

hope discover
transform
support inspire
advance

progress

ANNUAL REPORT 2018

community
breakthroughs
cure research
commitment

We are on the cusp of a new era in cystic fibrosis.

dear friends,

A highly effective therapy may soon be approved that will eventually address the underlying cause of cystic fibrosis for more than 90 percent of all people with the disease. It's a tremendous milestone, and one we couldn't have imagined just 10 years ago.

This is a moment for the CF community to reflect and take pride in what we have achieved together. Working side by side for more than six decades, we have redefined what it means to be diagnosed with CF, and we continue to set our sights ever higher as we pursue new possibilities to treat this disease. Our work is far from done: We will not rest until every person with CF has a cure.

WE WILL LEAVE NO STONE UNTURNED. ANY SCIENCE THAT WE BELIEVE HOLDS REAL PROMISE TO ADDRESS RARE AND NONSENSE MUTATIONS WILL BE FUNDED. EVERY STRATEGY WITH THE POTENTIAL TO CURE CF WILL BE EXPLORED. WE WILL WORK TIRELESSLY TO ENSURE THAT ALL PEOPLE WITH CF CAN LIVE FULL AND HEALTHY LIVES, AND HAVE HOPE FOR THE FUTURE.

Last year, the Cystic Fibrosis Foundation advanced a bold vision to address the top concerns of the CF community. We launched our Infection Research Initiative with a \$100 million commitment and expanded our Lung Transplant Initiative to ensure that individuals with advanced lung disease have treatment options. Most importantly, we progressed our efforts to develop highly effective treatments for every person with CF, including individuals with rare and nonsense mutations.

The CF community has been the driving force behind each of these achievements. Thank you for your continued resolve and dedication to achieving our shared mission.

The needs of people with CF, and those who love and care for them, will change and evolve in the coming years, but one thing is certain: With the determination of the CF community, now more than ever, we are stronger together.

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

advancing
research.

CFF.ORG/RESEARCH

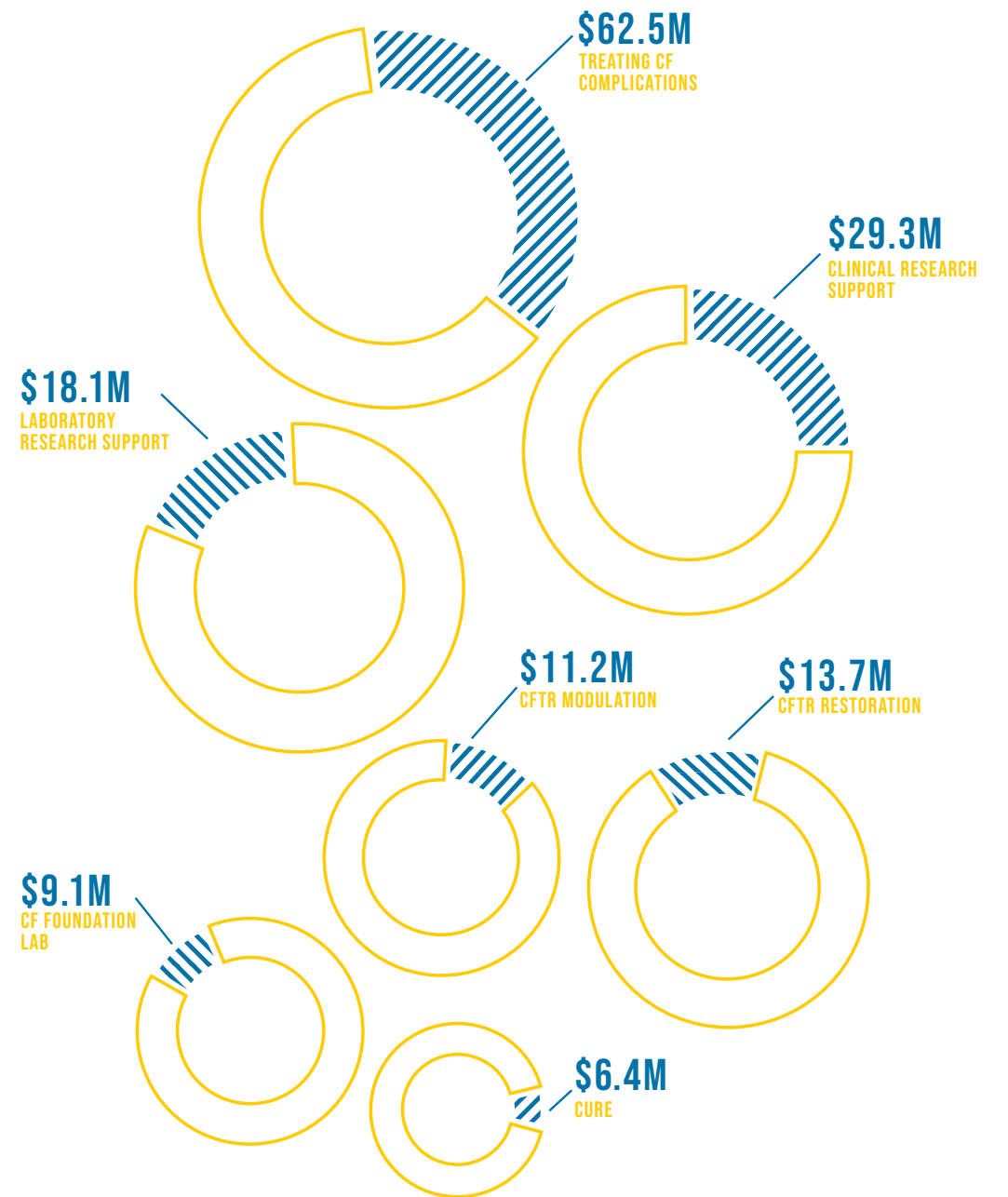
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The Cystic Fibrosis Foundation remains the world's leader in the fight to cure CF, and our scientific portfolio reflects our ambition to provide effective treatments — and someday, a cure — to every individual with this disease.

