

CYSTIC FIBROSIS FOUNDATION 2016 ANNUAL REPORT

Momentum





THE MISSION of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment, and ensuring access to high-quality, specialized care.

Dear Friends,

Some of you have heard me say that cystic fibrosis is the most amazing story in medicine. This has never been more true than it is right now. When parents today learn that their child has CF, they also learn there are many reasons to have hope. Thanks to advances in research and care, many children with CF will grow into adults and follow their dreams — attending college, pursuing careers, and having families of their own.

We didn't arrive at this moment overnight. The opportunities we are pursuing today exist thanks to our remarkable community of tireless volunteers and donors, dedicated care teams and scientists, and, above all, people with CF and their families. Their shared commitment and decades of hard work have transformed CF from a devastating diagnosis into a story of innovation and promise.

The progress we have made together is nothing short of astounding.

More than half of individuals with CF can now benefit from disease-modifying treatments. Next-generation therapies that could help as many as 95 percent of our community are entering clinical trials. And, perhaps

“The progress we have made together is nothing short of astounding.”



most exciting of all, we are in pursuit of a one-time cure for all people with CF. Even as we focus on the future, we are committed to enriching and improving the lives of people with CF today by helping them get the care they need to stay healthy and connecting them with others who are living with this disease.

But, there is still more work to be done. Our community is at a pivotal moment and must build on the powerful momentum first generated in 1955 by parents desperate to save their children's lives. We cannot stop until we finish the job they began.

Our story has always been one of hope and fierce determination, and I am so proud of all that we are achieving together. Thank you for being part of this amazing journey.

Sincerely,

PRESTON W. CAMPBELL, III, M.D.
PRESIDENT AND CHIEF EXECUTIVE OFFICER

Research

CFF.org/Research

We are facing a moment of unprecedented opportunity to change the course of cystic fibrosis. Thanks to decades of unwavering support from our community, approximately half of all people with CF may now benefit from treatments that address the underlying cause of their disease. The pipeline of therapies to treat CF is ripe with promising new approaches, and the next generation of disease-modifying and symptomatic therapies is on the horizon. We are working every day to build on this incredible momentum — aggressively funding an innovative research agenda and directing more money than ever to developing life-changing treatments.

To accelerate the pace of therapeutic advancements, the number of programs funded by the Cystic Fibrosis Foundation as well as our nonprofit drug discovery and development affiliate, CF Foundation Therapeutics Inc. (CFFT), has more than doubled since 2012. The Foundation made more than 1,100 awards to support basic and clinical research and care in 2016 alone. And, our support of more than 20 drug discovery and therapeutics development initiatives is enabling companies to advance new therapeutic programs that may not have moved forward otherwise.

In 2016, the CF drug development pipeline was the most robust in the history of the Foundation — a trend we expect to continue in the coming years — including 10 new and potentially more effective cystic fibrosis transmembrane conductance regulator (CFTR) modulators, as well as treatments that address complications of the disease. Keeping our promise to leave no one behind, the CF Foundation is also investing heavily in groundbreaking research to accelerate the development of therapies for individuals with nonsense and rare mutations and, ultimately, to find a cure for all people living with this disease.

