situation. In 2010, CF Services set a new record for prescriptions filled—nearly 180,000. More important, the pharmacy reached its highest level ever of support for the CF community, with contributions of more than \$700,000 in hardship assistance and sponsorships to CF care centers and other organizations.

The CF Services Pharmacy was also instrumental in bringing the inhaled antibiotic Cayston® and its Altera® nebulizer to the marketplace, working diligently with Gilead Sciences, Inc., to ensure that patients had access to this much-needed treatment. Since the launch of Cayston® in early 2010, nearly 4,000 patients have obtained the medication through CF Services.

CF CARE IN THE NEWS

Improvements in CF care gained through QI methods have continued to earn national media attention.

An August 2010 article in *U.S. News & World Report* highlighted the Foundation's role in leading CF care centers toward collaboration and best practices, with a close-up look at how the CF center at Cincinnati Children's Hospital Medical Center improved care and health outcomes through partnering with parents.



Cathy O'Malley, a CF respiratory specialist at Children's Memorial Hospital and Northwestern University Cystic Fibrosis Center, spends time evaluating 14-year-old Francisco.



Through the Foundation's Quality Improvement Initiative, the University of Nebraska CF Care Center participated in a Learning and Leadership Collaborative focused on improving overall lung health, nutritional status and self-management skills among people with CF.

CARE GUIDELINES

The Foundation funds and accredits a network of more than 110 care centers across the country. To maintain continuity of care across all centers, the Foundation prepares and updates guidelines on a broad spectrum of CF-specific topics.

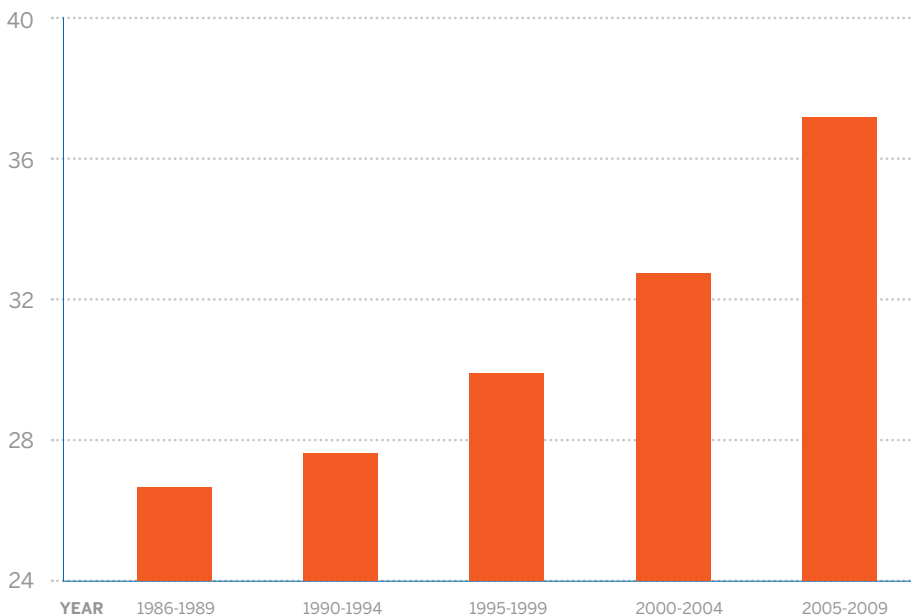
These guidelines are widely used and respected throughout the care center network and beyond, including among clinicians and care centers worldwide. This year, the Foundation published new guidelines on pulmonary complications and on cystic fibrosis-related diabetes.

CF PATIENT ASSISTANCE FOUNDATION

Since its inception in 2009, the Cystic Fibrosis Patient Assistance Foundation (CFPAF) has received close to 9,500 calls and researched hundreds of health insurance plans for CF patients. In addition to financial support and benefit investigations, CFPAF offers patients general case management assistance, including free assistance filing for government coverage, and has referred nearly 1,000 patients to alternative resources. CFPAF also assists patients who experience delays when applying for support from other programs.