We are undertaking a remarkable breadth of research, from groundbreaking new approaches to address nonsense and other rare mutations, to investments to better understand and address infections and other complications, improve transplant outcomes, and optimize care delivery.

RESEARCH FUNDING

In 2018, we invested \$189 million into research and care. More than \$150 million went to research focused not only on improving the quality of life for people with cystic fibrosis today, but also on accelerating innovative research and drug development to add tomorrows. A selection of the programs we are advancing is highlighted within this report.



\$150.3 MILLION
DIRECTED TO BASIC AND CLINICAL RESEARCH PROGRAMS

THERAPIES TO ADDRESS ALL MUTATIONS

We feel particular urgency to accelerate new strategies to treat individuals who have nonsense mutations, or other rare mutations that do not produce CFTR protein. We have been pursuing treatments that target these mutations for decades, and have drastically increased the size of our investment in this area in recent years following the launch of our Rare and Nonsense Mutations Research and Therapeutics Initiative.

By the end of 2018, this initiative encompassed nearly 100 ongoing projects at all stages of development in academic and industry settings around the world. By the close of 2018 we had committed more than \$90 million to this effort. As a result, more researchers are now funded to address nonsense and other rare mutations through a range of potential approaches including small-molecule compounds called readthrough drugs, mRNA therapy, gene therapy, and gene editing.

“WE HAVE COMMITTED MORE THAN \$90 MILLION TO RESEARCH TARGETED AT NONSENSE AND OTHER RARE MUTATIONS.”

In 2018, researchers achieved nonsense readthrough in primary cells, giving a fresh sense of possibility to the extensive screening efforts we have underway with researchers across the country.

The Foundation is pursuing a wide range of scientific approaches with the potential to result in highly effective treatment for ALL people with CF, regardless of their mutation, and committed more than \$90 million across these efforts by the end of 2018. Some of these approaches are targeted specifically at nonsense and other rare mutations.

APPROACH

How it works

READTHROUGH COMPOUNDS

Small-molecule drugs act as a patch over nonsense “stop” mutations in the CFTR gene and enable production of a functional protein.

THERATYPING

Cells are tested to determine if rare mutations respond to CFTR modulators in a lab, in order to match medicines (*therapies*) with mutations (*types*).

MRNA THERAPY MESSENGER RNA

Cells use mRNA as a “blueprint” to create proteins; repairing or replacing mRNA may enable the production of functional protein regardless of the underlying mutation.

TRNA THERAPY SUPPRESSOR RNA

Cells are instructed to insert the correct amino acid when building a protein, “suppressing” the nonsense mutation and enabling a full-length, functional CFTR protein regardless of the mutation.

GENE DELIVERY

Engineered DNA is transported into targeted cells.

GENE EDITING

The mutations in the CFTR gene of a person with CF are repaired.

GENE THERAPY

A normal CFTR gene is introduced into the cells of people with CF.



JAKE – AGE 16



A top priority at the Cystic Fibrosis Foundation Therapeutics Laboratory

is creating improved assays and cell lines for use in screening and vetting compounds for therapeutic development. We provide these resources to biopharmaceutical companies to ensure that CF drug discovery programs underway across the industry have the highest probability of success. The RARE cell collection study, which gathers samples from people with two nonsense mutations, will help expedite the development of promising treatments for these individuals. More than 40 samples were collected in 2018.

THE CF FOUNDATION LAB DEVOTES MORE THAN HALF OF ITS EFFORTS TO RESEARCH FOCUSED ON NONSENSE AND OTHER RARE MUTATIONS.

More than 200,000 readthrough compounds with the potential to address nonsense mutations were screened at the Cystic Fibrosis Foundation Therapeutics Laboratory in Lexington, Massachusetts, and we have an ongoing project with Southern Research and the University of Alabama to screen 500,000 additional compounds. In May, we signed an \$11 million research agreement with Icagen, Inc. through which an additional two million compounds will be screened.

Gene therapy and gene editing continue to hold great promise to cure CF, and the field has demonstrated that introducing a healthy gene stimulates the production of functional protein.



NICO – AGE 5 + HIS PARENTS ASTRID + ARNOLD


Our focus is now on devising ways to successfully deliver a healthy gene into airway cells. This is a particular challenge in CF because of the body's natural defenses against foreign bodies, like viruses or bacteria, in the lungs.

We are engaging the best and brightest minds in this endeavor. In August, we convened leaders in the fields of gene therapy and gene editing for a workshop, *Advancing Gene Editing Technologies and Tools for Cystic Fibrosis*. Over the course of two days, they identified key challenges to applying gene editing in CF, suggested new targets, and proposed ways to attract researchers in this area to CF.