INVESTING IN OUR MISSION IN 2016



51

clinical trials



1,100+

awards issued

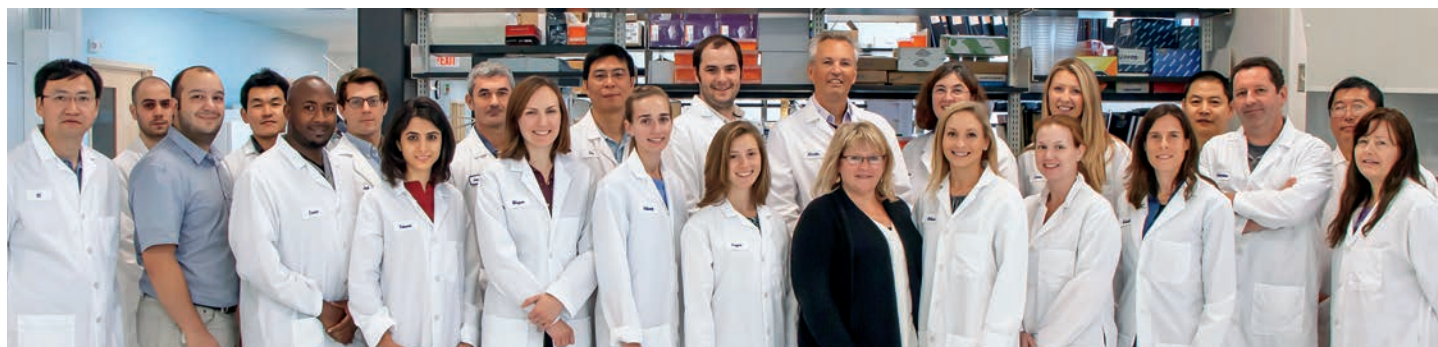
more than doubled since 2012



25

actively funded industry
drug discovery and
development programs

more than doubled since 2012



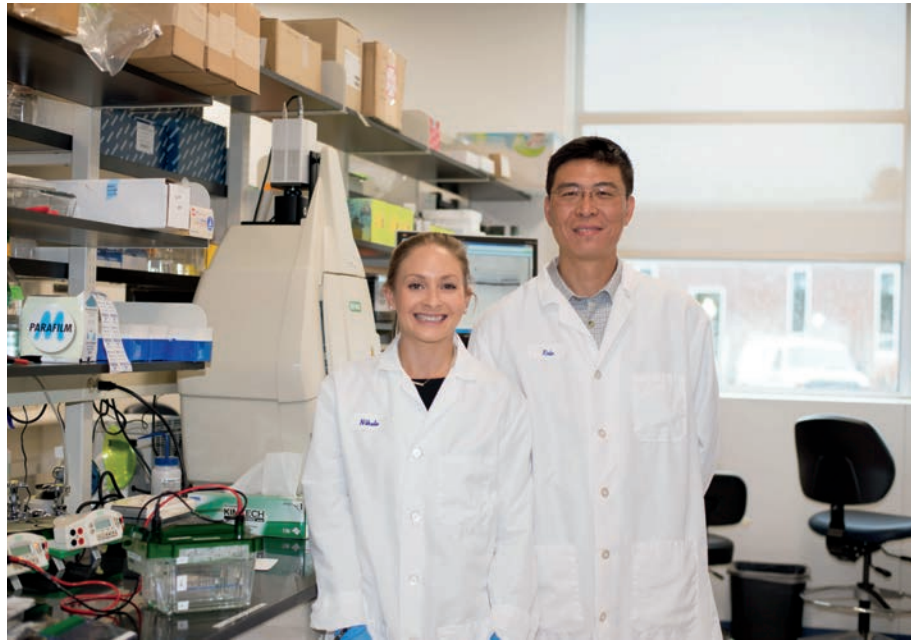
Scientists gather at the CFFT Lab, the first nonprofit research facility that is dedicated to finding new treatments and a cure for CF, with a particular emphasis on finding promising drugs for nonsense and rare mutations.

Research

One-Time Cure

Our long-term goal is a one-time cure that will benefit all people with CF. Using the latest scientific discoveries in gene editing and stem cells, the Foundation is investing in research to tailor gene editing techniques for CF, improve our understanding of stem cells in the lungs, and develop delivery systems to get these gene editing tools into the right cells.

As part of this initiative, the CFFT held the largest CF-focused conference of its kind in June on gene editing, gene delivery, and stem cell therapeutics. The New Technologies Basic Research Conference in Savannah, Ga., brought together more than 120 attendees, including scientists, trainees, and industry representatives, to facilitate collaboration and improve our understanding of how this cutting-edge technology will advance a cure for CF.



Nikole Jordan and Eric Wong, CFFT Lab scientists

MOMENTS TO CELEBRATE

CFFT Lab.

The CF Foundation celebrated the opening of a new, one-of-a-kind CF research facility to bridge the gap between academic discovery and the pharmaceutical industry. Based in Lexington, Mass., the CFFT Lab identifies and tests potential groundbreaking therapies for CF, readying them for further development.

The lab recently launched an initiative to create a cell culture bank from patients with rare CFTR mutations, which will aid in developing nonsense-targeted therapies and extending available therapies to people with rare mutations.

CF Lung Transplant Initiative.

As approximately 200 people with CF undergo lung transplantation every year, we need to improve both the referral and pre-transplant journey as well as the care and long-term outcomes for people with CF who undergo transplant. In July, the Foundation announced a \$15 million initiative for research into lung transplantation as part of the White House Organ Summit.

The CF Lung Transplant Initiative draws on the expertise of transplant clinicians, basic scientists, patient advocacy groups, and transplant centers to improve the delivery of lung transplant clinical care, improve understanding of post-transplant complications, and develop new therapies for lung transplantation through clinical trials.

Clinical Trials Finder.

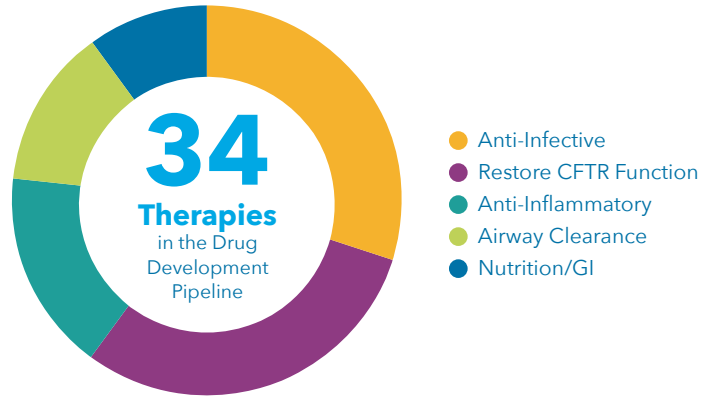
To increase enrollment in the growing number of clinical trials — including more than 50 studies anticipated in 2017 — the Foundation launched an online tool to empower the CF community to participate in clinical research. This resource enables people with CF and their families to find trials that are enrolling in their area and contact the researchers directly to find out more. In the first month after its release, the search tool activity increased from an average of 82 page visits per month to an astounding 26,263 page visits.

The Foundation is also providing support for clinical studies taking place in the United Kingdom, continental Europe, and Australia to ensure that enrollment keeps pace with the dramatic increase in the number of studies.

