



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.

A Message to Our Community



"Each day, we get closer to a world in which every person with CF can make plans that don't include being sick." Preston W. Campbell

One of the most inspiring and rewarding aspects of working at the Cystic Fibrosis Foundation is hearing the stories of people with CF and their families as they engage in our mission — through our care center and clinical trial networks, at fundraising and advocacy events, and through our growing community programs.

I recently heard from a young woman with CF, whom I met when I was the director of a CF pediatric care center 30 years ago. It was a different world then: There were no targeted treatments for the symptoms of CF, and the underlying science of the disease had yet to be unlocked.

Because of the unrelenting commitment and focus of our dedicated friends and supporters, we have made sweeping progress since that time. That child I treated in clinic sent me her wedding photo, and many others with CF are meeting milestones we could not have imagined. Even greater promise is on the horizon.

We now have three drugs that treat the underlying cause of the disease in more than half of all people with CF, and clinical trials of next-generation therapies underway now could help bring lifetransforming treatments to more than 90 percent of

people with CF as soon as 2020. Work being done by researchers around the world in cutting-edge fields like gene editing has the potential to change the future for every person with CF.

Even as we celebrate the extraordinary progress we have made, we know we still have much work to do to ensure all people with CF have the treatments they need, today and in the future.

Our community has defied the odds for years, coming together to realize the dream of a small group of parents who wanted to change what it meant to be diagnosed with CF. Each day, we get closer to the future they envisioned: a world in which every person with CF can make plans that don't include being sick.

Our biggest challenges lie ahead of us. I am confident that, with the power of collaboration and our record of success, we will cross the finish line together.

We will not give up until it's done.

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

Scientific Breakthroughs & the Road Ahead

cff.org/Research

"I was in the hospital for a tune-up when I got the call that I was approved for ivacaftor, and it's an indescribable feeling. Now I can take much deeper breaths than I could before, and I have a lot more energy." Callie Dolan

New Drug Approved

(TEZACAFTOR/IVACAFTOR)

For people with 2 copies of F508del or at least one of 26 specified mutations

Expanded Label

(IVACAFTOR)

for additional 5% of population

Phase 3 Trial Candidates Selected

TRIPLE COMBINATION **THERAPIES**

2017 was a year of unprecedented momentum in the development of new therapies to treat CF: The FDA approved the expansion of Kalydeco® (ivacaftor) for an additional five percent of people with the disease, and clinical trials suggested that next-generation combination therapies will be more effective and help more people than ever before.

Thanks to these and other scientific advances, the future is looking bright: We are poised to drastically expand the number of people with CF who have access to treatments that address the underlying cause of the disease in the next few years and hope around 90 percent will have a modulator by 2020.

This is thrilling progress, but it's only part of the story. Around 5 to 10 percent of individuals with CF have mutations that will never respond solely to modulator therapy, and they are counting on us to come up with another way to address the underlying cause of their disease. And many people with CF — even those who are on modulators — need better treatments today to address complications and help them live with advanced disease.

We are working diligently to respond to those needs and speed progress toward the day when all people with this disease can say, "I used to have CF." In 2017, we provided \$169 million to advance research and high-quality CF care.

HIGHLIGHTS FROM 2017:

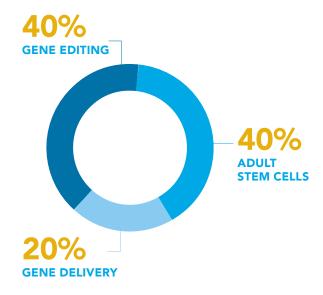
- Funded more than **200 research awards** to address complications ranging from infections to inflammation to digestive issues.
- Undertook more clinical trials than ever before, with a record 68 trials in progress over the course of the year.
- Aggressively pursued cutting-edge technologies, like RNA therapy and readthrough compounds, as part of our multiyear Nonsense and Rare Mutations Research and Therapeutics Initiative, to which the Foundation has already committed \$72 million.
- Worked toward a cure for all people with CF through 33 awards in novel areas like gene editing and gene therapy, with \$7.3 million committed in 2017 alone





Investing in a Cure

The CF Foundation is working to find a cure for all people with CF — regardless of their mutations. Here's a breakdown of our \$7.3 million spending in 2017.