“ WE ADVANCED A NEW CLINICAL-STAGE RESEARCH PROGRAM WITH THE POTENTIAL TO ADDRESS RARE AND NONSENSE MUTATIONS, AS THE FIRST-EVER MRNA THERAPY DIRECTED AT CF BEGAN ENROLLING PARTICIPANTS INTO A PHASE 1 STUDY IN JUNE. ”

Perhaps most excitingly, we advanced a new clinical-stage research program with the potential to address rare and nonsense mutations, as the first-ever mRNA therapy directed at CF began enrolling participants into a Phase 1 study in June. The study is being conducted by Translate Bio. If successful, mRNA therapy would be effective against any CF mutation.

While we have never been more optimistic about our prospects to deliver a cure for every individual with CF, we understand that no pace is fast enough when you or your loved one is waiting for a treatment. Improved therapies are urgently needed today to help treat the complications of CF and address advanced lung disease.



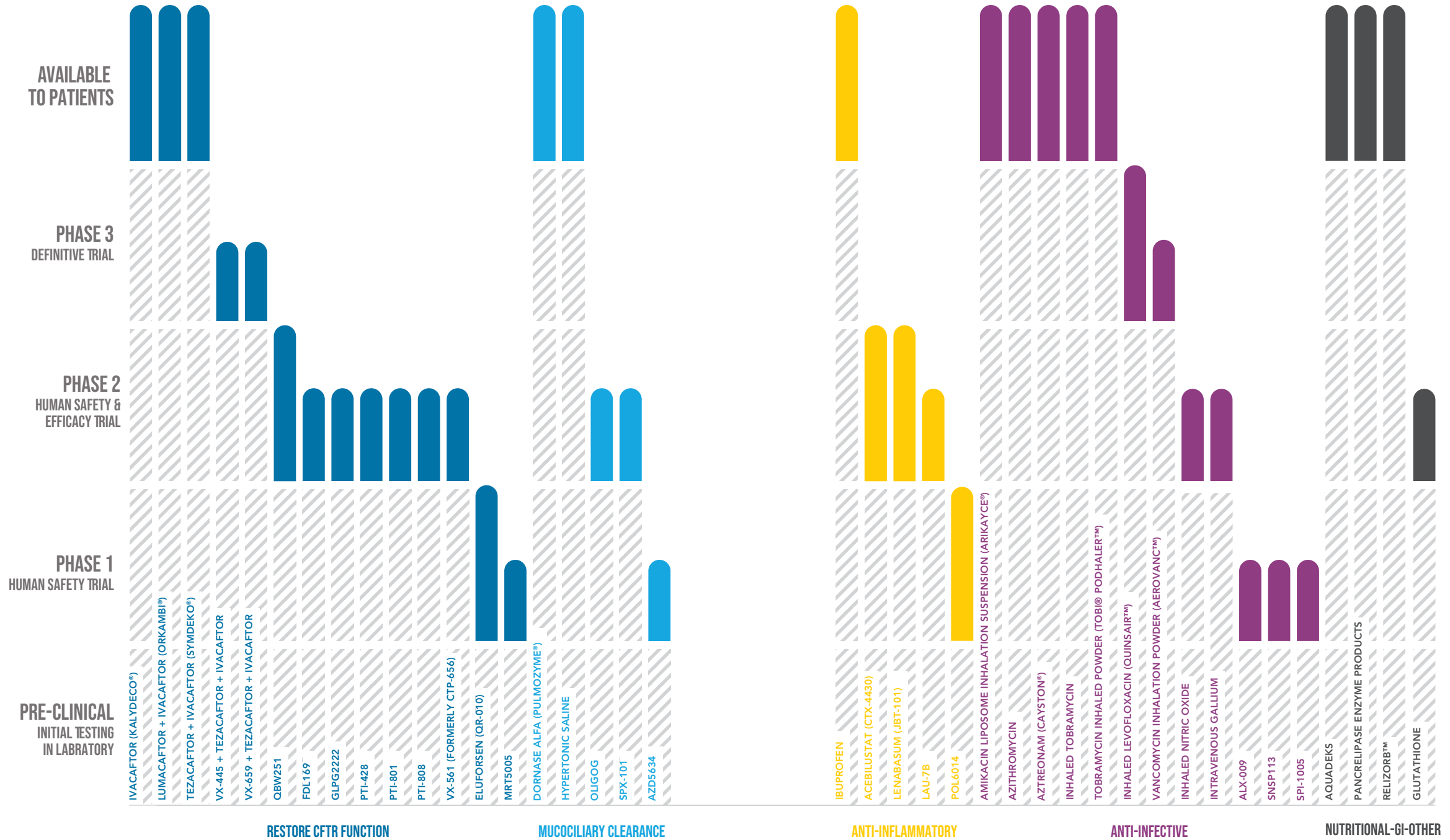
**We understand that no
pace is fast enough when
you or your loved one is
waiting for a treatment.**

We have never been more optimistic about our prospects to transform this research into reality and deliver a cure for every individual with CF.



DRUG DEVELOPMENT PIPELINE

As part of our overall research funding in 2018, we awarded \$44 million to clinical stage drug discovery and development programs and provided \$25 million to support a network for CF clinical trials. These funds are advancing the most robust pipeline of potential new therapies in the history of the Foundation. This funding enabled 64 multicenter clinical studies focused on new therapies to address the underlying cause of CF and treat complications of the disease, including infections, excessive mucus, inflammation, and gastrointestinal (GI) issues.