More Than Modulators

Even with the successful development of CFTR modulators, the CF Foundation is aggressively pursuing and funding a broad portfolio of new treatments to bring additional comprehensive, lifesaving therapies to the CF community as quickly as possible. These programs address complications of CF, including multidrug resistant bacterial infections, unchecked inflammation, and defective mucus clearance — as well as novel disease-modifying approaches such as ribonucleic acid (RNA) therapy, a method of replacing and repairing the defective messenger RNA responsible for producing the CFTR protein. For those people with CF unable to benefit solely from modulators, these therapeutic strategies will be critical to ensuring all people with CF have the treatments they need.

ADVANCING NEW TREATMENTS



VITAL STATS



MORE THAN
30,000 people
are living with cystic fibrosis
(more than 70,000 worldwide).



MORE THAN
10 million Americans
are symptomless carriers
of the defective CF gene.



MORE THAN
half of the CF population
is age 18 or older.

Anti-Infective

Nutrition/GI

PROGRESS AND PRIORITIES: CF THERAPEUTIC DEVELOPMENT

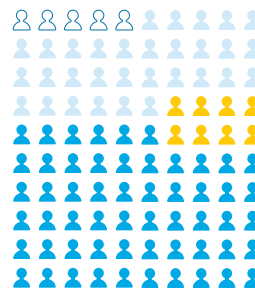
Expanding CFTR Modulators

In 2016, the U.S. Food and Drug Administration (FDA) approved lumacaftor/ivacaftor (Orkambi®) in individuals with CF ages 6–12 who are homozygous for the F508del mutation. Additional trials are underway to test the safety of ivacaftor (Kalydeco®) for children between the ages of 6 months and 2 years, and the safety of lumacaftor/ivacaftor for children between the ages of 2 and 5.

These developments mark important progress toward ensuring that people with CF have access to modulators as early as possible to potentially preserve and maintain lung function before the disease progresses and causes significant damage to the lungs. An exciting study published in December 2016 further supports the importance of starting treatment early by indicating the likely long-term benefits of these therapies, showing a 40 percent reduction in exacerbations and a 42 percent decrease in the loss of lung function in people taking lumacaftor/ivacaftor for nearly two years.

Next-Generation Modulators

The number of new modulator candidates in clinical trials continued to grow in 2016, potentially allowing more people to experience the benefits of these therapies than ever before. Researchers are optimistic that several next-generation modulators in development have the potential to be significantly more effective than lumacaftor/ivacaftor, and the first of these compounds entered clinical studies in late 2016.