Research to Address Complications

We are aggressively funding critical research to treat complications of CF.

MUCUS CLEARANCE

NUTRITION AND

ANTI-INFECTIVE

LUNG TRANSPLANT

ANTI-INFLAMMATORY

"How does it feel to watch these drugs being approved, knowing there isn't one for Hailey yet? Honestly, it gives me hope. We may not have one tomorrow, and we may not have one in Hailey's generation, but it gives me hope for the future." Leeann Huyser

Leeann's daughter, Hailey, is 13 years old and living with CF. Hailey has a rare mutation and is still waiting for a disease-modifying treatment that can address

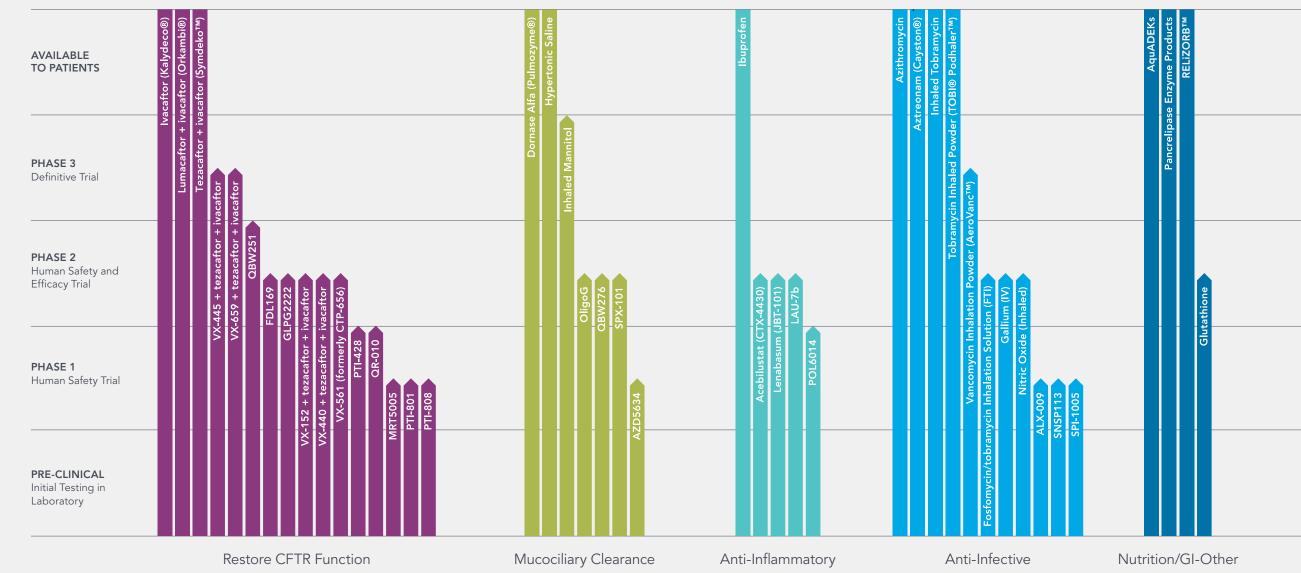


Partnering With Patients and Families to Advance **New Therapies**

Incredible breakthroughs in the treatment of CF have been achieved through clinical trials. Drugs and treatments that have added tomorrows — and make living with CF today better for thousands — are now available thanks to this research and the individuals who volunteered to participate. Across the country and around the world, people with CF are joining clinical trials that are instrumental in helping today's research become tomorrow's treatments.

As of March 31, 2018, the CF pipeline had more than 25 drug candidates in development — from therapies that better address serious complications to novel approaches that address the underlying cause of CF.