FOCUSING ON INFECTIONS

Infections are a leading cause of loss of lung function and take a significant physical and emotional toll, making them a top concern for people with CF, their families, and their care teams. We estimate that approximately half of the CF population will continue to require improved anti-infective treatments over the next 20 years.

In 2018, we announced a \$100 million commitment to the Infection Research Initiative, a comprehensive and forward-looking approach to improve outcomes associated with infections through enhanced detection, diagnosis, prevention, and treatment. The Initiative more than doubles the Foundation's investment in this area over the previous five years.

IMPROVING OUTCOMES FOR LUNG TRANSPLANT

Transplant is a vital treatment option for more than 200 people with CF each year, yet post-transplant outcomes vary widely among people with the disease, and the factors that drive those outcomes are not well understood. In 2016, the Foundation launched the Lung Transplant Initiative, a multifaceted effort to maximize the opportunity for transplant as a life-sustaining therapy and extend post-transplant survival. In 2018, we increased funding of this initiative to \$23 million and made meaningful progress in our efforts to improve all stages of the transplant journey for people with CF.

The Foundation worked with the CF community to provide greater social connection and support on the topic of transplant. Our peer mentoring program, CF Peer Connect, facilitated 49 connections related to transplant, and 283 members of the CF community participated in CF MiniCon: Transplant, a virtual event to ask questions and share their experiences.

We are also working to increase understanding of CLAD (chronic lung allograft dysfunction), a complication associated with organ rejection that is a primary obstacle to successful and lasting lung transplants.



JANEIL – AGE 28 + HER HUSBAND PETER + SON FENN

THE INFECTION RESEARCH INITIATIVE MORE THAN DOUBLED THE FOUNDATION'S INVESTMENT IN THIS AREA OVER THE PREVIOUS FIVE YEARS.



The Infection Research Initiative

committed \$100 million to a comprehensive strategy to improve outcomes associated with infections:

- Identify new ways to detect microorganisms and diagnose infections.
- Enhance understanding of CF microorganisms and how they are acquired.
- Support development of safe and effective treatments, including antibiotics, antivirals, and antifungals.
- Optimize current treatments to improve outcomes and minimize treatment burden.
- Evaluate the impact of long-term or frequent, intermittent antimicrobial use.
- Understand how infections are influenced by disease-modifying treatments.

BOBBY – AGE 24

We awarded \$4 million to researchers to identify potential strategies to prevent or treat CLAD, which impacts approximately 50 percent of transplant recipients within five years. Projects will explore the role of the microbiome, identify predictive biomarkers, and examine injury and repair following lung transplant.

PROGRESS ON CFTR MODULATORS

Our efforts to deliver highly effective modulator treatments to more individuals in the CF community gained considerable momentum in 2018.



CARMINE – AGE 3 MONTHS + HIS MOM EMILY

Thanks to label expansions of Kalydeco® (ivacaftor) and Orkambi® (lumacaftor/ivacaftor) in 2018, children with CF can start modulator therapy younger and younger — at 12 months and two years, respectively — which we believe has the potential to help slow or even prevent progression of the disease. Additional studies are underway to determine the effectiveness and safety of modulators in children as young as six months old.

A third CFTR modulator, Symdeko® (tezacaftor/ivacaftor), was approved for individuals ages 12 and older with two copies of the F508del mutation, offering an important treatment option for individuals who cannot take Orkambi due to side effects or drug interactions, or who didn't respond to treatment. Funding the development of additional, next-generation modulators continues to be a priority to ensure that alternative treatments exist for individuals who do not respond to currently approved modulators.

We saw rapid progress on a new therapy called the “triple combination” or more simply, “the triple.” This drug combines the already-approved CFTR modulators ivacaftor and tezacaftor with a next-generation modulator. In January 2018, the drug's sponsor, Vertex Pharmaceuticals, Inc., released promising Phase 2 clinical data from studies of two potential candidates, VX-659 and VX-445, and announced its commitment to select one to submit to the U.S. Food and Drug Administration (FDA) for approval.

These data, and subsequent results from the Phase 3 study of VX-659 in November, confirmed that “the triple” is likely to be effective for any individual with at least one F508del mutation — regardless of the other mutation. This means even individuals with a nonsense mutation may eventually benefit, provided they also have a copy of F508del (the most common CF-causing mutation).

AT THE TIME OF THIS PUBLICATION, WE EXPECT “THE TRIPLE” COULD BE APPROVED IN 2020.

2018 MILESTONES MODULATORS

JANUARY SYMDEKO[®]

Approved for two F508del mutations and one of 26 additional mutations

AUGUST KALYDECO[®]

Expanded to children ages 1–2

AUGUST ORKAMBI[®]

Expanded to children ages 2–5

OCTOBER PHASE II

Data on VX-445 and VX-659 demonstrated significant improvements in quality of life, FEV₁, and sweat chloride

NOVEMBER PHASE III

Data on VX-659 demonstrated marked improvements in lung function



commitment
to CF care.

CFF.ORG/CARE

—

Research and therapeutic development are paving the way for an ever-brighter future for people with CF. But the significant gains in life expectancy and quality of life we have achieved in just a few generations are due to our efforts to enhance the quality of CF care.