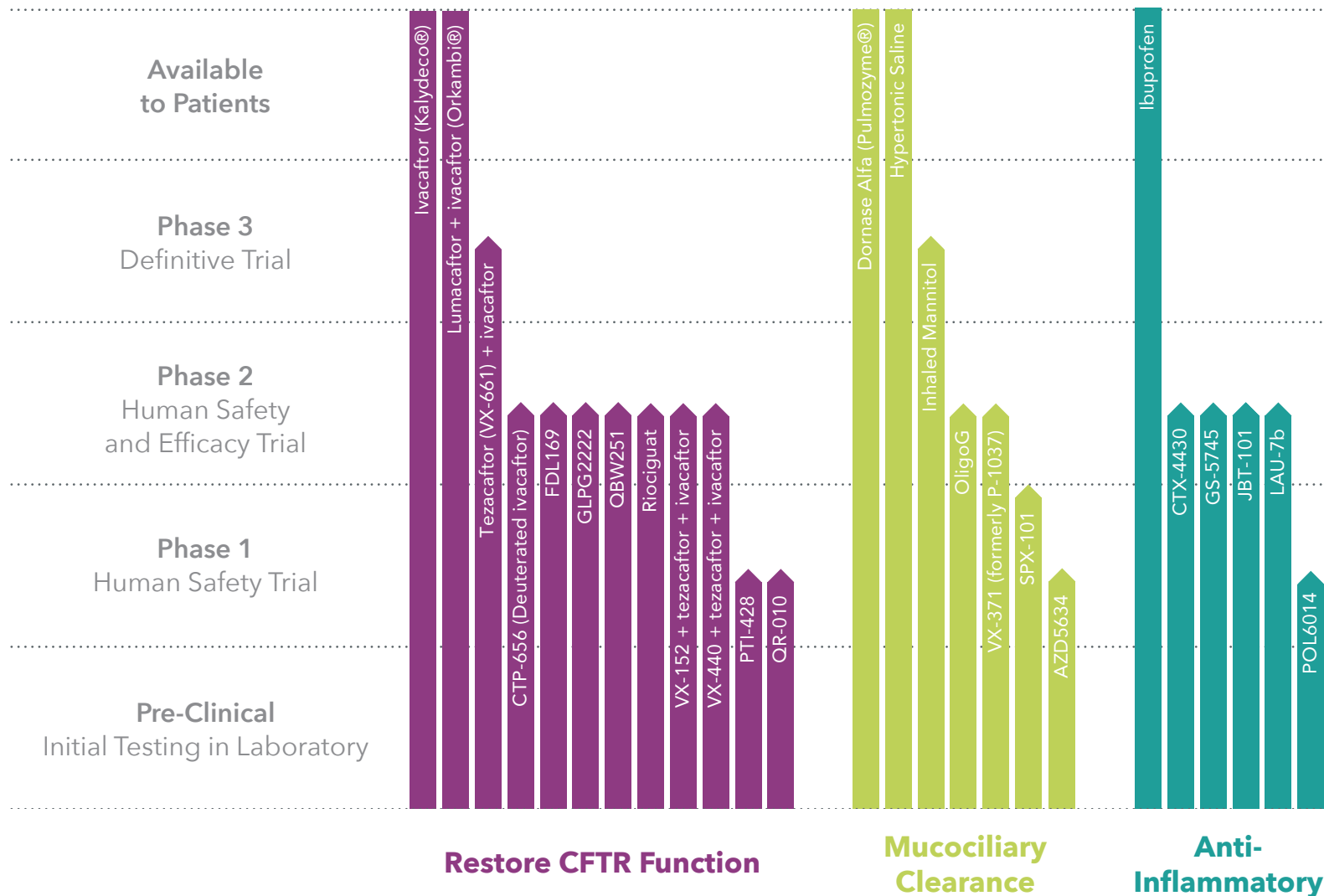


MODULATORS TODAY AND TOMORROW
(Totals are cumulative)

- **Ivacaftor • 8%**
- **Lumacaftor/ivacaftor • >50%**
- **Next-Generation • 95%***

* Anticipated

DRUG DEVELOPMENT PIPELINE AS OF MARCH 2017



Care

CFF.org/Care

People with cystic fibrosis and their families must manage the disease 24 hours a day, 365 days a year. Successfully sustaining that daily care goes well beyond taking prescribed treatments and therapies and making quarterly visits to a care center; it requires constantly balancing an individual's changing health needs and personal goals with the realities of daily life. We believe that this level of personalized treatment is only possible when people with CF fully partner with their care teams.

The CF care model — nationally recognized as an exemplary health care system for a complex, chronic disease — delivers high-quality, specialized care that is coordinated through a multidisciplinary clinical team and personalized in partnership with the people and families who live with the disease.

Thanks to dedicated volunteers and donors, the Cystic Fibrosis Foundation significantly increased its support of the CF care model by more than 44 percent in 2016. Almost \$43 million was invested to sustain and improve care delivery through the nationwide network of more than 120 care centers.

STRATEGIC INVESTMENTS IN CARE

A Strategic Investment Task Force, which included an adult with CF and the parent of a child with CF, initiated the following recommendations from the community about how increased funding could improve care:

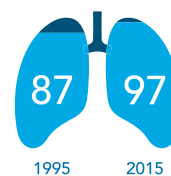
- Increased support** of Patient and Family Advisory Boards
- Center grants** to bolster programmatic support
- Recruitment and training** of endocrinologists
- Merit-based awards** to recruit part-time pharmacists and physical therapists to CF care teams



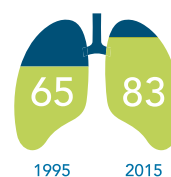
Providing data to inform partnerships between care teams, people with CF, and their families is one of the many ways that the CF Foundation is supporting daily care.

IMPROVEMENTS IN LUNG FUNCTION

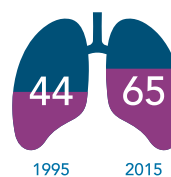
Median FEV₁ Percent Predicted in 1995 and 2015



For 10-year-olds



For 18-year-olds



For 30-year-olds

Lung function is the primary indicator of health and is associated with survival for people with CF.

MOMENTS TO CELEBRATE

Investing in Mental Health.

The CF Foundation helped care teams implement clinical guidelines on depression and anxiety by funding recruitment of mental health coordinators at 120 CF programs and launching an advisory committee on integrating mental health into standard CF care.

Patient-Driven Research Agenda.

The Insight CF Registry Research Project was launched at the North American CF Conference. For the first time ever, people with CF and their families can directly inform research efforts using the CF Patient Registry.

Innovation Through Quality Improvement.

Fourteen care teams, including patients and families, gathered in October to develop, test, and refine improvements that incorporate patient input in how CF care is delivered.

Policy and Advocacy

[CFF.org/Get-Involved/Advocate](https://www.cff.org/Get-Involved/Advocate)

In today's complex and rapidly changing health care system, the Cystic Fibrosis Foundation serves as a tenacious advocate for people with cystic fibrosis and their families by advancing research and promoting innovative policies to help them access high-quality, specialized care.

In early 2016, the Foundation rebranded its Patient Assistance Resource Center as CF Foundation *Compass* and significantly expanded the program's reach to support more people with CF than ever before. Our team of talented case managers is available to help navigate insurance, financial, legal, and other complex life issues.

MOMENTS TO CELEBRATE

Senate Cystic Fibrosis Caucus. In April, the Foundation celebrated the launch of the Senate Cystic Fibrosis Caucus. Led by Sens. Edward Markey (D-Mass.) and Charles Grassley (R-Iowa), this group will work closely with the House of Representatives' Congressional CF Caucus.

Value Symposium at North American CF Conference (NACFC). At NACFC, the Foundation held a symposium on the future of the CF care model in a rapidly changing health care landscape. Featured speakers included Patrick Conway, M.D., MSc, chief medical officer at the Centers for Medicare and Medicaid Services.