Improving Lives by Improving Care

cff.org/Care

"With CF, you can't take for granted being able to experience everything you hope to. My care team worked closely with me to make sure my health was strong enough when I was ready to have a baby. They helped me coordinate my care and manage my CF so that my biggest challenge was the same as many new moms: adjusting to life with lack of sleep." Emily May

\$5.8 MILLION

investment in mental health to help people with CF manage depression and anxiety related to their disease

> \$15 MILLION

multiyear commitment to our Lung Transplant Initiative to enhance lung transplant clinical care, address complications, and help advance new therapies



is being tackled from many angles, including clinical guidelines, innovative technologies, and best practices in transplantation and palliative care The premise is simple: By continuing to improve the quality of care that people with CF receive, we will help them experience better todays and add tomorrows. We work with the CF community — from people with CF and families, to clinicians and researchers — to collect data, look carefully at what works, and communicate what we learn back to people with CF and their clinical care teams.

What have we learned?

We know that people with CF do best when care is comprehensive, coordinated, and done in partnership with their care teams. The CF Foundation **funds and accredits more than 120 care centers around the country** to ensure people with CF can receive high-quality, specialized care.

Excitingly, outcomes for people with CF continue to improve because of this approach. In 2017, we saw steady progress in key measures that are correlated with survival, such as improved lung function and nutritional status, and decreased presence of harmful lung bacteria.

Based on feedback from people with CF about their needs, we have expanded this data-driven, evidence-based approach into other areas of clinical care — including mental health and advanced lung disease.

Finally, we continued to cultivate the next generation of CF specialists. Our PACE, DIGEST, and ENVISION programs recruited adult care physicians, gastroenterologists, and endocrinologists. Our mentoring program, which connects experienced CF clinicians with those who are earlier in their careers, also grew.





Championing the Needs of People With CF

cff.org/Advocate

"Cystic fibrosis is indiscriminate. It strikes people across the socioeconomic spectrum. I don't think there are easy answers, but I do know this: People with CF need access to high-quality care, and we need to be a voice for the voiceless on this issue." Jeremy Olimb

17,000

MEMBERS OF THE CF COMMUNITY

sent emails or tweets to their members of Congress

12,000+

CALLS TO COMPASS

COMPASS CASE MANAGERS

In 2017, our community faced a serious threat in the form of proposed legislation that endangered its access to adequate, affordable health insurance — which is essential to receiving high-quality, specialized care. We approached this challenge with one goal: Make sure that lawmakers understood the needs of people with CF and how their decisions would impact our community.

Most importantly, we worked to make sure people with CF had the opportunity to make their own voices heard.

Our community's response was overwhelming. People with CF and their loved ones told their stories to members of Congress in more than 70,000 messages and 800 face-to-face meetings, sending a clear signal about the importance of access to high-quality, specialized care.

Members of the community also connected with their representatives back at home. We held seven state advocacy days during which advocates shared their personal CF stories, highlighted the needs of people with CF, and asked legislators to protect key state legislation. Community members also advocated in 27 states for preserving access to Medicaid.

We also offered more hands-on assistance to help families tackle the challenges CF throws their way. Compass is a free, personalized service to help people with CF and their families with insurance, financial, legal, and other issues they may face — from the routine to the unexpected. Compass case managers went above and beyond to help members of the CF community who were affected by natural disasters continue their treatments by finding them shelter and coordinating emergency refills of their medications.

Facilitating Connections Across the CF Community

cff.org/Community

"I continue to be involved with CF community programs because of the impact they have had not only on me, but on others with CF and those that are close to us. While I hope I've made a difference in the lives of others, I know for certain that being involved in these programs has changed my life and made me a happier, stronger person." Chad Riedy





Elaine Phelan, Mark Bettinger, and David Turnow (left) connect through the CF Peer Connect program, which allows people living with CF to talk with and learn from someone who has shared similar experiences.