The Foundation has been a leader in quality improvement for decades, and we continue to build on this heritage today. In 2018, we continued to fund important infrastructure to sustain this progress — such as the CF Foundation Patient Registry and the Care Center Network — to ensure that the CF community will benefit from these resources for years to come.

We also strengthened our model that redefines traditional notions of care to emphasize mental health, effective care partnerships, and a supportive community.

The underlying principles of our approach appear simple: People with CF do best when they receive highly individualized care, when they can balance their treatments with daily life, and when their care plans address all aspects of life with CF — physical, emotional, and social. In practice, those tenets have profoundly altered the prognosis for this devastating disease.

What's most important are the outcomes this work enables: Today, more people with CF are planning for their future and living out their dreams than ever before. Over the last ten years, the number of people with CF who are married or living with a

 **MORE THAN 30,000 PEOPLE WITH CF WERE SEEN BY AN ACCREDITED CARE CENTER IN 2018, REPRESENTING MORE THAN 90 PERCENT OF THE CF POPULATION IN THE U.S.**

partner and the number of people with CF with a college degree have almost doubled. Pregnancies are also at an all-time high as people with CF are increasingly able to have families of their own.

INVESTING IN CARE

The Foundation continues to fund and accredit a nationwide network of more than 130 care centers that provide specialized care to thousands of individuals with CF each year. In 2018, we provided more than \$47 million of support for care centers and clinicians, and expanded the network to add four accredited centers and one adult program.

“ WE PROVIDED \$47 MILLION OF SUPPORT FOR CARE CENTERS AND CLINICIANS. ”

A major emphasis for 2018 was enriching the quality of partnerships between people with CF, their families, and their care teams. We launched a pilot program to enhance communications skills among multidisciplinary care teams to deepen collaboration and improve care. We convened more than 100 meetings where people with CF and clinicians worked together on quality improvement — a systematic approach to analyze current treatment practices, determine what works, and apply those learnings to improve care.

On a daily basis, we facilitated clinician learning networks across more than 20 disciplines, in which members of CF care teams could connect on best practices and challenging cases.



KEY OUTCOMES

HIGHLIGHTS FROM THE 2017 CF FOUNDATION PATIENT
REGISTRY DATA REPORT

44 YEARS

LIFE EXPECTANCY ROSE BY MORE THAN 10 YEARS OVER THE LAST DECADE. THIS MEANS MOST PEOPLE WITH CF BORN BETWEEN 2013 AND 2017 ARE PREDICTED TO LIVE TO 44 YEARS OLD OR MORE.

52%

MORE THAN HALF OF ADULTS WITH CF MET OR EXCEEDED THEIR BMI GOAL, A KEY PREDICTOR OF LUNG FUNCTION.

54%

MORE THAN HALF OF ALL PEOPLE WITH CF ARE ADULTS, REPRESENTING AN INCREASE OF NEARLY 24 PERCENT OVER THE LAST TWO DECADES.

Melanie Abdelnour, an adult with CF, was featured as a plenary speaker at the North American Cystic Fibrosis Conference (NACFC) and relayed the real-life importance of successful partnership to 5,000 CF clinicians and researchers. Through NACFC, the Foundation brought together scientists, clinicians, and caregivers from around the world to share ideas on the latest advances in CF research, care, and drug development.

TREATING THE WHOLE PERSON

People with CF and their parent caregivers exhibit symptoms of depression and anxiety at rates two to three times greater than the general population, making mental health a critical element of the standard of care for CF.

We continued to bring our commitment to mental health to life throughout the year, and as of December, the Foundation's investment into efforts to expand the availability of mental health services for people with CF totaled \$5.8 million.

A portion of those resources provided seed funding to embed mental health coordinators into the multidisciplinary care teams at 138 pediatric and adult CF programs. The third round of Mental Health Coordinator Awards was announced in April, with 18 total programs funded. In June, we announced a Mental Health Coordinator Pilot Mentoring Program and formally updated care center accreditation criteria to include a mental health coordinator as a recommended member of the multidisciplinary care team.

"The outcomes that really count have to do with living an unquantifiably full and meaningful life with cystic fibrosis. Only genuine partnership makes it possible for us to see beyond the numbers, beyond "what's the matter with you" to "what matters to you."

— Maren Batalden, MD, during her plenary presentation at the 2018 North American Cystic Fibrosis Conference (NACFC)