MEDIAN PREDICTED SURVIVAL AGE 1986-2009

Over Five-Year Bands



The median predicted age of survival for people with CF has risen dramatically over the past two decades. Many people with the disease are now living into their 30s, 40s and beyond.

PATIENT INSURANCE CENTER

The Foundation laid the groundwork in 2010 to launch the Patient Insurance Center, an online information hub designed for patients, insurers and health care providers. With rollout planned for 2011, the Patient Insurance Center will offer CF patients the help and information they need to get insurance coverage for essential medication and health care services. Along with this new resource, the Foundation will continue to engage state and federal regulatory agencies to ensure that patients receive appropriate coverage for their treatments and do not experience undue denials or delays in coverage.

VIRTUAL PATIENT

EDUCATION DAY WEBCASTS

The Foundation has long been dedicated to expanding health awareness and knowledge of CF care. With the advent of patient- and family-centered care, educational tools have become even more central to fostering a well-informed population equipped to be full members of the CF team and make sound decisions about their own care. More than 82,000 people have viewed Foundation webcasts on topics ranging from nutrition and infection control to health care coverage and fertility.

The Foundation debuted its Partnering for Care webcast series in 2010, covering such issues as the transition to adult care, lung transplantation and the role of various members of the CF care center team. More than 1,200 people viewed the annual CF clinical research update, “Research and the Future of CF Care.”

NEW ON WWW.CFF.ORG

More resources than ever before are now available on the Foundation’s website. Check out www.cff.org/LivingWithCF for a new special section on newborn screening and for Spanish-language resources to help meet the needs of the growing population of people with CF who are Hispanic or only speak Spanish. CF care guidelines developed for health care providers are also available to the wider CF community at www.cff.org/treatments.

BUILDING A FACEBOOK COMMUNITY

In 2010, the number of people on the Foundation’s Facebook page more than doubled. It now has over 100,000 members or “fans”—a following that far exceeds the number of people with cystic fibrosis worldwide.

Since 2008, Facebook has provided an interactive space where supporters can connect with the Foundation and with others who share the same mission. With this extraordinary network, the Foundation continues to share timely updates and information about cystic fibrosis, as well as news important to the CF community. Through Facebook, the Foundation also has engaged active volunteers and increased awareness of ways to get involved and support its mission.

Join the Foundation’s Facebook fans at WWW.FACEBOOK.COM/CYSTICFIBROSISFOUNDATION.



CLINICAL TRIALS BILL IS SIGNED INTO LAW

Teen advocates were among the scores of volunteers who helped achieve a major victory with the passage of the Improving Access to Clinical Trials Act. Signed into law by President Obama on Oct. 5, the bill allows people with rare diseases to participate in clinical trials without losing eligibility for government health care benefits.

The law is particularly important to the CF community because a limited patient population makes it challenging to find enough people to participate in research studies to evaluate promising new drugs.

The Foundation was the first organization to identify this barrier to clinical research and worked closely with Congressional CF Caucus Co-Chairs Reps. Edward Markey (D-Mass.) and Cliff Stearns (R-Fla.) and with Sens. Ron Wyden (D-Ore), Richard Shelby (R-Ala.), James Inhofe (R-Okla.) and Chris Dodd (D-Conn.) to write the bill and secure the endorsement of more than 120 other health advocacy organizations. The bill was co-sponsored by 21 U.S. senators and 142 representatives and passed unanimously in both chambers.

Rep. Markey (above) joined participants at the Foundation’s second annual Teen Advocacy Day on June 24. The teenagers traveled to Capitol Hill from across the country to advocate on behalf of their siblings and cousins with CF, and urged Congress to pass the bill.



New York Giants center and Super Bowl champion Shaun O'Hara and 13-year-old Sean Squires, who has CF, share more than just a love of football. Together with Sean's parents Bill and Jodi and sisters Sydney and Ashley, they were proud to lead Sean's Pals, the top Great Strides team in the country in 2010, raising \$240,000 to tackle the disease.