THE POWER OF CONNECTION

Each day, people with CF are living their lives — going to school and work, nurturing their relationships with loved ones, managing treatments — and many are also looking for ways to actively support themselves and one another through the challenges of living with a severe, chronic disease. This year, hundreds of people with CF and their loved ones came together and found meaningful, sometimes life-changing, connection through Foundation-sponsored events.



Chad Riedy is a member of the CF Adult Advisory Council, Community Voice, and CF Peer Connect. He has volunteered for several CF virtual events, including co-chairing BreatheCon 2017. ADULTS WITH CF & FAMILY MEMBERS INVOLVED IN COMMUNITY VOICE

Community Voice provides opportunities for people with CF and their family members to have an active say in programs and initiatives affecting the CF community.

PEER MENTORING MATCHES MAD

CF Peer Connect is a topic-based peer mentoring program for people with CF ages 16 and older, enabling a one-to-one virtual connection with someone who has gone through similar experiences.

550 PEOPLE WITH CF ATTENDED VIRTUAL EVENTS

Virtual Events designed by and for adults with CF, including BreatheCon, CF MiniCon: Transplant, and CF MiniCon: Young Adult Transitions, provide an opportunity for the CF community to connect, share, and learn from peers through open and honest dialogue.

\$100,000
IN IMPACT GRANTS AWARDED

Impact Grants provide up to \$10,000 per year to individuals or organizations that are benefitting the CF community in new and important ways, from initiatives that focus on exercise or singing, to a program supporting spouses of those with CF.

COMMUNITY
MEMBERS FEATURED
ON OUR BLOG

CF Community Blog features community members sharing their stories. No subject is off limits — they write candidly about issues ranging from coordinating treatment across care teams to teenage rebellion, and from lung transplantation to feeding tubes and body acceptance.

INSTAGRAM TAKEOVERS
FEATURING PEOPLE
LIVING WITH CF

Social Media provides a platform for community members to connect with the Foundation and each other. Through Instagram takeovers, people share what life with CF looks like for them, and Facebook Live enables community members to participate in conversations, ask questions, and hear about the latest innovations with leaders in the fields of research, care, and clinical trials.

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Supporting the Fight Against CF

cff.org/Give

"If Arjun had been born in the 1950s, we wouldn't have been able to imagine the kind of future for him that we can now. We hope he lives a long, healthy life — but his mutations are rare, and like many with CF, he won't benefit from current modulators. That's why we're doing everything we can to support the development of new treatments that can help people with rare mutations — and one day, provide a cure." Arathi Cole

CF CHAMPIONS BY THE NUMBERS

8,500+

MONTHLY TO THE ANNUAL FUND

Since the Foundation's earliest days, the fierce determination of supporters and volunteers has fueled tremendous progress for people like Arjun. These teamMATEs have attended dinner dances, walked in Great Strides, golfed, fished, and held countless passion fundraising events — all to make an impact in the lives of those living with CF.

This past year, these dedicated individuals held more than 1,000 events from coast to coast and helped raise more than \$84 million in the fight against CF.

We are especially thrilled that there was increased participation in our endurance events, particularly among younger generations, as thousands of people raced up the stairs of tall buildings or stadiums, hiked along scenic trails, and cycled through towns across America to help advance a cure for CF.

In addition, we held the 14th annual Volunteer Leadership Conference (VLC) in Dallas, Texas, the largest VLC ever — with more than 600 attendees in person and hundreds more tuning in remotely via livestream. The conference, themed "teamMATEs for a Cure," was co-chaired by Ginger Birnbaum and Mike Beatty and was the first VLC to be held outside of the Washington, D.C., area.

Together, these supporters and volunteers of all ages are helping to carry forth the powerful momentum first generated in 1955 by parents determined to save their children's lives. It is this hope in action that will help us realize our dream of a cure.