Health Care Reform. As part of our broader efforts related to health care reform, the Foundation joined 72 other chronic and rare disease organizations to send a letter to President Trump and congressional leadership to explain the critical role that high-quality, affordable health insurance plays in helping our communities access essential treatments and care, thereby expressing our desire to work together to create a health care system that benefits all Americans.



Senators Charles Grassley (R-Iowa) and Edward Markey (D-Mass.) speak at the Senate CF Caucus launch event on Capitol Hill in June.



OVER THE PAST YEAR, COMPASS INCREASED ITS
call volume by 31%
AND
caseload by 128%



IN 2016, CF CLINICIANS MET WITH
PUBLIC AND PRIVATE INSURERS ACROSS
22 states
TO ADVOCATE FOR THE UNIQUE NEEDS
OF OUR COMMUNITY.



ALTHOUGH NEARLY ALL PEOPLE
WITH CF HAVE INSURANCE,
about 1 in 4
SKIP OR DELAY CARE OR ALTER DOSES
OF PRESCRIBED MEDICATIONS DUE TO COST.

OUR POLICY PRINCIPLES

Everyone with CF must have access to care that is:

Adequate: Enables access to therapies and care delivered by an accredited care team

Affordable: Ensures timely access to necessary care without undue financial burden

Available: Provides adequate benefits at an affordable cost regardless of an individual's income, employment, health status, or geographic location

Transparent: Ensures that people with CF, clinicians, and institutions have all available evidence when making important health decisions

Value-based: Increases our understanding of the value of CF care

Community Partnerships

[CFF.org/Get-Involved/Community](https://www.cff.org/Get-Involved/Community)

Today, more than half of all people with cystic fibrosis are age 18 or older. This significant shift is the result of the tireless efforts by our community of volunteers, donors, caregivers, and researchers. People with CF are experiencing milestones like going to college and getting married — goals that seemed impossible a few short decades ago.

Community Partnerships spearheads the development and expansion of innovative initiatives designed by the growing adult community to help them have “better todays” — even as we continue to advance our mission of adding tomorrows. Although the initial focus is on adults, the aim is to better serve the entire community of people with CF and their families in the years to come.



Adults with CF connected through small video breakout groups during BreatheCon, providing an opportunity for open and honest dialogue around topics specific to living with CF.

BREATHECON BY THE NUMBERS



188 participants



**80%+ rated
BreatheCon a “10”**



**23 small group
breakout sessions**



1 live mindfulness session



1 live yoga session



**34 states and 6 countries
represented**

“I will be thinking ‘before BreatheCon’ and ‘after BreatheCon’ as a pivotal moment in my life that impacted me and empowered me to better manage my disease and mindset.”

BREATHECON PARTICIPANT

MOMENTS TO CELEBRATE

BreatheCon. Nearly 200 adults joined BreatheCon, the first virtual conference by and for people with CF. Participants heard keynote and panel presentations and participated in small group discussions focused on crucial topics including fertility, CF in the workplace, and parenthood. They also enjoyed virtual yoga and stress reduction sessions led by people with CF.

Impact Grants. The first annual Impact Grants were awarded to seven programs proposed by and for people with CF and their families. Recipients of the \$10,000 awards were selected by the CF Adult Advisory Council, an external panel composed entirely of adults with CF.

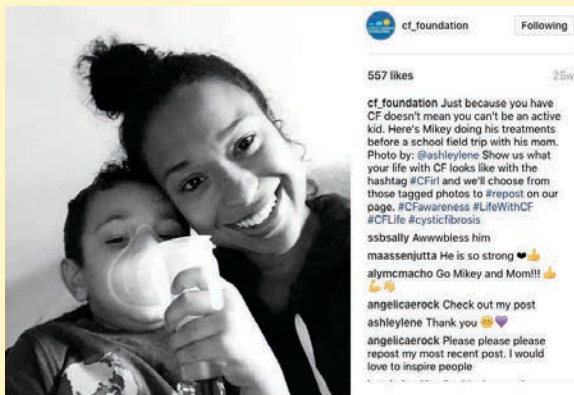
Peer-to-Peer Mentoring. Our newly launched mentoring pilot program enables adults with CF to share their experiences of living with a chronic illness through meaningful connections with their peers. In its first year, the program trained more than 50 mentors and facilitated 75 connections with peers through phone or video conferences.

Stories From the Community

CFF.org/Blog

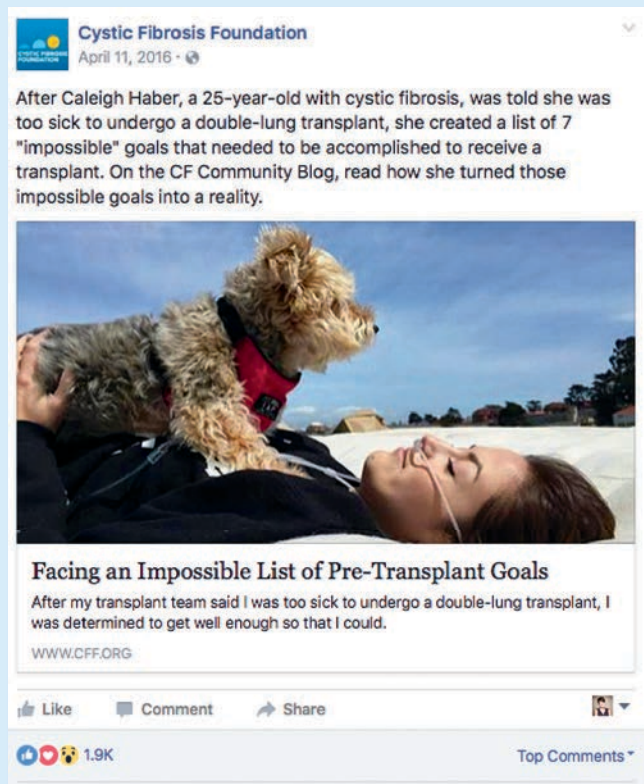
Our community's voices offer insights into living with this challenging disease, and they inspire our work each day. Here are a few of the stories that resonated most among our community in 2016.