FUNDRAISING

Fueling Dreams, Ensuring Progress

The CF Foundation's accomplishments are powered by the many volunteers and partners who work together to support the search for a cure. Through their impassioned efforts, in 2010 volunteers across the country continued to fuel scientific progress and bring hope and optimism to families affected by CF.

The *Milestones to a Cure* campaign, led by volunteer chair Joe O'Donnell, achieved its ambitious goal this year, with major donors raising \$175 million since the campaign launched six years ago to help fuel critical research. Donors also contributed over \$1.5 million through charitable bequests.

Foundation volunteers showed off their athletic prowess for a good cause in the launch of two new fundraising initiatives: *CF Cycle for Life* bike tours and *CF Climb for Life* stair-climbing events. New national Great Strides family and corporate teams stepped forward, expanding their support to additional walk sites throughout the nation.

From families walking, biking and climbing for a cure, to businesses and corporations forming company-wide fundraising initiatives, every contribution—no matter the size—helped to strengthen and expand the Foundation's vital research and care programs over the past year.



Casey's Batters joined hundreds of volunteers at the Rockville, Md., Great Strides walk to support the search for a cure.

GREAT STRIDES

Volunteers laced up and hit the pavement in communities nationwide to raise \$35.5 million and once again make Great Strides an awe-inspiring success. The Foundation's flagship volunteer event saw significant growth in 2010, with 125,000 walkers, 62 new walk sites and a \$2 million increase in online fundraising from the previous year.

New national corporate and family teams stepped out for the first time, organizing walkers in at least three distinct regions while raising almost \$1 million. A strong corporate presence, including national sponsorship by Solvay (now Abbott Laboratories) and national teams from Toshiba, Vertex Pharmaceuticals, Inc., Unum, GEICO, Lockheed Martin Corp. and many more dedicated companies, brought employees together for the CF cause.

With an eye on taking their fundraising to a new level, 48 family teams walked as national teams as well. Friends of KC, led by Board of Trustees member KC Bryan White, who has CF, featured 11 teams from Washington, D.C., to California.



Cyclists and committee members Dave Tarnow and Mark Fry pedaled for a cure at the Louisiana Chapter – Baton Rouge Regional Office's first *CF Cycle for Life* race.

CF CYCLE FOR LIFE

Expanding upon the success of Great Strides, the Foundation launched two additional fundraising initiatives: the *CF Cycle for Life*, sponsored nationally by Eurand (now Axcan), and the *CF Climb for Life*.

Volunteers from coast to coast took part in cycling events at 17 sites, including rides hosted by the Massachusetts/Rhode Island, Colorado and Georgia chapters, which led the pack as the top three outstanding fundraisers. Pedaling enthusiasts cycled through the Georgia countryside, the back roads of Louisiana and other scenic routes. Volunteers raised a total of \$970,000—an enormous success for the series' first year.



With 10 teams stationed across the country, Unum walked as a national corporate Great Strides team in 2010. Here, members of Unum Michigan pose at the Detroit Great Strides.

CF CLIMB FOR LIFE

The Foundation's new *CF Climb for Life* events provide unique fitness challenges in which participants climb flights of stairs to the top floor of a tall building. At the Texas Gulf Coast Chapter's first annual *Dancing with the Stairs*, presented by Hanover Real Estate Partners, members of the Houston Fire Department and other ambitious volunteers climbed 41 flights of stairs and raised \$45,000.

Altogether, determined volunteers at 18 sites from Texas to Colorado climbed thousands of stairs to raise well over \$300,000 and earn bragging rights for completing the test of endurance.

GALAS AND SPECIAL EVENTS

Volunteers of the Foundation's more than 75 chapters and branch offices donned their finest attire, dined on first-class cuisine and danced the night away at festive events held throughout the year. The following are just a few highlights of the many dinner dances and special events held in 2010.