400+

GREAT STRIDES WALKS

50+

150
THEMED DINNER

80
ENDURANCE EVENTS
40 Cycle, 21 Climb, 19 Hike



















1. Cyclists enjoy the ride during the Woodinville, Wash., Cycle for Life event. 2. The 2017 Volunteer Leadership Conference co-chairs, Michael Beatty and Ginger Birnbaum, take the stage. 3. Kieran Donahue Marinucci (left); Allison Grammer; Joshua Bryant, who has CF; and Olivia Bryant at the Metro D.C. Chapter's Celebrate Every Breath Gala. 4. Walkers gearing up for the Rome, Ga., Great Strides walk. 5. Bill Skach, M.D., (left) with Joe O'Donnell and Preston W. Campbell, Ill, M.D., at the CFFT Lab tour. 6. Shawnna Johnson, Liz Robards, Anna Villani, and Michelle Ashton enjoy a round of golf at the 2017 Ultimate Golf Experience. 7. Marc Ginsky and Colleen Weiss at the CFFT Lab tour. 8. Hikers gather in Vail, Colo., for the CF Foundation's Xtreme Hike event.

TOMORROW'S LEADERS

To further engage the next generation of philanthropists, the Foundation launched its Tomorrow's Leaders program. This young professionals program is designed to offer committed young adults skills and networking opportunities while they make a difference in the lives of those with cystic fibrosis.

PARTNERS IN PROGRESS ANNUAL FUND CAMPAIGN

Thanks to donors across the country, the Annual Fund raised more than \$3.4 million. We are especially grateful to the many organizations and businesses that offered a matching gift opportunity, which significantly increased this year's revenues.

LEGACY GIVING

We were honored that 133 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, corporate America was an important part of our success — contributing almost \$20 million.

American Airlines alone raised more than \$1 million to advance our mission through its annual Celebrity Ski event and continued to sponsor special events through donations of American Airlines AAdvantage Miles.

American is a longtime champion of people with CF and has been working to raise awareness and funds to fight this disease for more than 30 years. We are grateful for their steadfast support, and to the current and former American employees who worked hundreds of hours to make this event a success.

We especially salute the following companies, which in 2017 were recognized for their exceptional contributions.

- Top National Corporate Team: CISCO Systems, Inc.
- Rising Star National Corporate Team: BEST BUY
- Spirit of American Award: Kroger

CORPORATE LEADERSHIP COUNCIL MEMBERS

The Cystic Fibrosis Foundation recognizes and thanks all corporate leaders for their generosity and support in the fight against CF. Members of the Corporate Leadership Council (right), provided direct corporate support of \$250,000 or more. These corporate leaders have made outstanding commitments to help support the search for a cure and improve the lives of people with CF.





























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Cystic Fibrosis Foundation Condensed Financial Information*

CONSOLIDATED STATEMENTS OF FINANCIAL POSITION AS OF DECEMBER 31, 2017 AND 2016

	2017	2016
ASSETS		
Cash and cash equivalents	\$ 138,231,954	\$ 101,987,992
Investments	4,239,695,576	3,795,790,436
Receivables, net	12,137,402	15,658,290
Other assets	5,403,261	11,401,161
Fixed assets, net	11,959,914	7,069,182
Total Assets	\$4,407,428,107	\$ 3,931,907,061
LIABILITIES AND NET ASSETS		
Accounts payable and other liabilities	\$ 36,422,049	\$ 27,044,203
Awards payable	176,819,993	172,707,680
Total liabilities	213,242,042	199,751,883
UNRESTRICTED NET ASSETS		
Undesignated net assets	881,431,067	420,457,947
Board-designated net assets	3,300,000,000	3,300,000,000
Total unrestricted net assets	4,181,431,067	3,720,457,947
Temporarily restricted net assets	8,657,764	7,954,458
Permanently restricted net assets	4,097,234	3,742,773
Total net assets	4,194,186,065	3,732,155,178
TOTAL LIABILITIES AND NET ASSETS	\$4,407,428,107	\$ 3,931,907,061

Organization

The accompanying consolidated financial statements include the operations of the Cystic Fibrosis Foundation, including all of its field offices (the "Foundation") and Cystic Fibrosis Foundation Therapeutics, Inc. ("CFFT"). The Board of Trustees authorized management of the Foundation to transfer the activities of CFFT to the Foundation in 2018.

