OUR MISSION

The mission of the Cystic Fibrosis Foundation is to find a cure for cystic fibrosis and to improve the quality of life for people living with the disease.

Thanks to the determination and passion of an extraordinary team of families, scientists, caregivers, donors and devoted volunteers, we are adding more tomorrows today — and every day — to the lives of all people with CF.

WE WILL NOT REST UNTIL WE FIND A CURE.

Justin, 12, who has CF
Dear Friends,

As we look back on 2012, we can all be proud of the amazing progress we have made in our quest to cure cystic fibrosis. The year kicked off with the exciting news of the FDA approval of Kalydeco™ — the first drug to treat the underlying cause of CF in a small group of people with the disease and a historic breakthrough for the entire CF community.

For the hundreds of people with CF who are now taking the drug, it has been life-changing. They are breathing more easily, gaining weight and spending less time in the hospital.

When we set out on our journey to develop potential small molecule therapies, we did not know if it would be possible to target the basic defect in cystic fibrosis and improve key symptoms of the disease. Kalydeco has proved that it is possible, and offers a roadmap that could help us move forward quickly to bring lifesaving treatments to all people with the disease.

As our efforts to tackle the root cause of CF gain momentum, we continue to vigorously support initiatives that could lead to new strategies to better manage the symptoms of the disease and expand opportunities for quality CF care. We have also expanded our patient assistance and advocacy programs to help ensure that people with CF can access quality, specialized care and obtain essential treatments.

With the launch of our rebranding initiative, we were very excited to release our new logo, reflecting the CF community’s strong sense of hope and optimism for continued progress. Thanks to the untiring dedication and generosity of the Foundation’s friends, volunteers and donors across the country, we are better positioned than ever to power our mission forward.

Through our successful venture philanthropy model, our affiliate, Cystic Fibrosis Foundation Therapeutics, is entitled to royalties from certain drugs that are developed with Foundation support. With this revenue, this year we have been able to fund exciting new research opportunities with Vertex, Pfizer, Genzyme and others to help accelerate the development of more potential drugs targeting the basic defect and assure that we are in the best position to treat 100 percent of CF mutations.

Our work is not yet done, and we cannot stop now. But with such a remarkable team of health care professionals, researchers, donors, volunteers, families and friends working together, I am confident that we will continue to add more tomorrows to the lives of all people with CF and reach our ultimate goal of ending this disease.

Sincerely,

Robert J. Beall, Ph.D.
President and Chief Executive Officer
Cystic Fibrosis Foundation
In early 2012, the Cystic Fibrosis Foundation shared the exciting news that the U.S. Food and Drug Administration (FDA) had approved Kalydeco™, the first drug to treat the underlying cause of the disease for a portion of people living with CF.

The result of a collaboration between the Foundation’s nonprofit drug discovery and development affiliate, Cystic Fibrosis Foundation Therapeutics (CFFT), and Vertex Pharmaceuticals Inc., the approval of Kalydeco marks a significant turning point in the fight against CF and could help pave the way for the development of more groundbreaking new therapies. The Foundation is now pursuing new and expanded CF projects with leading pharmaceutical companies to discover and develop more potential therapies targeting the root cause of CF.

The Foundation also continued to actively support vital initiatives to identify potential new treatments and strategies to help people with CF better manage the symptoms of the disease and improve their health, including programs to combat respiratory problems, the most serious complication for those living with the disease.

Targeting the Underlying Cause of CF

Kalydeco Approval
On Jan. 31, 2012, the FDA approved the oral drug Kalydeco (formerly known as VX-770) for people with at least one copy of the G551D mutation of CF who are ages 6 and older.

The decision followed more than a decade of CFFT investments in the discovery and development of CFTR modulators — small molecule compounds designed to target the defective CFTR protein caused by mutations in the CF gene and tackle the disease at its root.
The G551D mutation is classified as a gating mutation and is found in about 4 percent of people with CF in the United States. In gating mutations, the defective CFTR protein does not function correctly once it is at the surface of the cell; instead, it acts like a locked gate. Kalydeco is designed to unlock that gate and restore the normal flow of salt and fluids into the airways, helping to prevent the buildup of mucus in the lungs that increases the risk of infections in those with CF.

The FDA's approval was based on the results of two yearlong, international Phase 3 clinical trials of Kalydeco, which showed that people with the G551D mutation who received the drug had significant improvements in lung function and weight gain. In addition, their sweat chloride levels — a key indicator of CF — dropped toward normal, a sign that the drug had an effect on the underlying cause of the disease.

The European Commission later approved Kalydeco for people with the G551D mutation ages 6 and older in the European Union, followed by a similar decision by Health Canada. By the end of the year, regulatory agencies in Canada and the 27 countries of the European Union were reviewing the drug to determine how it would be made available to eligible CF patients.

**Additional Kalydeco Studies Planned**

Vertex plans to begin Phase 3 trials of Kalydeco in children ages 2 to 5 who have the G551D mutation and in people with other gating mutations of CF besides G551D, as well as in those with the R117H mutation, which causes abnormal function of the CFTR protein at the surface of the cell. If these trials are successful, Kalydeco when taken alone could potentially become available to up to 8 percent of people with CF. It is hoped that additional trials of Kalydeco in people with other CF mutations will raise the number of those benefiting from the drug to 15 percent of the CF population.

The G551D Observational (GOAL) Study, a multicenter trial funded by CFFT, is now collecting clinical data and samples from people with the G551D mutation who are receiving Kalydeco. As data is gathered from trial volunteers, the GOAL Study could provide researchers with valuable information on the physiologic changes that occur with CFTR modulation — knowledge that could ultimately help advance the development and study of more CFTR modulators.
About 50 percent of people with CF in the United States have two copies of the Delta F508 mutation, and nearly 90 percent have at least one copy. In people with this mutation, the CFTR protein does not fold into the correct shape to reach the surface of the cell. VX-809 is designed to help move CFTR to the cell surface, while Kalydeco increases the protein’s activity once it is there.

Vertex has initiated two Phase 3 studies of the combination treatment in people with two copies of the Delta F508 mutation ages 12 and older. The six-month studies will be conducted at approximately 200 sites in North America, Europe and Australia and enroll about 1,000 CF patients.