At the Metropolitan Washington, D.C., Chapter's *Breath of Life Gala*, a crowd of more than 800 gathered to raise \$2.5 million. Guests of the dazzling black-tie affair, which was the Foundation's top fundraising special event in 2010, bid on exciting items during the world-class live and silent auctions, including a fire-engine red 1957 Ford Thunderbird convertible that raised \$47,000 and a matching \$50,000 gift from the donor. Before the night's end, the crowd was treated to a special performance by Ali and Christina Christensen, the "singing sisters" from the hit television show *America's Got Talent*.

The Foundation also experienced great success with its series of "Finest" events that showcased the best and brightest professionals in dozens of cities across the

country, attracting new talent in support of the fight against CF.

The Greater Cincinnati Chapter highlighted the accomplishments of 20 young professionals—all first-time volunteers for the CF cause—who are committed to using their talent, compassion and leadership qualities to further the Foundation's mission. After a 12-week fundraising blitz, honorees and other guests celebrated their success in supporting the Foundation's lifesaving programs with an enthusiastic local crowd at the *Cincinnati's Finest Finale* party.



Academy Award-winning director James Cameron and accomplished actress Suzy Amis Cameron served as honorary chairs of the Oklahoma City Sooner Chapter's *Breath of Life Gala*, joining the fight against the disease that afflicts their nephew Bo.

CORPORATE OUTREACH

As a result of the Foundation's emphasis on corporate development, more than \$3.3 million was raised or committed in 2010, with \$1.3 million in new support. These gains were achieved in part through optimizing longtime collaborations and expanding programs like the holiday DVD sales conducted jointly by CVS/pharmacy and Warner Home Video, which alone raised \$200,000.

The Foundation has also developed new relationships with generous corporations dedicated to the fight against CF, including GEICO, Unum, Chubb, Johnson & Johnson and Toshiba. In addition, Eurand Pharmaceuticals (now Axcan) signed on at \$300,000 to be the title sponsor of the inaugural 16 *CF Cycle for Life* events.

Laying a groundwork for future growth, the Foundation has identified industries, including cable, construction, and service and hospitality, whose leaders are well-positioned to work together to strengthen support of the Foundation's mission. Executives in the construction industry joined together to create a plan for raising \$250,000 in 2011.

VOLUNTEER LEADERSHIP INITIATIVE

United by their shared dream to cure cystic fibrosis, members of the Volunteer Leadership Initiative (VLI) are devoted to raising much-needed funds and recruiting new volunteers to fill the Foundation's

"people pipeline." This next generation of volunteers is critical to raising the funds needed to accelerate the search for a cure for all people with CF. With the guidance of co-chairs Kelli and Perry Clark, more than 250 VLI members and friends of the Foundation gathered in March for the annual CF Foundation leadership conference.

To jumpstart the three-day event, volunteers gathered at "March on the Hill," the Foundation's annual advocacy outreach effort that unites volunteers and members of Congress on Capitol Hill. In addition, volunteers and staff attended workshops and presentations in which they offered personal stories of fundraising triumphs, shared techniques to recruit volunteers, and added new tools to their fundraising strategies.



CF Foundation Board of Trustees member KC Bryan White, her husband Justin, son Mac and hundreds of friends across the nation came together to walk as part of her national Friends of KC Great Strides team.



GEICO employees rallied around the CF Foundation's mission and spread their enthusiasm to offices from coast to coast in 2010, walking as a national corporate Great Strides team.

THE PAUL DI SANT'AGNESE PLANNED GIVING SOCIETY

Through groundbreaking research that led to the development of the sweat test, Paul di Sant'Agnese, M.D., revolutionized CF diagnosis. Named in his honor, the Society recognizes special donors who make a lasting impression on the CF Foundation through their estate plans. Members of this visionary group contributed more than \$1.5 million through bequests to the CF Foundation in 2010.