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 \$35,000,000 of investments as of December 31, 2017. The cash associated with these commitments is classified as cash and cash equivalents as of December 31, 2017, and the purchases were completed in January 2018.

Investments

Investments as of December 31, 2017 included primarily corporate bond mutual funds, short duration bond mutual funds, equity mutual funds, global equity securities, 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 \$2,622,920,750 in Level 1 assets, \$106,967,523 in Level 2 assets and \$5,084,571 in Level 3 assets. Investments totalling \$1,611,420,265, which are measured at fair value using net asset value as a practical expedient, have not been categorized in the fair value hierarchy.

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, 2017, the Foundation and CFFT have medical scientific grant commitments of approximately \$59,292,000, which extend through December 31, 2022. These subsequent year awards are contingent upon renewal criteria, and therefore the costs and liabilities are not reflected in the consolidated financial statements. Certain agreements provide for future contracted drug discovery and development research payments amounting to approximately \$149,262,000. 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, 2017 to be spent in support the mission of the Foundation over the long term.

CONSOLIDATED STATEMENTS OF ACTIVITIES FOR THE YEARS ENDED DECEMBER 31, 2017 AND 2016

	2017	2016
REVENUE		
SUPPORT RECEIVED FROM THE PUBLIC Special event revenue Direct benefit expenses	\$ 98,751,719 (14,630,047	
Net special event revenue General contributions	84,121,672 26,602,759	
Total support received from the public Royalty and other revenue	110,724,431 24,957,306	117,244,182 64,672,016
Total revenue	135,681,737	181,916,198
EXPENSES		
PROGRAM SERVICES Medical programs Public and professional information and education Community services	213,999,714 16,900,416 17,822,831	
Total program services	248,722,961	307,148,120
SUPPORTING SERVICES Management and general Fundraising	15,968,460 24,702,883	
Total supporting services	40,671,343	36,697,529
Total expenses	289,394,304	343,845,649
Provision for lease commitment	(4,358,356) —
Decrease in net assets from operations	(158,070,923) (161,929,451)
OTHER CHANGES IN NET ASSETS Net nonoperating investment income Proceeds from sale of remainder of member interest in specialty pharmacy	606,956,685 13,145,125	
INCREASE IN NET ASSETS	\$ 462,030,887	\$ 52,730,650

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 discontinued operations and 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. 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.

Lease commitments

In June 2017, the Foundation entered into a lease agreement for new office space in Maryland. The Foundation secured a favorable long-term rental rate for this space, which better meets the present and future needs of the Foundation. In 2017, the Foundation recognized a one-time charge of approximately \$4,358,356 to recognize the net future liability and exit costs (including costs to prepare the space for rental), associated with former office space. The liability is calculated as the net present value of future cash outlays under the existing lease and the net present expected receipts from sublease arrangements. The Foundation remains obligated to pay rental costs and abide by terms of the original lease, which expires in April 2023. The Foundation has entered into sublease agreements for substantially all of the original office space.

The Foundation is obligated under various operating leases for office space as of December 31, 2017. The approximate future minimum rental commitments, subject to escalation, are \$42,950,000. The Foundation has entered into lease agreements with tenants to occupy its former headquarters space. As of December 31, 2017, the approximate future minimum sublease rental payments due from sublease tenants are \$4,566,000.

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^{*}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 Ave, Suite 1100N, Bethesda, MD 20814.

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"He doesn't know anything different. But I hope someday he does. I hope one day he can say, 'You know, I used to have to sit tethered to a chair for an hour every day and have it shake me like a can of paint.' As the mother of a person who has CF, I can't stop — until it's done." Patty Mei, mother to Brandon, 15



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