Most Phase 3 clinical trials are about one year long. The considerably shorter timeframe of the Phase 3 trial of Kalydeco plus VX-809 is the result of the FDAs awarding the combination treatment “Breakthrough Therapy Designation,” intended to speed the development of select potential therapies that treat life-threatening diseases or conditions. Vertex also will begin a six-month safety study of Kalydeco and VX-809 in combination in children ages 6 to 11 with two copies of the Delta F508 mutation.

In addition, Vertex is studying Kalydeco coupled with another CFTR modulator, VX-661. As this report went to press, Vertex announced results from a Phase 2 trial of the two drugs in combination in people with two copies of the Delta F508 mutation ages 18 and older. People who took the Kalydeco and VX-661 combination treatment showed a statistically significant improvement in lung function, compared with those who received a placebo. Vertex plans to conduct additional studies of Kalydeco and VX-661 in combination, pending discussions with regulatory agencies.
EXPERRT Act
The Foundation and its volunteer CF advocates helped achieve a major legislative victory for the CF community with the passage in June of the Expanding and Promoting Expertise in Review of Rare Treatments (EXPERRT) Act. EXPERRT streamlines the drug approval process, making it easier for the FDA to access outside expertise to understand the science behind new drugs for CF and other rare diseases and move lifesaving new treatments into the hands of patients more quickly. Part of the FDA Safety and Innovation Act, EXPERRT was developed by Sen. Sheldon Whitehouse (D-R.I.) and Congressional Cystic Fibrosis Caucus Co-Chairs Reps. Edward Markey (D-Mass.), Tom Marino (R-Pa.) and Cliff Stearns (R-Fla.). Below, Rep. Ileana Ros-Lehtinen (R-Fla.) speaks with Bonnee Binker, whose granddaughter has CF.

Expanded CFTR Modulator Discovery Efforts
To help speed the discovery of more potential therapies targeting the underlying cause of the disease, CFFT has significantly expanded its research funding opportunities with leading pharmaceutical companies, focusing on potential treatments for those with the most common CF mutation.

In November, CFFT began a new $58 million, six-year program with Pfizer Inc. aimed at discovering potential drugs that restore the normal function of the CFTR protein in people with the Delta F508 mutation. The goal of the program is to move one or more drug candidates into clinical trials by the end of the multiyear collaboration.

One of the largest pharmaceutical companies in the world, Pfizer will draw on its massive library of about 5 million chemical compounds to screen for potential therapies, as well as on its researchers’ expertise in developing therapies that help mutated proteins fold and move correctly within the cell. CFFT is providing the financial support to help advance the pre-clinical program.

The new agreement builds on CFFT’s existing collaboration with Pfizer, which began in 2010 when Pfizer acquired FoldRx Pharmaceuticals Inc. That acquisition included FoldRx’s CF research program that was funded by CFFT and begun in 2007.

CFFT also supports research to identify compounds to treat the most common mutation of CF through robust programs with Genzyme, a Sanofi company, as well as with Vertex.

Ataluren
In June, PTC Therapeutics Inc. released results from a large, international Phase 3 clinical trial of the potential drug ataluren in people who have nonsense mutations of CF. These mutations, found in about 10 percent of people with CF, interrupt the production of the CFTR protein, causing it to be too short to function normally. Ataluren is designed to enable the production of a full-length and fully functional protein.

The Phase 3 trial did not meet its primary outcome measures, including improved lung function. PTC is now in discussions with its clinical researchers and others to determine the next steps for ataluren.

CFFT Launches Drug Discovery Laboratory
As part of its effort to support and help speed the early discovery of potential therapies to treat the underlying cause of CF, CFFT opened its own research laboratory in Bedford, Mass. The CFFT Lab’s primary focus is to develop new screening tools to find chemical compounds that could move forward in development and potentially into CF clinical trials. The CFFT Lab is working closely with university research laboratories and others to test new approaches to tackling the genetic defect that causes CF.
Preserving and Improving Health in People with CF

Lung Health

Respiratory problems remain the most serious and persistent complication for people living with CF. Through CFFT, the Foundation supports a range of robust basic science and clinical research programs to help develop potential new treatments to slow or stop lung damage in those with the disease.

The bacteria *Pseudomonas aeruginosa* is a leading cause of chronic CF lung infections and is found in half of all people with the disease and in more than 70 percent of adults with CF. To control the growth of *P. aeruginosa* in the lungs, people with CF are commonly prescribed the inhaled antibiotic tobramycin inhalation solution (TOBI®), which is taken through a nebulizer.

As this report went to press, the maker of TOBI, Novartis, announced that the FDA had approved a dry powder formulation of TOBI to treat *P. aeruginosa* in people with CF. The new form of the antibiotic, TOBI Podhaler™, is administered with a pocket-sized inhaler, and does not require a nebulizer or need to be refrigerated, shortening the treatment time significantly and making the medication more convenient.
For a number of years, the Foundation has closely tracked the growing prevalence of the bacteria methicillin-resistant *Staphylococcus aureus* (MRSA), which is now found in the lungs of 25 percent of people with CF. MRSA is resistant to multiple antibiotics and the lung infection caused by the bacteria can quickly become a chronic one, associated with worse survival.

To combat this serious problem, CFFT is supporting research to evaluate new therapies that could target MRSA, including two separate clinical studies to determine whether it is possible to eradicate MRSA using aggressive therapy in people with CF who have recently acquired the bacteria and in those with chronic infection.

*Burkholderia cepacia* is a group of several species of bacteria that are also resistant to many antibiotics and can be spread between people with CF. While tighter infection control practices recommended by the Foundation have helped reduce the prevalence of *B. cepacia* in recent years, the bacteria is still found in 2.5 percent of people with CF and can cause serious lung infections.

CFFT is funding research to find new ways to prevent or eliminate lung infections caused by these bacteria. CFFT also supports the *B. cepacia* Research Laboratory and Repository at the University of Michigan, Ann Arbor, which enables scientists to learn more about how *B. cepacia* causes infection and serves as a resource to help the CF medical community investigate the spread of *B. cepacia* and store samples of the bacteria for future research.

Nontuberculous mycobacteria (NTM) are another group of bacteria that can cause lung problems in people with CF. Current treatment for NTM requires lengthy multidrug regimens that can be poorly tolerated and are often not very effective, especially in patients with severe lung disease. CFFT is supporting studies to determine the prevalence of NTM infections, assess their effect on people with CF and evaluate new therapies that target the bacteria.