THE DORIS F. TULCIN MAJOR GIVING SOCIETY

As a founding parent of the CF Foundation, Doris F. Tulcin made it her personal goal and the Foundation's national mission to cure and control CF. More than 50 years later, the Doris F. Tulcin Major Giving Society honors her leadership and vision by recognizing the outstanding generosity of donors who have made total commitments of \$100,000 or more to the Foundation's major giving initiatives since 1998.

Milestones to a Cure: Unprecedented Generosity = Unprecedented Progress

Thanks to the generosity of an ever-growing number of major donors across the country, the CF Foundation exceeded its goal of raising \$175 million by the end of 2010 through its *Milestones to a Cure* campaign. These cherished friends of the Foundation helped propel the tremendous strides made toward a cure and control for cystic fibrosis since the campaign kicked off just six years ago.

Milestones was born out of an ambitious initiative to assure the CFFT's Therapeutics Development Program was built and nurtured to help advance essential research opportunities. By successfully closing the gap between promising drug development opportunities and the funding necessary to pursue them, the *Milestones* campaign enabled the Foundation to drastically intensify its efforts and establish a new, heightened pace for progress in drug development that matches the urgency of our mission.

Because of this progress, today children and adults with CF are living longer, healthier lives.

When the idea of a multi-year major giving campaign of this size, conducted by a voluntary health agency, was conceived, it was viewed as a herculean—if not impossible—task. Yet from the opening phase, the support from the CF community and beyond was astounding.

Gifts ranging from \$10,000 to multiple commitments in excess of \$10 million each gave way to confidence and commitment at unprecedented levels. This past year alone, a \$5 million gift from the Boomer Esiason Foundation and another very generous family that requested anonymity was critical in reaching the campaign goal.

One of the many advancements made possible is the development of the inhaled antibiotic Cayston®, a much-needed alternative for CF patients who battle recurrent lung infections. Approved by the U.S. Food and Drug Administration in early 2010, Cayston is now being widely used by people with CF.

In addition, *Milestones* donors played a critical role in accelerating the development of VX-770 and achieving a momentous “proof of concept” that a drug can target the basic defect in CF and significantly improve key symptoms of the disease. By the end of 2010, the Foundation's drug development pipeline contained nearly 30 potential new therapies, including four drugs that address the root cause of CF.

The credit for this success goes to many caring and generous people. They were willing to listen to our story and embrace our vision. More important, they were willing to invest in the concept of a “pipeline” of science that could be built with focused and quantifiable objectives. And while the campaign's success is a tribute to many, it would never have evolved and certainly never have exceeded its goal if not for the unparalleled leadership of Joe O'Donnell, its chair.

To accelerate the vital pace of progress and build on recent advances that show small molecule therapies can dramatically improve health for people with CF, Joe has selflessly pledged his continued leadership in a new phase of the campaign, *Milestones II*.

The goal of *Milestones II* is to raise \$75 million to ensure that the Foundation's drug development arm, CFFT, is in the best position to:

- Accelerate the development of drugs currently being tested that are viewed as most promising to treat the basic defect for segments of the CF population;
- Discover and develop new drugs that will give us the best chance of developing lifesaving therapies for *all* those with cystic fibrosis;
- Attract more biopharmaceutical companies to the CF drug development effort;



Mike Beatty, Foundation Major Giving chair for Colorado; Foundation Board of Trustees chair Catherine McLoud; *Milestones* campaign chair Joe O'Donnell; and Mac Tisdale, co-chair of the Maryland Chapter Board of Directors.



C. Richard Mattingly, Foundation executive vice president and COO; Kate Niehaus, member of the *Milestones* Executive Committee; and National Advocacy co-chairs Amy and Peter Barry.



Milestones campaign volunteer Connie Brown and Doris F. Tulcin, a founding parent of the CF Foundation for whom the Major Giving Society is named.

Contributors to the *Milestones to a Cure* major giving campaign gathered at the 2010 North American Cystic Fibrosis Conference to celebrate raising \$175 million in just six years.

- Advance the development of treatments that attack the disease from every angle, from symptom and nutrition management to infection and inflammation therapies;
- And continue to pursue every promising avenue toward a cure until we reach our goal.