BOBBY – AGE 39 + HIS WIFE ANNE + THEIR DAUGHTER BROOKE



NICOLE – AGE 31



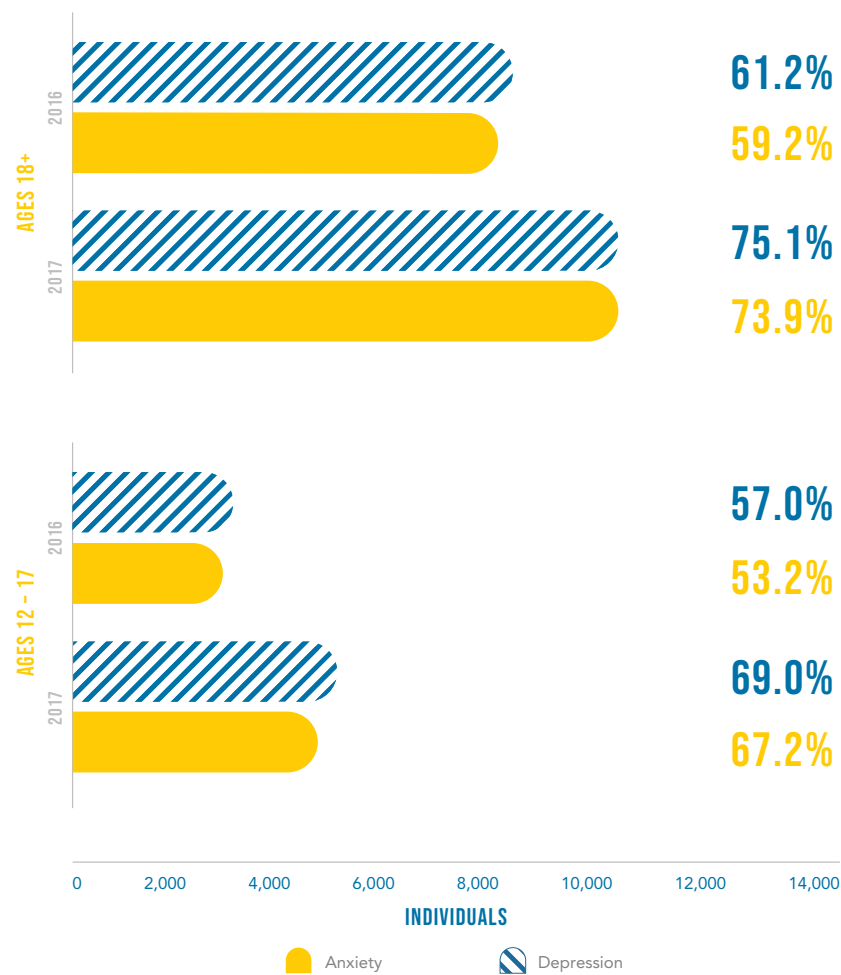
The CF Foundation Patient Registry

contains decades of longitudinal data and is an indispensable tool in our efforts to ensure all people with CF receive the highest quality care and most effective treatments. Establishing the Registry in 1966 was a visionary step by our founding families and laid the groundwork for research and care improvements that have added decades of life for people with CF. This vital resource would not be possible without the contributions of people with CF and their families who generously agree to share their data.

DEPRESSION AND ANXIETY SCREENING COMPARISON

(2016 TO 2018)

Data from the CF Foundation Patient Registry shows an increase in screening for depression and anxiety following the publication of clinical guidelines in 2015. In the same time frame, the number of patients and families who reported being asked about mental health increased by 55 percent.



Looking ahead, we are creating resources for siblings of individuals with CF and continue to support the Mental Health Advisory Committee, established in 2016, to help implement clinical guidelines related to mental health and more comprehensively meet the needs of patients and families.

“ 73 PERCENT OF PATIENTS AND FAMILIES WHO ARE SEEN AT AN ACCREDITED CARE CENTER REPORT THAT THEY WERE ASKED ABOUT MENTAL HEALTH AS PART OF THEIR VISIT. ”

Because of these efforts, more people with CF are being screened for anxiety and depression, and 73 percent of patients and families who are seen at an accredited care center report that they were asked about mental health as part of their visit — a 55 percent increase since 2015.

SUPPORTING & EMPOWERING PEOPLE WITH CF

Living with CF is a full-time job. Most of that work — sustaining daily care, accessing needed therapies and treatments, and coping with the financial and emotional burden of a complex, chronic disease — happens outside of the clinic, in real life. CF impacts patients’ and their loved ones’ relationships, emotional health, and plans for the future.

Through programs like Community Voice, people with CF have told us they need resources and support to successfully manage the challenges of this disease — particularly feelings of isolation and disconnection. Since 2016, the community has

●
**COMMUNITY VOICE
 ENABLES PEOPLE WITH
 CF AND THEIR FAMILY
 MEMBERS TO ACTIVELY
 SHAPE RESEARCH
 PRIORITIES AND
 OTHER FOUNDATION
 PROGRAMS.**

co-led the development of programs to help forge connections and provide social support, beginning with our flagship BreatheCon event. In 2018, approximately 1,243 people with CF and their family members participated in virtual events. By the close of the year, 319 matches had been made through our peer mentoring program.

In 2018, based on feedback from the CF community, we expanded this focus on connection to include parents and loved ones. More than 200 individuals participated in the first-ever FamilyCon, and 42 family members of people with CF received support and encouragement from peer mentors. CF Cares, a new series of local events that provide an unstructured environment for connection and support, provided an opportunity for parents of people with CF to access community in a more intimate setting.



TRÉ – AGE 24

"It has been uplifting to hear from speakers who have faced tremendous adversities and left the battles stronger and more motivated than before."

– Ella Balasa, an adult with CF



DESI – AGE 2 + HER MOM JAMIE



The CF community

has played a central role in advancing our mission since the Foundation was established in 1955 and remains the driving force behind our work. For the 30th straight year, our Great Strides program provided local communities with opportunities to come together, celebrate their loved ones with CF, and raise awareness and funds for a cure. In 2018, more than 90,000 individuals participated in more than 450 walks around the country, raising \$36 million.

advocating
for people
with CF.