A Phase 3 clinical trial is investigating an inhaled form of the antibiotic Arikace to treat people with CF who have NTM lung disease. This form of the antibiotic can target the specific site in the cells of the lungs where NTM bacteria can hide from the body’s defenses. Arikace is also being studied in a Phase 3 trial to treat *P. aeruginosa* infections in people with CF.

**Nutrition and Good Growth**

In people with CF, thick secretions build up in the pancreas and prevent the release of enzymes that aid with digestion. More than 90 percent of people with CF take pancreatic enzyme replacements to help the body absorb essential vitamins and nutrients. While these therapies have been in use for decades, in 2004 the FDA required all pancreatic enzyme products on the market to undergo a more rigorous review to ensure people with CF receive the best and most effective enzyme treatments. In March, the FDA approved Ultresa™ delayed-release capsules under the new FDA testing and review procedures. Ultresa, which is manufactured by Aptalis Pharma, is the fourth such product to receive FDA approval.

The standardized use of pancreatic enzyme replacement therapy and early diagnosis through universal newborn screening have helped reduce malnutrition in infants with CF, but many babies and children with CF still have poor growth.

Through CFFT, the Foundation supports different studies to address this problem, including the Baby Observational and Nutritional Study (BONUS), a long-term, multicenter observational study aimed at better understanding the factors that enable good growth in infants with CF.

In addition to closely following the growth of infants with CF through their first year, BONUS is collecting information on their diets, respiratory and gastrointestinal symptoms, medications and hospitalizations to evaluate the characteristics that might be linked to poor growth. Several participating care centers are also conducting sub-studies to help determine the optimal dose of pancreatic enzyme supplements for infants with CF. Findings from BONUS could potentially inform future large-scale studies to explore effective interventions that help children with CF get off to the best start at the earliest age.
**Adherence to CF Treatments**

Adherence to prescribed CF treatments contributes significantly to good health outcomes and decreased hospitalizations among people with cystic fibrosis. CF treatments present a significant time and lifestyle burden for people with CF and their families, and are increasingly costly, creating barriers to adhering to the treatment regimen. However, health care providers often do not have all the information they need to help patients follow prescribed treatments.

A number of studies are exploring ways to make adherence more practical and economical for people with CF, their families and CF care teams, including strategies that use new online and mobile technologies to help people with CF monitor their health and benefit from personalized, real-time feedback.

A multicenter observational trial partially supported by CFFT, the iCare study, is looking at two intervention strategies to help improve adherence: a web-based tool to measure adherence based on pharmacy refill data, and a comprehensive adherence promotion program that incorporates assessment of an individual’s knowledge of the disease and problem-solving skills to overcome key barriers to adherence.

**Depression and Anxiety**

Recent data from the Foundation’s Patient Registry show that 22 percent of adults with CF in the United States have depression and nearly 8 percent have an anxiety disorder. While there is substantial evidence that people with chronic illnesses are at greater risk of depression and anxiety, there have been limited studies of the connection between CF and mental health.

The Foundation provided funding for the U.S. component of a large study to identify the prevalence of depression and anxiety in people with CF around the world. Findings from the International Depression/Anxiety Epidemiological Study (TIDES) will be linked to data in the Foundation’s Patient Registry to investigate the relationship between psychosocial problems and other health outcomes in people with CF.

**Clinical Trials Initiative**

To increase participation in CF clinical trials and help speed the progress of potential therapies in its drug development pipeline, the Foundation continues to expand its resources on clinical trials for people with CF, families and clinical research teams throughout the CFFT Therapeutics Development Network.

As part of its successful “I Am the Key” campaign, the Foundation published a comprehensive brochure on CF clinical trials to give more detailed information to those considering volunteering in a trial. Available in English and Spanish, “About Clinical Trials” explores key steps in a clinical study and addresses common questions that people with CF and their families may have about participating in a trial. The brochure is complemented by a new fact sheet that explains the informed consent process to help potential volunteers or parents of a child with CF as they make a decision about taking part in a clinical trial.

The Foundation also launched a new online tool to keep the CF community informed about clinical trials. By signing up on the Foundation’s website, those interested receive an automatic email alert whenever new CF clinical trials begin or when trial results are posted.

To help improve clinical research processes, the Foundation created an interactive program that equips researchers with the tools and information they need to apply the principles of quality improvement (QI) to clinical research. Based upon QI best practices and findings from several highly effective CF clinical research programs, the eQUIP-CR program is designed to encourage and help clinical research teams integrate QI into their day-to-day activities. A coaching program piloted in 2012 provides QI coaching, by a principal investigator and a research coordinator, to five CF clinical research centers to help them strengthen their programs.

*In keeping with the Foundation's venture philanthropy business model, CFFT has contractual agreements with Vertex, Pfizer, Genzyme and other companies to receive royalties in the event of the approval and/or the sales of certain drugs — including Kalydeco, VX-809 and ataluren — that are developed as a result of CFFT funding. Any royalties CFFT receives are reinvested in support of the Foundation’s mission.*
# Cystic Fibrosis Foundation Therapeutics Pipeline

*As of December 31, 2012*

<table>
<thead>
<tr>
<th>Pre-Clinical</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
<th>Available to Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial Testing in Laboratory</td>
<td>Human Safety Trial</td>
<td>Human Safety &amp; Efficacy Trial</td>
<td>Definitive Trial</td>
<td>Patients</td>
</tr>
</tbody>
</table>

**CFTR Modulation**
- **KALYDECO™**
- **ATALUREN**
- **CORRECTOR VX-809 PLUS KALYDECO™**
- **CORRECTOR VX-661 PLUS KALYDECO™**

**Restore Airway Surface Liquid**
- **HYPERTONIC SALINE**
- **BRONCHITOL**

**Mucus Alteration**
- **PULMOZYMÉ®**
- **IBUPROFEN**
- **KB001**
- **SILDENAFIL**
- **ALPHA 1 ANTI-TRYPSIN**
- **PUR 118**

**Anti-Infective**
- **TOBI®**
- **AZITHROMYCIN**
- **CAYSTON®**
- **TIP (TOBRAMYCIN INHALED POWDER)**
- **LEVOFLOXACIN (INHALED)**
- **ARIKACE™**
- **AEROVANC™**

**Anti-Inflammatory**
- **IBUPROFEN**
- **KB001**
- **SILDENAFIL**
- **ALPHA 1 ANTI-TRYPSIN**
- **PUR 118**

**Nutrition**
- **AQUADEKS®**
- **PANCRELIPASE PRODUCTS**
- **LIPROTAMASE**
The Cystic Fibrosis Foundation is committed to helping people with cystic fibrosis get the specialized care they need to live longer, healthier lives. Through supporting and promoting partnerships among people with CF, families and care center staff, the Foundation works continuously to improve the quality and delivery of care across its network of more than 110 CF care centers nationwide.