CYSTIC FIBROSIS FOUNDATION
CONDENSED FINANCIAL INFORMATION*
CONSOLIDATED STATEMENT OF FINANCIAL POSITION
As of December 31, 2010 and 2009

	2010	2009
ASSETS		
Cash and cash equivalents	\$21,677,916	\$30,961,284
Investments	136,749,336	107,668,776
Receivables, net	104,226,549	34,438,910
Inventories	6,583,935	8,099,543
Prepaid expenses and other assets	1,281,371	1,511,570
Fixed assets, net	2,015,703	2,179,032
Total assets	<u>\$272,534,810</u>	<u>\$184,859,115</u>
LIABILITIES AND NET ASSETS		
Awards payable	\$42,166,994	\$42,758,590
Accounts payable and accrued expenses	42,074,107	16,027,809
Total liabilities	<u>84,241,101</u>	<u>58,786,399</u>
Unrestricted net assets	165,901,802	100,674,842
Temporarily restricted net assets	19,046,213	22,579,133
Permanently restricted net assets	3,345,694	2,818,741
Total net assets	<u>188,293,709</u>	<u>126,072,716</u>
Total liabilities and net assets	<u>\$272,534,810</u>	<u>\$184,859,115</u>

INVESTMENTS

Investments as of December 31, 2010 included primarily U.S. government/agency bonds, corporate bonds, low duration bond funds, equity mutual funds and funds of funds. Authoritative guidance on fair value measurements requires an entity to maximize the use of observable inputs and minimize the use of unobservable inputs when measuring fair value. The guidance describes three levels of inputs that may be used to measure fair value: Level 1 - Quoted prices in active markets for identical assets or liabilities. Level 2 - Observable inputs other than Level 1 prices, such as quoted prices for similar assets. Level 3 - Unobservable inputs that are supported by little or no market activity and that are significant to the fair value of the assets. The Foundation carries its cash and cash equivalents, all investment balances and certain other assets at fair value. Financial instruments measured at fair value on a recurring basis were \$104,476,464 in Level 1 assets, \$13,755,815 in Level 2 assets and \$26,630,169 in Level 3 assets.

OPERATING LEASE COMMITMENTS

The Foundation is obligated under various operating leases for office space as of December 31, 2010. The approximate future minimum rental commitments, subject to escalation, are \$17,242,335.

AWARDS PAYABLE AND COMMITMENTS

The Foundation and Cystic Fibrosis Foundation Therapeutics, Inc. (CFFT) generally awards medical/scientific grants and contracts for periods of three years or less. Grants are awarded contingent upon the availability of funds at the beginning of each award period. As of December 31, 2010, the Foundation and CFFT have medical scientific grant commitments of approximately \$4,412,000 which extend through December 31, 2011, in addition to those presented on the consolidated statement of financial position. Subsequent year awards are contingent upon renewal criteria, and therefore, the costs and liabilities are not reflected in the consolidated financial statements. Certain awards contain clauses whereby CFFT is obligated to make additional payments if awardees achieve certain CF drug discovery or development milestones. As of December 31, 2010, total additional payments contingent on these milestones were approximately \$10,200,000. These contingent payments are not recognized as liabilities as the likelihood that the milestones will be achieved cannot be determined at this time. Additionally, certain agreements provide for future contracted drug discovery and development research payments amounting to \$6,440,000. These costs will be expensed when the services are provided.