INSTAGRAM



"Just because you have CF doesn't mean you can't be an active kid."

FACEBOOK

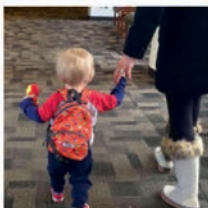


"After my transplant team said I was too sick to undergo a double-lung transplant, I created a list of seven 'impossible' goals that I needed to be accomplished."

BLOG POST

CF COMMUNITY BLOG

An Open Letter to My Son's Future Wife



By Jaclyn Strube | March 21, 2016

I often think about the woman who will eventually marry my son. I think about what she is doing right now and what her life is like. Although I can't wait to meet her, at this point, I'm also sad thinking about not being the number one woman in Major's life.

Topics: [Parents and Guardians](#), [Social Life and Relationships](#)

In 2016, the CF Community Blog had 50 contributors including people with cystic fibrosis, parents, volunteers, clinicians, researchers, Foundation employees, and donors.

teamMATEs in Action

CFF.org/Get-Involved/Donate

Passion. Tenacity. Resilience. These are the qualities that our Cystic Fibrosis Foundation teamMATEs* bring to bear every day in the fight against cystic fibrosis. Our volunteers and donors are the driving force behind transformative medical advancements that have dramatically improved people's lives over the past 60 years — and it is this group of exceptional individuals who remain our greatest hope for defeating CF once and for all.

We are especially proud to have welcomed more than 6,500 new volunteers to the role of CF Foundation teamMATEs in 2016, including more than 2,700 new donors to the *Partners in Progress* Annual Fund campaign. Together, they held a staggering 1,000+ events across the country and helped raise more than \$100 million, inspiring participation by sharing the CF Foundation's incredible story.

These committed volunteers reached out to people from all walks of life and encouraged them to do whatever they could to make an impact. Some walked, others climbed, fished, golfed, or attended galas. Thanks to these teamMATEs, thousands of people from coast to coast were inspired to give their time, talent, and dollars in the fight against CF — ultimately enabling the continued acceleration of progress toward a cure for all.



The Woods family, who walk in Great Strides each year

MOMENTS TO CELEBRATE

"One Team, One Dream" Volunteer Leadership Conference (VLC).

Volunteers and donors attended the annual VLC in March, where they connected, shared stories, and celebrated successes. Special thanks go to volunteer Co-Chairs Laura Gordon from Maryland and Kim Mroczkowski from Northern California for leading this energizing event.

Making "Great Strides" Toward a Cure.

With more than 125,000 participants, Great Strides remains the Foundation's biggest fundraising event and the largest CF awareness activity in the world. Aside from generating an astounding \$40 million in donations, this event helps educate people about CF. Through new mission stations, participants had the opportunity to learn more about Foundation services and how to access them.

Exceptional Impact Through Individual Giving.

Individual giving, which includes major gifts, legacy giving, direct mail, and the annual fund, rose dramatically, with contributions exceeding \$21 million. This year also saw the successful launch of a planned giving program for supporters interested in leaving a gift to the Foundation in their will.

* Make Adding Tomorrows Easier

TOP NATIONAL CORPORATE TEAM **CISCO Systems, Inc.** | RISING STAR NATIONAL CORPORATE TEAM **First Allied Securities** | SPIRIT OF AMERICAN AWARD **Unum Insurance,**

**CORPORATE
LEADERSHIP
COUNCIL**

abbvie

**Bank of America
Merrill Lynch**

BB&T

American Airlines



Joe O'Donnell, Keenan Flynn, Sen. Edward Markey (D-Mass.), Preston W. Campbell, III, M.D., and Cam C. McLoud



Jane and Rex Huggins, Bill Skach, Michael and Valerie Franklin



Laura Gordon, Kathy, and Joe O'Donnell



Karen and Scot Rittenbaum with Marc Ginsky (center) at the CFFT Lab opening



CF Cyclists take action in the fight against CF.



At Finest and Endurance events across the U.S., teamMATEs raised money and awareness.



LEGACY GIVING

Over the year, we were honored that 147 donors enrolled in the Paul di Sant'Agnese Legacy Society, which recognizes donors who make a lasting commitment to the CF Foundation through their estate plans — more than tripling the number of individuals who have made a significant difference in this way. The society pays tribute to Paul di Sant'Agnese, M.D., who revolutionized CF diagnosis by developing the sweat test.