These efforts to improve care and treatment have led to steady advances in the length and quality of life in people with CF. In 2012, the overall health of people with CF of all ages continued to improve, with steady gains seen in lung function and nutrition. In addition, the number of people with CF who are living into adulthood continues to grow, with nearly half of the CF population age 18 or older.

Tracking Progress in CF Care
Each year, the Foundation’s Patient Registry tracks the health and treatments of the more than 27,000 people with CF who receive care at Foundation-accredited care centers and makes this information available to people with CF, their families and health care professionals. The Patient Registry offers an in-depth look at specific health outcomes, such as lung function, nutrition and age of survival in people with CF, and is used to help identify areas where more work can be done to improve the health of those with the disease.

The Patient Registry has become a widely recognized model for other nonprofit health organizations. The Foundation has worked closely with CF advocacy groups in other countries, including Australia, Canada, France, New Zealand and the U.K., and is currently collaborating with the Cystic Fibrosis Trust in the U.K. to compare health outcomes between the two countries based on data from CF patient registries.
Partnering to Advance CF Care
As part of its ongoing quality improvement (QI) initiative, the CF Foundation supports several programs that actively engage people with CF, their families and health care professionals in collaborative work to improve the processes and experience of care at CF centers.

In its latest series of the Learning and Leadership QI Collaborative, the Foundation targeted adult care programs, engaging health care professionals and adults with CF to improve care. Adults and their care partners have been instrumental in identifying top concerns and finding ways to enhance processes, such as improved communication and overcoming barriers to accessing clinical care.

New efforts undertaken as part of the Foundation’s QI initiative include a national patient and family experience of care survey, carried out at 21 care centers. Developed by the Foundation in collaboration with the Dartmouth Institute for Health Policy and Clinical Practice and Quality Data Management, the survey provides people with CF and their families the opportunity to share their personal experiences of and insights on important care issues, such as infection control and ease of communication with care center staff. The survey findings will be used to guide improvement efforts at individual care centers.

The Foundation’s mentoring program engages experienced health professionals to work as mentors with those new to CF care or their discipline to help them develop skills and gain hands-on experience in CF care. The program continues to receive positive feedback, with 94 percent of care center directors reporting that apprentices have shown an increased knowledge and confidence in their role following their involvement in the program. More than 300 health professionals in six distinct disciplines have completed the program to date, with both mentors and apprentices reporting that they have benefited from participating.

The Foundation also supports quality care across its care center network through up-to-date treatment guidelines on a range of CF-specific topics. To create the guidelines, the Foundation convenes a committee of subject-matter experts, including people with CF and their families, to review the latest medical evidence and research.

This year, a committee began updating the practice guidelines on infection prevention and control to reflect the latest research and identify ways to help prevent the spread of destructive germs among people with CF, and it expects to release its recommendations in 2013.

The Foundation released new guidelines for the use of chronic pulmonary medicines in CF, which were subsequently published in the *American Journal of Respiratory and Critical Care Medicine*, the flagship journal of the American Thoracic Society.

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New Website Offers Information on CF Gene Mutations
A major international research collaboration, supported by Cystic Fibrosis Foundation Therapeutics, has led to a new website that provides information on CF gene mutations to people with CF and their families, researchers and health professionals. The aim of the website — www.CFTR2.org — is to help determine the relationships between specific mutations and symptoms of CF.

The first of its kind for a genetic disease, the CFTR2 website uses a database with information from nearly 40,000 people with CF, contributed by patient registries and care centers around the world. The site currently includes the 160 most common CF mutations of the more than 1,800 that have so far been identified, allowing visitors to search for information such as reported lung function and sweat chloride levels in people who have a specific mutation.

In the future, as new potential therapies targeting specific CF mutations are developed and become available, the CFTR2 website could help physicians pinpoint the best treatments for a person living with CF.
Expanding Educational Resources
The Foundation is dedicated to providing people with CF and their families with the latest information on cystic fibrosis and works to increase health awareness and knowledge of CF care through a variety of educational platforms.

In response to the growing number of adults with CF, the Foundation launched a new section on its website tailored specifically to this population. Incorporating the firsthand experiences of adults with CF, the Adult Guide offers up-to-date information and practical advice on living with CF, and delves into the distinct challenges that many adults with CF face, such as dealing with depression and anxiety, testing for and diagnosing CF-related diabetes and the importance of exercise. The Adult Guide categories currently include: respiratory, nutrition, gastrointestinal, germs, insurance and finances, daily life and other health issues.

The Foundation presented more than a dozen webcasts on such topics as infant care, lung transplantation, CF genetics and CF diagnosis in adulthood, and also offered videos for people with CF on exercise techniques, nutrition, airway clearance and balancing daily life with cystic fibrosis care. Select print materials were translated into Spanish to help meet the needs of the growing Spanish-speaking CF population.

The new Adult Guide on the Foundation’s website — www.cff.org/adults — offers information to help adults with CF manage the disease and work with their CF health care professionals to improve and maintain their health and quality of life.

Thirteen-year-old Bryant, who has CF, does his airway clearance at a routine clinic visit.
A growing number of people with cystic fibrosis reported having difficulty affording their medical care in 2012. With the rising out-of-pocket costs for CF medications, many CF patients and their families face pressures to skip or cut their prescribed therapies, delay seeking care or manage their CF treatment in other ways to reduce the financial burden. Many are also unable to obtain new therapies because coverage for the drugs is denied or delayed.

To combat these challenges, the Foundation has expanded its programs to help people with CF get the coverage and support they need to keep their health on track and navigate the complexities of managing life with the disease.

Helping People with CF Access Quality Care
The Foundation created the Patient Assistance Resource Center, an information hub that links to numerous Foundation-supported assistance programs. The Center was developed to help people with CF and their families make the most of their health care coverage, decide on coverage that is right for them and find programs to help them pay for treatments. This year, the Center expanded a case management program to help coordinate patients’ benefits and give guidance on health care coverage.