—

We have come so far in the fight against CF through our efforts in research, care, and community, and we cannot jeopardize this progress. Individuals with CF must have access to high-quality, specialized care and adequate, affordable health insurance.

 OVER A 12-MONTH PERIOD, 58 PERCENT OF PEOPLE WITH CF REPORTED DELAYING OR FORGOING CARE DUE TO COST.

PROTECTING ACCESS TO CARE

In 2018, health care reform remained a top policy priority at both the federal and state level, and our focus centered on maintaining protections for individuals with pre-existing conditions, supporting efforts to stabilize the health insurance market, and preserving and expanding access to Medicaid — a critical source of coverage for more than one-third of adults and half of all children with CF.

As always, members of the CF community used their voices to speak with policymakers about the topics that mattered most to them. For the first time, the CF community weighed in on regulatory comments, challenging a proposed rule to expand short-term limited-duration health plans, which hold the potential to increase costs and erode coverage for people with CF.

More than 2,800 individuals from the CF community provided input during the public comment period — representing more than a third of the feedback on the rule overall. The community also rallied around local actions in their home states to convey the potential impact of work requirements and other policies with the potential to erode access, sending more than 32,000 messages and holding more than 1,000 face-to-face meetings with policymakers and decision-makers.

PROVIDING INDIVIDUALIZED SUPPORT

Despite our efforts to make the system work for people with CF, we hear daily from individuals who are concerned about cost and report challenges in accessing the treatments and care they need. Our free support program, CF Foundation *Compass*, continues to provide personalized assistance to help with the challenges of living with CF.

As coverage has become more restrictive, *Compass* increasingly helps individuals select insurance plans that will cover their needs, maximize their benefits, and navigate issues in accessing care. We know that the cost burden of living with CF is high, and *Compass* identifies and refers individuals to other resources to help offset the burden of this illness.

“Talking to *Compass* felt like someone was finally on my side and understood how much trouble it is to figure this all out on your own.”

— Sarina Sandstrom, an adult with CF

thank
you.

In 2018, we continued to change the lives of people with CF and advance the science that will someday lead to a cure for everyone with this disease.

None of these achievements would be possible without the CF community. From Tomorrow's Leaders to "Grampions," and adults with CF, to parents, siblings, and friends, the CF community led our progress. In 2018, you walked, climbed, surfed, danced, golfed, and skied to raise more than \$80 million for a cure.

You relayed the needs of people with CF in discussions with policymakers at home and in Washington, D.C. And in 2018, nearly 1,000 people with CF and family members from all 50 states helped us to shape Foundation programs and activities in ways that are relevant to them through Community Voice.



NATIONAL ADVOCACY CO-CHAIRS ATTENDING MARCH ON THE HILL



RIDERS EMBARK ON THE ANNUAL CYCLE FOR LIFE EVENT IN SEATTLE



MEMBERS OF SURF TEAM PINEAPPLE POSSE AT THE SURF FOR CF FUNDRAISER IN SAN DIEGO

TOMORROW'S LEADERS

Tomorrow's Leaders is a program for young professionals to obtain leadership development and networking opportunities while making a difference in the lives of people with CF.

LEGACY GIVING

The Paul di Sant-Agnese Legacy Society recognizes donors who make a lasting commitment to the CF Foundation through their estate plans and pays tribute to the physician who revolutionized CF diagnosis by developing the sweat test.

THE DORIS F. TULCIN MAJOR GIVING SOCIETY

The society honors Doris F. Tulcin — a founding parent of the Cystic Fibrosis 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.

ANNUAL FUND AND 65 ROSES CLUB

Contributors to the Annual Fund and 65 Roses Club play a vital role in sustaining the mission of the Foundation through annual or monthly gifts.

TOP NATIONAL CORPORATE TEAM

CISCO Systems, Inc.

RISING STAR NATIONAL CORPORATE TEAM

CARSTAR

"SPIRIT OF AMERICAN" AWARD

Choate Construction

NATIONAL CORPORATE CHAMPIONS

Corporate Champions provide direct support of \$100,000 or more to support the search for the cure and improve the lives of people with CF.

PLATINUM

abbvie **American Airlines** 

GOLD

ARRIS 



VERTEX 

SILVER

AllianceRX Walgreens Prime/Walgreens, BJ's Restaurants, Choate Construction, Genentech, Gilead, Novartis, Snellings Walters

BRONZE

Bank of America, CARSTAR, Chiesi, Chubb Ltd., CISCO Systems, Inc., Duke Energy, Kroger, Mastercard, Noodles & Company, Quantum, Wells Fargo



We are stronger together.

• And together, we will keep advancing the fight against CF — until it's done.

condensed financial information.

CYSTIC FIBROSIS FOUNDATION CONDENSED FINANCIAL INFORMATION AS OF DECEMBER 31, 2018 AND 2017*

*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.