THE DORIS F. TULCIN MAJOR GIVING SOCIETY

The Doris F. Tulcin Major Giving Society continued to grow, with more than 2,500 members. The society honors Doris F. Tulcin — a founding parent of the CF Foundation and a pillar of the CF community — by recognizing members who have helped advance the Foundation's mission through their generosity of a total commitment of \$100,000 or more.

CORPORATE ENGAGEMENT

Whether through employee engagement, matching gifts, or sponsorship of a special event, our corporate sponsors played an important role in supporting our success. The companies listed below were recognized for their exceptional contributions in 2016.

PARTNERS IN PROGRESS ANNUAL FUND CAMPAIGN

Thanks to the leadership of Peter Hodge, national volunteer chair of the Annual Fund, and longtime volunteer Mark Harvey, M.D., the Annual Fund raised more than \$4.7 million — the largest amount in the campaign's six-year history. For the second year in a row, Dr. Harvey and the Marlin Oil Corporation offered a matching gift opportunity of up to \$500,000 nationally.

Don Baylor, The Mark Harvey Family | OUTSTANDING REGIONAL CORPORATE SUPPORT Choate Construction | CORPORATE CHAMPION AWARD James Darling, Chubb Insurance



Cystic Fibrosis Foundation Condensed Financial Information*

CONSOLIDATED STATEMENTS OF FINANCIAL POSITION

As of December 31, 2016 and 2015

ASSETS	2016	2015
Cash and cash equivalents	\$ 101,987,992	\$ 281,082,509
Investments	3,795,790,436	3,485,971,990
Receivables, net	15,658,290	50,472,210
Other assets	11,401,161	8,808,007
Fixed assets, net	7,069,182	4,550,154
TOTAL ASSETS	\$3,931,907,061	\$3,830,884,870
LIABILITIES AND NET ASSETS		
Accounts payable and other liabilities	\$ 27,044,203	\$ 24,589,948
Awards payable	172,707,680	126,870,394
Total liabilities	199,751,883	151,460,342
UNRESTRICTED NET ASSETS		
Undesignated net assets	420,457,947	364,492,149
Board-designated net assets	3,300,000,000	3,300,000,000
Total unrestricted net assets	3,720,457,947	3,664,492,149
Temporarily restricted net assets	7,954,458	11,255,303
Permanently restricted net assets	3,742,773	3,677,076
Total net assets	3,732,155,178	3,679,424,528
TOTAL LIABILITIES AND NET ASSETS	\$ 3,931,907,061	\$ 3,830,884,870

Cash and cash equivalents

Cash and cash equivalents represent demand deposits, money market funds and money market mutual funds. Cash equivalents consist of highly liquid investments with original maturities of three months or less and present an insignificant risk of change in value. The Foundation had outstanding commitments to purchase \$100,000,000 of investments as of December 31, 2015. The cash associated with these commitments is classified as cash and cash equivalents as of December 31, 2015, and the purchases were completed in January 2016.

Investments

Investments as of December 31, 2016, included primarily corporate and other bond mutual funds, short duration bond mutual funds, equity mutual funds, global equity securities, exchange traded equity funds, fixed

income and public equity commingled funds, hedge funds and private equity funds. Authoritative guidance on fair value measurements requires an entity to maximize the use of observable 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 \$2,646,257,923 in Level 1 assets, \$41,254,879 in Level 2 assets and \$3,792,791 in Level 3 assets. Investments totalling \$1,141,087,821,

which are measured at fair value using net asset value as a practical expedient, have not been categorized in the fair value hierarchy.

Operating lease commitments

The Foundation is obligated under various operating leases for office space as of December 31, 2016. The approximate future minimum rental commitments, subject to escalation, are \$48,032,575.

Awards payable and commitments

The Foundation and Cystic Fibrosis Foundation Therapeutics, Inc. (CFFT) generally award medical/scientific grants and contracts for periods of three years or less. Grants are awarded contingent upon the renewal criteria at the beginning of each award period. As of December 31, 2016, the Foundation and CFFT have medical scientific grant commitments of approximately \$76,535,000, which

extend through December 31, 2020. 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 \$148,077,000. These costs will be expensed when the services are provided.

Unrestricted - Board-designated net assets

The Foundation's Board of Trustees has designated \$3,300,000,000 of the Foundation's net assets as of December 31, 2016 to be spent in support the mission of the Foundation over the long term. These board-designated net assets are known as the Opportunity Fund.

* 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, 4550 Montgomery Avenue, Suite 1100 N, Bethesda, MD 20814.

Cystic Fibrosis Foundation Condensed Financial Information

CONSOLIDATED STATEMENTS OF ACTIVITIES

For the years ended December 31, 2016 and 2015

REVENUE	2016	2015
SUPPORT RECEIVED FROM THE PUBLIC		
Special event revenue	\$ 100,103,099	\$ 105,489,279
Direct benefit expenses	(13,839,765)	(14,091,052)
Net special event revenue	86,263,334	91,398,227
General contributions	30,980,848	31,821,862
Total support received from the public	117,244,182	123,220,089
Royalty revenue	52,695,149	32,038,457
Other	11,976,867	17,799,687
TOTAL REVENUE	181,916,198	173,058,233
EXPENSES		
PROGRAM SERVICES		
Medical programs	277,291,061	189,985,364
Public and professional information and education	14,539,590	20,922,456
Community services	15,317,469	12,260,201
Total program services	307,148,120	223,168,021
SUPPORTING SERVICES		
Management and general	13,912,941	12,393,843
Fundraising	22,784,588	17,041,113
Total supporting services	36,697,529	29,434,956
Total expenses	343,845,649	252,602,977
Decrease in net assets from operations	(161,929,451)	(79,544,744)
OTHER CHANGES IN NET ASSETS		
Net nonoperating investment income (loss)	214,660,101	(55,393,674)
INCREASE (DECREASE) IN NET ASSETS	\$ 52,730,650	\$ (134,938,418)