The Cystic Fibrosis Patient Assistance Foundation (CFPAF) helps people with cystic fibrosis get the medications and devices they need. A subsidiary of the CF Foundation, the CFPAF is funded by contributions from the pharmaceutical industry. Throughout the course of the year, the CFPAF helped more than 950 people with CF.

The Cox family siblings (from left) Easton, 12; Kinzy, 17; Riley, 3; and Cameron, 11, smile for the camera. Riley and Cameron have CF and are receiving assistance for their medications from the CFPAF.
The Foundation also expanded its Patient Assistance Resource Library, which offers extensive resources that help people with CF gain and maintain health care coverage. Patients can search the Library for information on assistance programs for CF medications, how-to guides for navigating common insurance obstacles and sample letters of medical necessity and prior authorization to send to insurance companies. CF providers and insurers can access the Library to find care guidelines, evidence-based journal articles and white papers.

Funded by the CF Foundation, the CF Legal Information Hotline™ remains an invaluable resource for people with CF who are uninsured or facing workplace or school issues. More than 5,200 people with CF called the Hotline in 2012 regarding eligibility requirements for Medicaid, Medicare and other public coverage programs; health care coverage obstacles; and employment and school issues.

This year, the Foundation launched its Mutation Analysis Program (MAP), which offers free and confidential genetic testing to identify which CF mutations a person has. As more potential therapies are developed to treat specific CF mutations, knowing an individual’s mutations can help doctors and people with CF and families make informed decisions about the best treatment options.

Protected State-Level Funding

The Foundation engages more than 90,000 volunteers to help build support at the federal and state levels for policies and vital programs that support CF research and people living with the disease and their families. This year, the Foundation continued to protect and promote state-by-state initiatives that are important to the CF community and bring greater awareness of the disease to Capitol Hill.

A primary focus of the Foundation’s advocacy efforts this year was protecting state-level funding for CF programs, which serve as a vital bridge for families that need additional assistance for prescription co-pays, in-patient and out-patient hospital visits and other services. Because these programs are relatively small, they are attractive targets to state legislatures looking to trim annual budgets.

The Foundation successfully defended adult programs in the 20 states where they faced budget cuts and actively engaged decision makers in all 50 states to promote care programs and urge increased protections for CF families that use a wide net of children’s programs, such as the State Children’s Health Insurance Programs (S-CHIP) and Children with Special Health Care Needs programs.

The Foundation also worked with decision-makers across the country following the U.S. Supreme Court’s upholding of the federal Affordable Care Act. The new law allows states to decide how they will administer key components of the law — such as the establishment of health exchanges, expansion of Medicaid eligibility and creation of health benefits. As each state determines how it will comply with the provisions of the law, the Foundation has been working directly with key officials to ensure that the needs of people with CF are considered.

New Pharmacy Alliance with Walgreens

Established in 1988 as a specialty CF pharmacy and subsidiary of the Foundation, CF Services Inc. served nearly 10,000 people with CF in 2012 and filled more than 175,000 prescriptions. In October, the Foundation entered into a new alliance with Walgreens, giving the chain a significant ownership stake in CF Services. The Foundation remains a partial owner of the pharmacy. As part of Walgreens’ network of specialty pharmacies and more than 7,900 stores nationwide, CF Services will be able to offer people with CF greater access to high-quality pharmacy services. CF Services will also continue to provide case management services and reimbursement support and will offer enhanced services to help people with CF better manage their treatments to maintain and improve their health.
Advocating for CF Support on Capitol Hill
The Foundation continued to build momentum in Congress to garner support for those living with the disease. Through targeted visits with elected officials, the Foundation worked to successfully advance CF research and drug development, promote access to care and raise awareness of cystic fibrosis.

Advocacy leaders conducted nearly 500 meetings with elected officials to communicate the importance of maintaining funding for the National Institutes of Health and the U.S. Food and Drug Administration to safely and efficiently move new therapies to people with CF.

In October, the Foundation partnered with other nonprofit health organizations to host a congressional briefing on the advances in CF research and the value of investing in biomedical research. Co-sponsored by Reps. Tom Marino (Pa.), Cliff Stearns (Fla.) and Edward Markey (Mass.), co-chairs of the Congressional Cystic Fibrosis Caucus, the briefing featured a panel of experts and a 38-year-old with CF who shared his experiences of living with the disease.

Speaking Out on Behalf of Loved Ones
In the Foundation’s fourth annual Teen Advocacy Day, 50 teenagers and their families traveled from around the country to Washington, D.C., to speak out on behalf of their siblings, cousins, friends and other family members living with CF.

The teens met with representatives and senators from their areas to discuss how CF affects their loved ones and how members of Congress can support the Foundation’s mission to find a cure and improve the quality of life for those with the disease.

More than 40 Foundation volunteers also came together on Capitol Hill for the annual “March on the Hill.” Volunteers met with 119 members of Congress to share their personal stories and ask them to support the Foundation’s mission to cure cystic fibrosis.

Communications Highlights
Rollout of New Brand and Logo
In July, the CF Foundation launched its new brand and logo, featuring the words “adding tomorrows” and an image of a rising sun. The new logo is only the second in the Foundation’s history and captures today’s spirit of hope and forward momentum in the fight against the disease. The Foundation applied the new visual identity and logo to its website, www.cff.org, which remains a hub for the CF community, drawing 2.2 million visitors in 2012.

“Adding Tomorrows” Wins YouTube Award
Online audiences voted the Foundation’s video “Adding Tomorrows” — selected from among more than 1,000 entries — as the best video for a large nonprofit in YouTube’s 2012 DoGooder Nonprofit Video Awards. The annual contest recognizes the creative and effective use of video to promote the contributions of the nonprofit sector.

Connecting with the Community
Facebook continued to be an important channel for the Foundation to reach people with CF and their families and help connect them to others living with the disease. The Foundation’s Facebook community grew to 150,000 members, the majority of whom have CF or are related to someone with CF.
Adding more tomorrows to the lives of people with cystic fibrosis was the united mission of thousands who came together in 2012 to help the Cystic Fibrosis Foundation achieve its ultimate goal: finding a cure. Families affected by the disease, dedicated volunteers, corporate sponsors and other friends contributed to and participated in hundreds of events nationwide, raising millions of dollars to help support CF research, education, care and other Foundation programs.