CONSOLIDATED STATEMENTS OF FINANCIAL POSITION

AS OF DECEMBER 31, 2018 AND 2017

| | 2018 | 2017 |
|---|-------------------------|-------------------------|
| ASSETS | | |
| CASH AND CASH EQUIVALENTS | \$ 82,921,497 | \$ 81,580,161 |
| INVESTMENTS | 3,869,931,266 | 4,296,347,369 |
| DUE FROM INVESTMENT MANAGER | 33,757,653 | — |
| RECEIVABLES, NET | 12,264,592 | 12,137,402 |
| OTHER ASSETS | 3,515,006 | 5,403,261 |
| FIXED ASSETS, NET | 11,545,942 | 11,959,914 |
| TOTAL ASSETS | \$ 4,013,935,956 | \$ 4,407,428,107 |
| LIABILITIES AND NET ASSETS | | |
| ACCOUNTS PAYABLE AND OTHER LIABILITIES | \$ 41,689,767 | \$ 36,422,049 |
| AWARDS PAYABLE | 196,882,717 | 176,819,993 |
| TOTAL LIABILITIES | 238,572,484 | 213,242,042 |
| NET ASSETS | | |
| WITHOUT DONOR RESTRICTIONS | 3,764,331,282 | 4,181,431,067 |
| WITH DONOR RESTRICTIONS | 11,032,190 | 12,754,998 |
| TOTAL NET ASSETS | 3,775,363,472 | 4,194,186,065 |
| TOTAL LIABILITIES AND NET ASSETS | \$ 4,013,935,956 | \$ 4,407,428,107 |

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.

INVESTMENTS

Investments as of December 31, 2018 included primarily corporate and other debt securities, 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 as of December 31, 2018 were

\$1,964,949,603 in Level 1 assets, \$526,178,708 in Level 2 assets and \$5,072,810 in Level 3 assets. Investments totaling \$1,424,394,921, 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 generally awards 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, 2018, the Foundation has medical scientific grant commitments of approximately \$60,562,000, which extend through December 31, 2023. 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 \$157,353,000. These costs will be expensed when the services are provided.

LIQUIDITY AND AVAILABILITY OF RESOURCES

The Foundation's financial assets available for general expenditures, such as program expenses, grants and other operating expenses, within one year of December 31, 2018 are \$3,066,809,786. The Foundation's Board of Trustees approves an annual operating budget and the Investment Committee of the Board of Trustees approves redemptions from the investment portfolio sufficient to meet projected cash needs. The Foundation maintains cash and highly liquid securities sufficient to meet anticipated cash needs for operations, capital commitments, and new investments over an eighteen-month rolling period.

CONSOLIDATED STATEMENTS OF ACTIVITIES
FOR THE YEARS ENDED DECEMBER 31, 2018 AND 2017

| | 2018 | 2017 |
|--|-------------------------|-----------------------|
| REVENUE | | |
| SUPPORT RECEIVED FROM THE PUBLIC | | |
| SPECIAL EVENT REVENUE | \$ 95,743,556 | \$ 98,751,719 |
| DIRECT BENEFIT EXPENSES | (14,813,644) | (14,630,047) |
| NET SPECIAL EVENT REVENUE | 80,929,912 | 84,121,672 |
| GENERAL CONTRIBUTIONS | 27,217,734 | 26,602,759 |
| TOTAL SUPPORT RECEIVED FROM THE PUBLIC | 108,147,646 | 110,724,431 |
| OTHER | 27,456,695 | 24,957,306 |
| TOTAL REVENUE | 135,604,341 | 135,681,737 |
| EXPENSES | | |
| PROGRAM SERVICES | | |
| MEDICAL PROGRAMS | 237,133,914 | 213,999,714 |
| PUBLIC AND PROFESSIONAL INFORMATION AND EDUCATION | 15,998,432 | 16,900,416 |
| COMMUNITY SERVICES | 20,043,322 | 17,822,831 |
| TOTAL PROGRAM SERVICES | 273,175,668 | 248,722,961 |
| SUPPORTING SERVICES | | |
| MANAGEMENT AND GENERAL | 22,963,205 | 15,968,460 |
| FUNDRAISING | 26,896,581 | 24,702,883 |
| TOTAL SUPPORTING SERVICES | 49,859,786 | 40,671,343 |
| TOTAL EXPENSES | 323,035,454 | 289,394,304 |
| PROVISION FOR LEASE COMMITMENT | — | (4,358,356) |
| DECREASE IN NET ASSETS FROM OPERATIONS | (187,431,113) | (158,070,923) |
| OTHER CHANGES IN NET ASSETS | | |
| NET NONOPERATING INVESTMENT (LOSS) INCOME | (231,391,480) | 606,956,685 |
| PROCEEDS FROM SALE OF REMAINDER OF MEMBER INTEREST IN SPECIALTY PHARMACY | — | 13,145,125 |
| (DECREASE) INCREASE IN NET ASSETS | \$ (418,822,593) | \$ 462,030,887 |

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 revenues with or without donor restriction. All support with donor restriction, including related investment income and realized and unrealized gains and losses, is reported as an increase in net assets with donor restrictions. When a restriction expires (that is, when a stipulated time restriction ends or purpose restriction is accomplished), net assets with donor restriction are reclassified to net assets without donor restriction and reported in the consolidated statement of activities as net assets released from restrictions.

The Foundation retains 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.

LEASE COMMITMENTS

The Foundation is obligated under various operating leases for office space as of December 31, 2018. The approximate future minimum rental commitments, subject to escalation, are \$45,490,000. The Foundation has entered into sublease agreements with tenants to occupy its former headquarters space. As of December 31, 2018, the approximate future minimum sublease rental payments due from sublease tenants are \$4,287,000.

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MISSION STATEMENT

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.

resolve future

momentum

vision science

groundbreaking

tomorrows