*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 STATEMENT OF ACTIVITIES
For the years ended December 31, 2010 and 2009

	2010	2009
REVENUE		
Support received from the public		
Special event revenue	\$93,739,643	\$90,025,792
Direct benefit expenses	(12,245,988)	(11,675,074)
Net special event revenue	81,493,655	78,350,718
General contributions	37,057,721	39,949,748
Total support received from the public	118,551,376	118,300,466
Pharmacy services	137,975,525	96,196,306
Investment income	585,008	800,439
Royalty revenue	53,933,009	143,748
Other	2,263,955	2,097,232
Total revenue	313,308,873	217,538,191
COSTS OF SERVICES		
Program services		
Medical programs	215,001,258	181,576,864
Public and professional information and education	15,034,221	18,470,716
Community services	6,644,778	7,282,441
Total program services	236,680,257	207,330,021
Supporting services		
Management and general	9,276,491	5,986,634
Fundraising	15,343,759	17,505,771
Total supporting services	24,620,250	23,492,405
Total costs of services	261,300,507	230,822,426
Increase (decrease) in net assets from operations	52,008,366	(13,284,235)
OTHER CHANGES IN NET ASSETS		
Net nonoperating investment income (losses)	10,212,627	(3,061,364)
Increase (decrease) in net assets	\$62,220,993	\$(16,345,599)

MEASURE OF OPERATIONS

The Foundation includes in its measure of operations all support received from the public, pharmacy services revenue, 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 nonoperating investments.

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. Conditional pledges of \$5,805,336 have not been recorded as of December 31, 2010. Contributions of assets other than cash, including gifts-in-kind, are recorded at their estimated fair value at the date of the gift. Pharmacy services revenue is recorded upon receipt of pharmaceuticals by customers and net of contractual discounts. 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.

At times CFFT may sell its rights under certain agreements in exchange for a lump sum. Amounts received under these agreements are recorded as royalty revenue when rights are forfeited and proceeds are receivable. In 2010, CFFT recorded approximately \$47,760,000 in royalty revenue under such agreements. Gross proceeds of \$63,000,000 were due from a third party under an agreement as of December 31, 2010, and were received by CFFT in January 2011. A balance of \$15,240,000 was payable to another party under an agreement relating to the same intellectual property.

BOARD OF TRUSTEES AND CORPORATE OFFICERS

As of December 31, 2010

BOARD OFFICERS

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Boynton Beach, Florida

EXECUTIVE VICE CHAIR

Gary B. Sabin
San Diego, California

VICE CHAIR

Richard L. Dandurand
Birmingham, Alabama

VICE CHAIR

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Corona Del Mar, California

VICE CHAIR

Charles J. Thayer
Fort Lauderdale, Florida

TREASURER

J. Taylor Crandall
Menlo Park, California

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COUNCIL CHAIR

Barry M. Gump
Santa Clarita, California

MEDICAL ADVISORY

COUNCIL CHAIR

(nonvoting)
Frank J. Accurso, M.D.
Aurora, Colorado

CYSTIC FIBROSIS

FOUNDATION

THERAPEUTICS CHAIR

Theodore J. Torphy, Ph.D.
Spring House, Pennsylvania

CYSTIC FIBROSIS

SERVICES, INC. CHAIR

David A. Mount
Indian Wells, California

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Menlo Park, California

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Birmingham, Alabama

Richard J. Gray
Chicago, Illinois

Barry M. Gump
Santa Clarita, California

Susan L. Hook
Corona Del Mar, California

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Chad T. Moore
Anchorage, Alaska

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Redwood City, California

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Spring House, Pennsylvania

Amy S. Weinberg
Greenwich, Connecticut

Paul W. Whetsell
Arlington, Virginia

KC Bryan White
Chagrin Falls, Ohio

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Bethesda, Maryland

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AND CHIEF OPERATING

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SECRETARY
C. Richard Mattingly
Bethesda, Maryland

EXECUTIVE VICE PRESIDENT

FOR MEDICAL AFFAIRS

Preston W. Campbell, III, M.D.
Bethesda, Maryland

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AND CHIEF FINANCIAL

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Bethesda, Maryland

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(nonvoting)

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Westport, Connecticut

Doris F. Tulcin
White Plains, New York

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(nonvoting)

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Lewis Black
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Boomer and Cheryl Esiason
Kenny G
Brian and Kay Hill
Richard Marx
Rosie O'Donnell
Jim Palmer
Mike Schmidt
Mike Scioscia



We will not rest until we find a cure.





| Adding *tomorrows* every day.

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