The Foundation saw the rapid growth of its sports-based fundraising efforts, including Xtreme Hike and CF Cycle for Life, as athletes from all corners of the United States pushed themselves physically and mentally to support lifesaving programs.

Partners in Progress, the Foundation’s Annual Fund, drew the support of thousands of dedicated friends of the Foundation in its second year.

Major donors renewed their commitment to the Foundation’s major giving campaign, Milestones II: Accelerating the Search for a Cure, to help support vital CF drug discovery and development efforts and accelerate the search for a cure.

From walking, cycling, surfing and climbing to dancing the night away at fundraising galas, volunteers once again used their collective talents to help the Foundation continue to make progress in the quest to find a cure.
Friends of the Foundation Take “Great Strides” to Support the Search for a Cure

Great Strides, the Foundation’s largest fundraising event, continued to expand its reach, generating an outstanding $39.7 million. Moved by the tremendous difference the Foundation is making in the lives of those with the disease, more than 125,000 walkers participated at 600 different sites across the country in 2012.

For the second year in a row, the Georgia Chapter’s Atlanta Great Strides walk reached an incredible milestone, raising more than $1 million in a single year, while the Louisiana Chapter – New Orleans Office’s Great Strides more than doubled its impact over last year. Team Sean’s Pals, led by the Squires family of New Jersey, and the Baker Boys Battalion, headed by Pam and Jon Baker of Atlanta, were the top overall fundraising teams, raising $273,000 and $252,000, respectively.

Foundation’s Sporting Events Gain Momentum

Professional and amateur athletes from across the country came out to support the Foundation’s mission by participating in two of its fastest-growing fundraising events: CF Cycle for Life and Xtreme Hike.

For the third year in a row, cyclists rode through the picturesque landscape of America’s countryside, raising awareness and money to support the Foundation’s mission, including at the Carolina Chapter’s inaugural cycling event, held in Charlotte, N.C., which brought in almost $90,000.

Inspired by the exciting advances in CF research and care, motivated hikers came together to scale some of the nation’s most rugged terrain in the Foundation’s newest fundraising event, Xtreme Hike. Among the most successful of the inaugural hikes was the Massachusetts/Rhode Island Chapter’s Jiminy Peak Xtreme Hike to Cure Cystic Fibrosis, where dedicated climbers in New England trekked through 24 miles of trail and raised $100,000 to support the mission of the Foundation.

Noah Colbert, 4, who has CF, prepares for Great Strides by reminding walkers in Colorado what they are fighting for.

Kaleb Bowers, age 12, who has CF, invited members of his class to join his team at the Sooner Chapter – Tulsa Office’s Great Strides walk. In 2012, Team Kaleb expanded its fundraising efforts by becoming a National Family Team.

Team Finnegan, led by Mike McGurk, raised $20,000 at the 2012 CF Cycle for Life ride in Massachusetts.
Guests at Special Events Across the Country Show Their Commitment to the Cause

Volunteers new to the CF cause and longtime Foundation friends came together at hundreds of galas and other special events, contributing more than $27.8 million in 2012.

Celebrating its 10th year, the Metropolitan Washington, D.C., Chapter’s Breath of Life Gala raised an astonishing $3.3 million to support the Foundation. Scott Pelley, managing editor and anchor of the CBS Evening News, was the Master of Ceremonies at the event and co-chairs Don Wood and Cameron Pratt were instrumental in making the evening an incredible success. Friends and volunteers of the Delaware Valley Chapter’s Breath of Life Gala demonstrated their commitment to finding a cure when they raised nearly $450,000 for the Foundation just days after Hurricane Sandy devastated the region.

Silver screen stars, prime-time TV entertainers and other dedicated showbiz supporters from major entertainment studios, retailers and suppliers gathered in Hollywood for the first-ever Los Angeles Entertainment Summit, raising $400,000 at a three-day event that included live and silent auctions, casino table games and VIP studio backlot tours.

The nation’s top chefs entertained and delighted guests at 11 culinary events throughout the year, serving up more than $1.6 million in steadfast support for the fight against CF. At the Greater Illinois Chapter’s Grand Chefs Gala: Havana, attendees bid on exciting live-auction items, including a culinary competition and private dinner for 10 prepared by two contenders from the television show Top Chef: Texas.

Surfers from both the East and West Coasts rode the waves to raise more than $500,000 at two different events: Orange County Southern California Chapter’s Pipeline to a Cure and Carolinas Chapter – Raleigh Office’s Pipeline to a Cure East. Now in its fourth year, the unique events celebrate the development of hypertonic saline and the role that surfers played in identifying the therapeutic benefits of saltwater for people who have CF.

Partners in Progress

In its second year, Partners in Progress, the Foundation’s Annual Fund, generated almost $2 million from 6,500 members across the United States. Gifts to the Annual Fund provide vital resources needed to help the Foundation reach its goal of finding a cure and control for all people with CF.
Volunteers Honored at Leadership Conference

More than 500 of the Foundation's most committed volunteers, corporate donors and staff came together at the 2012 Volunteer Leadership Conference to learn new and better ways of raising funds and recruiting new friends in the fight against CF.

Led by co-chairs Mary and Lou DeFalco, the conference’s theme, “Growing Hope, Achieving Results,” highlighted the tremendous progress the Foundation has achieved thanks, in part, to the active volunteers who dedicate their time and talents to help find a cure.

The conference also provided a venue to honor many of the Foundation’s most inspirational volunteer leaders, corporate sponsors and other steadfast friends who work tirelessly to fundraise for the Foundation, educate local communities and give hope to families touched by the disease. Kelli and Perry Clark received the From the Heart Award for their dedication to the Foundation’s mission and service as Volunteer Leadership Initiative co-chairs for the past three years.

Margarete Cassalina congratulates Southern California Chapter volunteer Judy Burlingham, who was the recipient of the 2012 Jena Award. Named in honor of Marc and Margaret’s daughter Jena, who lost her battle with CF at 13, the award recognizes an outstanding volunteer with no direct personal connection to CF who has gone above and beyond for the cause.

Gordon Kluzak, retired Boston Bruins hockey player, was given the Decades of Service Award for his work to raise awareness of CF in the Boston-area sports and business communities. Over the last 25 years, Kluzak has raised more than $5 million for the Foundation.