Measure of operations

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

Revenue recognition

Support received directly or indirectly from the public is recorded as revenue when received or when the donor has made an unconditional promise to give. Conditional promises to give are not

recognized until the conditions on which they depend are substantially met. Contributions of assets other than cash, including gifts-in-kind, are recorded at their estimated fair value at the date of the gift. Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence or nature of any donor restrictions. All donor-restricted support, including related investment income and realized and unrealized gains and losses, is reported as an increase in temporarily or permanently restricted net assets, depending on the nature of the restriction. When a restriction expires (that is, when a stipulated time restriction ends or

purpose restriction is accomplished), temporarily restricted net assets are reclassified to unrestricted net assets and reported in the consolidated statement of activities as net assets released from restrictions.

The Foundation and CFFT retain legal and beneficial rights to intellectual property developed under certain scientific grants and drug discovery agreements. Revenues received under these agreements are recorded when earned. In addition, at times CFFT may sell its intangible rights under certain agreements in exchange for a lump sum. Amounts received under these agreements are recorded when rights are forfeited and proceeds are

receivable. In November 2014, CFFT entered into an agreement to sell its intangible rights to future revenues under a drug discovery agreement and recognized net revenue of \$3,274,431,963. In October 2016, CFFT entered into an amendment to the 2014 agreement and recognized an additional \$51,400,000 in royalty revenue related to the sale. In 2015, under the same drug discovery agreement, CFFT earned additional one-time royalties of \$27,792,000. This amount was earned upon achievement of certain milestones, as defined in the agreement. This amount is included in royalty revenue and accounts receivable as of December 31, 2015 and was received during 2016.

Board of Trustees and Corporate Officers

AS OF DECEMBER 31, 2016

OFFICERS

Chair

Catherine C. McLoud
Johns Island, S.C.

Executive Vice Chair

Paul W. Whetsell
Potomac, Md.

Vice Chair

Richard J. Gray, Esq.
Chicago, Ill.

Vice Chair

Robert H. Niehaus
New York, N.Y.

Vice Chair

Louis DeFalco
Chicago, Ill.

Treasurer

David A. Mount
Palm Desert, Calif.

TRUSTEES

Michael L. Beatty, Esq.
Denver, Colo.
(nonvoting, Leadership
Council Chair)

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

Richard L. Dandurand
Birmingham, Ala.

Louis DeFalco
Chicago, Ill.

Richard J. Gray, Esq.
Chicago, Ill.

Carole B. Griego, M.D.
Paradise Valley, Ariz.

Susan L. Hook
Corona Del Mar, Calif.

Catherine C. McLoud
Johns Island, S.C.

Peter J. Mogayzel Jr., M.D., Ph.D.
Baltimore, Md.

(nonvoting, CF Care Center
Representative Advisor)

Chad T. Moore
Anchorage, Alaska

David A. Mount
Palm Desert, Calif.

Robert H. Niehaus
New York, N.Y.

Eric R. Olson, Ph.D.
Cambridge, Mass.

Steven Shak, M.D.
Redwood City, Calif.

Eric J. Sorscher, M.D.
Atlanta, Ga.

(nonvoting, Medical
Advisory Council Chair)

Charles J. Thayer
Palm City, Fla.

Theodore J. Torphy, Ph.D.
Bryn Mawr, Penn.

Amy S. Weinberg
Greenwich, Conn.

Paul W. Whetsell
Potomac, Md.

KC Bryan White
Chagrin Falls, Ohio
(Adult Advisory Council Chair)

CORPORATE OFFICERS

President and CEO

Preston W. Campbell, III, M.D.

Executive Vice President and COO

Marc S. Ginsky

Executive Vice President and CFO

Vera H. Twigg

CHAIRS EMERITI

(nonvoting)

Frank Deford
New York, N.Y.

Doris F. Tulcin
White Plains, N.Y.

HONORARY TRUSTEES

(nonvoting)

Don Baylor
Lewis Black
Michael Bolton
Jay Buhner
Boomer and Cheryl Esiason
Kenny G
Brian and Kay Hill
Richard Marx
Rosie O'Donnell
Jim Palmer
Scott Pelley
Rick Rizzs
Mike Schmidt
Mike Scioscia

.....

Thanks to the wonderful community that makes our efforts possible.
Because of your support, we will continue to add more tomorrows
and help all people with CF live better today.

.....





**CYSTIC FIBROSIS
FOUNDATION**
ADDING TOMORROWS

4550 MONTGOMERY AVENUE
SUITE 1100 N
BETHESDA, MD 20814
1.800.FIGHT.CF
WWW.CFF.ORG

 facebook.com/CysticFibrosisFoundation

 instagram.com/CF_Foundation

 youtube.com/CysticFibrosisUSA

 twitter.com/CF_Foundation