Mitch Greenberg, a dedicated father and husband, was honored with the Alex Award for his perseverance in the face of adversity and his commitment to living life to the fullest. Named in memory of the daughter of Frank Deford, chair emeritus of the Foundation Board of Trustees, the award recognizes someone with CF who is a role model for others with the disease.

Singer Julie Rae, who has CF, performed at the conference and dedicated her song “Singing at the Top of My Lungs” to Foundation volunteers who have helped achieved the great gains in CF research and care that have allowed her to pursue her dreams.

Pam Baker (left) accepts the award for the Top National Family Great Strides Team from Ann Palmer, senior vice president of field management, and Robert J. Beall, Ph.D., president and CEO of the CF Foundation, at the 2012 Volunteer Leadership Conference.

Volunteer Leadership Conference co-chairs Mary and Lou DeFalco helped lead a successful conference in Bethesda, Md.
Milestones II
Cystic Fibrosis Foundation

Major Donors Fuel Groundbreaking Progress

Following the successful completion of the Milestones to a Cure campaign, and inspired by the development and approval of the breakthrough treatment Kalydeco, major donors continued to fuel the second phase of the major giving campaign, Milestones II: Accelerating the Search for a Cure, led by Joe O’Donnell. Eager to help support more vital advances in CF research and care for all people with the disease, major donors raised an extraordinary $21 million, making 2012 the biggest major giving fundraising year for the Foundation since 2008.

To help the campaign reach its goal of $75 million, new Milestones II initiatives were unveiled, including a cultivation effort aimed at introducing potential new friends and donors to the CF cause and the recent medical advancements made possible through the support of major gifts. In addition to the more than 35 new cultivation events, Milestones II leaders and other major donors gathered at a summit in New York to learn about new business strategies the Foundation is pursuing for the years ahead and to further fundraise for the campaign.

The purpose of the campaign is to ensure the Foundation’s nonprofit drug development arm, Cystic Fibrosis Foundation Therapeutics, is in the best position to:

• Accelerate the development and discovery of drugs currently being tested to treat the underlying cause of cystic fibrosis.
• Discover new drugs that will give us the best chance of developing lifesaving therapies.
• Attract more biopharmaceutical companies to the CF drug development effort.
• Advance new trials to study potential therapies that can be used in combination to treat a larger segment of the CF population.
• Discover and develop more therapies to treat the range of symptoms experienced by people with CF, including those who have undergone transplants.

The Foundation hosted a major giving leadership summit in New York City, bringing together (from left) Paul Whetsell, Gina Schewe, Bob and Kate Niehaus, Mike Beatty, Bob and Cyndi Troop, Joe O’Donnell, chair of the Milestones II campaign, Amy Weinberg, Jeff Joyce, Cynthia Kempner, Rich Gray, Martine Denis and C. Richard Mattingly, executive vice president and chief operating officer of the CF Foundation.

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 $800,000 through bequests to the CF Foundation in 2012.

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 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 its 307 members who have made total commitments of $100,000 or more to the Foundation’s major giving initiatives since 1998.
Corporate Partners

Longtime corporate friendships and valuable new collaborations were instrumental in supporting the work and mission of the Foundation.

For more than 25 years, American Airlines has supported the CF cause and community through its signature Celebrity Ski event and other activities. The company again served as the Foundation’s Outstanding Corporate Partner.

CVS/pharmacy raised $2.6 million through a five-week, in-store fundraising campaign, Advancing Medical Research. From late May through early June, shoppers were invited to donate $1 or $3 at the register in CVS/pharmacy locations nationwide or online.

Party City expanded its support of the Foundation through a festive in-store fundraising campaign around Halloween, the company’s busiest time of year. Customers had the opportunity to donate $1 at checkout, raising more than $180,000 in less than a month for the Foundation’s work.

Corporate support also played a critical role on Great Strides walk days around the nation, with thousands of employees of AbbVie, GEICO, Chubb and many other corporate partners coming together to find a cure for CF and help improve the quality of life for those with the disease.
Cystic Fibrosis Foundation Condensed Financial Information*
Consolidated Statement of Financial Position as of December 31, 2012 and 2011

<table>
<thead>
<tr>
<th>Assets</th>
<th>2012</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$89,335,582</td>
<td>$41,407,502</td>
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<tr>
<td>Marketable investments</td>
<td>315,250,322</td>
<td>160,154,669</td>
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<tr>
<td>Receivables, net</td>
<td>22,927,904</td>
<td>23,062,469</td>
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<tr>
<td>Prepaid expenses and other assets</td>
<td>1,716,452</td>
<td>2,342,004</td>
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<tr>
<td>Membership interest in specialty pharmacy</td>
<td>7,286,043</td>
<td>-</td>
</tr>
<tr>
<td>Fixed assets, net</td>
<td>3,204,597</td>
<td>2,291,483</td>
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<tr>
<td>Pharmacy assets (disposed in 2012)</td>
<td>-</td>
<td>24,972,917</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td>$439,720,900</td>
<td>$254,231,040</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Awards payable</td>
<td>$63,954,487</td>
<td>$46,990,392</td>
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<tr>
<td>Accounts payable and accrued expenses</td>
<td>25,136,530</td>
<td>15,856,176</td>
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<tr>
<td>Pharmacy liabilities (disposed in 2012)</td>
<td>-</td>
<td>15,935,557</td>
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<td><strong>Total liabilities</strong></td>
<td>89,091,017</td>
<td>78,782,125</td>
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<tr>
<td>Unrestricted – undesignated net assets</td>
<td>177,610,330</td>
<td>154,243,452</td>
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<tr>
<td>Temporarily restricted net assets</td>
<td>16,291,346</td>
<td>17,895,922</td>
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<tr>
<td>Permanently restricted net assets</td>
<td>3,728,207</td>
<td>3,309,541</td>
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<tr>
<td><strong>Total net assets</strong></td>
<td>350,629,883</td>
<td>175,448,915</td>
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<tr>
<td><strong>Total liabilities and net assets</strong></td>
<td>$439,720,900</td>
<td>$254,231,040</td>
</tr>
</tbody>
</table>

**Investments**
Investments as of December 31, 2012 included primarily U.S. government-agency bonds, corporate bond mutual funds, short duration bond mutual funds, equity mutual funds and alternative investment 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 $212,228,700 in Level 1 assets, $85,839,055 in Level 2 assets and $47,766,629 in Level 3 assets.

**Operating lease commitments**
The Foundation is obligated under various operating leases for office space as of December 31, 2012. The approximate future minimum rental commitments, subject to escalation, are $20,165,003.

**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, 2012, the Foundation and CFFT have medical scientific grant commitments of approximately $14,014,000, which extend through December 31, 2014. These subsequent year awards are contingent upon renewal criteria, and therefore, the costs and liabilities are not reflected in the consolidated financial statements. Certain CFFT agreements provide for future contracted drug discovery and development research payments amounting to approximately $100,113,000. These costs will be expensed when the services are provided.

**Unrestricted – Board-designated net assets**
The Foundation’s Board of Trustees has designated $153,000,000 of the Foundation’s net assets as of December 31, 2012 to be used for drug discovery and development programs.

*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.*
## Consolidated Statement of Activities for the Years Ended December 31, 2012 and 2011

<table>
<thead>
<tr>
<th></th>
<th>2012</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support received from the public</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special event revenue</td>
<td>$104,375,857</td>
<td>$99,214,627</td>
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<tr>
<td>Direct benefit expense</td>
<td>(12,866,218)</td>
<td>(11,850,938)</td>
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<tr>
<td>Net special event revenue</td>
<td>91,509,639</td>
<td>87,363,689</td>
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<tr>
<td>General contributions</td>
<td>42,580,399</td>
<td>38,930,999</td>
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<tr>
<td>Total support received from the public</td>
<td>134,090,038</td>
<td>126,294,688</td>
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<tr>
<td>Investment income</td>
<td>1,372,381</td>
<td>182,553</td>
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<tr>
<td>Royalty revenue</td>
<td>156,593,238</td>
<td>121,552</td>
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<tr>
<td>Other</td>
<td>5,624,365</td>
<td>3,797,128</td>
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<tr>
<td><strong>Total revenue</strong></td>
<td>297,680,022</td>
<td>130,395,921</td>
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<tr>
<td><strong>Cost of services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical programs</td>
<td>114,438,974</td>
<td>92,693,104</td>
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<tr>
<td>Public and professional information and education</td>
<td>17,241,391</td>
<td>16,388,031</td>
</tr>
<tr>
<td>Community services</td>
<td>7,801,153</td>
<td>7,277,568</td>
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<tr>
<td><strong>Total program services</strong></td>
<td>139,481,518</td>
<td></td>
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<tr>
<td>Supporting services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management and general</td>
<td>10,588,156</td>
<td>9,306,193</td>
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<tr>
<td>Fundraising</td>
<td>16,092,899</td>
<td>16,137,612</td>
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<tr>
<td><strong>Total supporting services</strong></td>
<td>26,681,055</td>
<td>25,443,805</td>
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<tr>
<td><strong>Total costs of services</strong></td>
<td>166,162,573</td>
<td>141,802,508</td>
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<tr>
<td>Increase (decrease) in net assets from operations</td>
<td>131,517,449</td>
<td>(11,406,587)</td>
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<tr>
<td><strong>Discontinued operations</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gain from discontinued pharmacy operations</td>
<td>29,203,832</td>
<td>2,562,845</td>
</tr>
<tr>
<td><strong>Other changes in net assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Net nonoperating investment income (losses)</td>
<td>14,459,687</td>
<td>(4,001,052)</td>
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<tr>
<td>Increase (decrease) in net assets</td>
<td>$175,180,968</td>
<td>$(12,844,794)</td>
</tr>
</tbody>
</table>

### 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.

### 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.

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 May 2012, CFFT entered into an agreement to sell a portion of its future royalty revenue under a drug discovery agreement. Net royalty revenue includes $146,120,334 relating to this transaction, which consists of gross proceeds of $150,000,000 net of $3,879,666 of transaction costs.

### Discontinued operations

On December 6, 2012, the Foundation completed its sale of pharmacy operations and recorded a gain on sale totalling $27,022,449. Under the terms of the sale agreement, the purchaser, an unrelated third party, acquired 80% of the outstanding membership interests of Cystic Fibrosis Foundation Pharmacy, LLC (CFFP). The Foundation retained a 20% interest in CFFP totalling $7,286,043 which is reported on the statement of financial position as membership interest in specialty pharmacy. The results of operations of CFFP (and its fully-owned subsidiary, Cystic Fibrosis Services, Inc. (CFS)) through December 6, 2012 total $2,181,383 and are included in the Consolidated Statement of Activities as income from discontinued operations.
Board of Trustees and Corporate Officers
As of December 31, 2012

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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
Susan L. Hook
Corona Del Mar, California

Vice Chair
Paul W. Whetsell
Potomac, Maryland

Treasurer
Charles J. Thayer
Fort Lauderdale, Florida

Leadership Council Chair
Richard J. Gray
Chicago, Illinois

Medical Advisory Council Chair
Frank J. Accurso, M.D.
Aurora, Colorado

Cystic Fibrosis Foundation Therapeutics Chair
Christy L. Shaffer, Ph.D.
Chapel Hill, North Carolina

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(nonvoting)
Aurora, Colorado

Robert J. Beall, Ph.D.
Bethesda, Maryland

Michael L. Beatty
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J. Taylor Crandall
Menlo Park, California

Richard L. Dandurand
Birmingham, Alabama

Richard J. Gray
Chicago, Illinois

Barry M. Gump
Santa Clarita, California

Susan L. Hook
Corona Del Mar, California

Catherine C. McLoud
Boynton Beach, Florida

Chad T. Moore
Anchorage, Alaska

David A. Mount
Mountain Center, California

Gary B. Sabin
San Diego, California

Christy L. Shaffer, Ph.D.
Chapel Hill, North Carolina

Steven Shak, M.D.
Redwood City, California

Charles J. Thayer
Fort Lauderdale, Florida

Amy S. Weinberg
Greenwich, Connecticut

Paul W. Whetsell
Potomac, Maryland

KC Bryan White
Chagrin Falls, Ohio

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President and Chief Executive Officer
Robert J. Beall, Ph.D.
Bethesda, Maryland

Executive Vice President and Chief Operating Officer, Secretary
C. Richard Mattingly
Bethesda, Maryland

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

Senior Vice President and Chief Financial Officer
Vera H. Twigg
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(nonvoting)

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(nonvoting)

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Michael Bolton
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Brian and Kay Hill
Richard Marx
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Jim Palmer
Mike Schmidt
Mike Scioscia