2019 **ANNUAL REPORT**

ENTERING a new era IN CF

CYSTIC FIBROSIS FOUNDATION®

the mission of the Cystic Fibrosis Foundation

is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high–quality, specialized care.

MADDIE

AGE 16, AND HER MOM, JENNIFER

Maddie is a cheerleader, gymnast, and runner. Her family – along with countless others in the CF community – is helping to drive unprecedented momentum in research and care. Their efforts are helping Maddie and others with CF live longer, more fulfilling lives than ever before and give us great hope for the future.

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dear friends,

As we were preparing this report, the cystic fibrosis community and the team at the CF Foundation faced a new challenge with the emergence of the global coronavirus pandemic. In response, we have seen the CF community come together and demonstrate the amazing resilience that has made the story of CF so unique and successful. This is consistent with our long history of taking on challenges that seem insurmountable and emerging even stronger.

2019 was a shining example of overcoming challenges and making transformative progress. In October, the U.S. Food and Drug Administration (FDA) approved Trikafta® – the first triple-combination therapy targeting the underlying cause of cystic fibrosis, which could eventually benefit more than 90 percent of people living with CF. The FDA's rapid approval underscored the importance of this highly effective treatment and validated the decades of hard work and selfless determination of so many.

Yet even with this transformative breakthrough, we know this story is far from finished. Critical work remains to help all people with CF live long, fulfilling lives. Our focus is firmly on the future and the work that lies ahead. At the 2019 North American Cystic Fibrosis Conference, the Foundation launched its *Path to a Cure*, an ambitious research agenda to deliver treatments for the underlying cause of the disease and accelerate progress toward a cure for every person with CF.

Through the Infection Research Initiative, and our growing programs in advanced lung disease and lung transplantation, the Foundation is supporting research to address some of the most serious complications of living with CF. In close partnership with people with CF and their families, we are finding new and innovative ways to help the community connect with one another and access practical and emotional support, especially in challenging times.

Every step forward has been made possible by your unwavering commitment to our shared mission. It is a great privilege to have stepped into my new role at the Foundation at such an important time in CF and I am excited by all we will do together to advance our mission. At the start of 2020, we set out a bold vision for the next five years and created the roadmap to get us there. I am committed to continuing the CF community's legacy of tenacity and innovation as we move into this next phase of our journey.

Working side by side, we will make CF stand for Cure Found.

— **MICHAEL P. BOYLE, MD**
President and CEO

SECTION 2

celebrating with the community

The approval of Trikafta (elexacaftor/tezacaftor/ivacaftor) was the result of decades of progress driven by the CF community – from tireless work raising funds for our mission, to the courage and commitment of hundreds of people who participated in clinical studies.

Trikafta was heralded as one of the most significant medical breakthroughs of the decade and organizations – ranging from the American Association for the Advancement of Science to the *Washington Post* Editorial Board – recognized the critical and unique role that people with CF played in its development.

Thirty years after the discovery of the cystic fibrosis transmembrane conductance regulator (CFTR) gene, Trikafta represents one of the most important therapeutic advancements in the history of CF, offering a treatment for the underlying cause of the disease that is significantly more effective than current modulator therapies and can be used by a much larger segment of the CF community.

In clinical trials, Trikafta showed dramatic improvements in key measures of the disease, including lung function, sweat chloride, and quality of life – results that are already having a transformative effect on many people's day-to-day lives.

Also in 2019, Kalydeco® (ivacaftor) was approved for people with CF as young as 6 months of age, making it possible for a new generation of patients to begin these critical therapies before their disease progresses. It is believed that starting modulator treatment early could fundamentally alter what it means to have CF.

"The achievement is the result of persistence by patient advocates and scientists, who never threw in the towel, even when the goal seemed impossible. A lot of bake sales went into supporting the quest, and that kind of support is priceless."

— *Washington Post* Editorial Board

WHAT TO KNOW

- Trikafta is approved for people ages 12 and older who have at least one copy of F508del – even if they have one nonsense or rare mutation
- Clinical studies are already underway in ages 6–11
- The Foundation continues to engage public and private payers in all 50 states to support access to this critical medicine
- Two new studies will examine the short- and long-term clinical effects of Trikafta (PROMISE study) and how people with CF may be able to stop taking select medications after taking Trikafta (SIMPLIFY study)

EVAN

AGE 6

Evan loves video games, Star Wars, and playing outside with his two brothers. As effective modulators become approved for younger and younger ages, we are hopeful that kids like Evan may never experience severe manifestations of CF.

together,

we have

effectively transformed a genetic disease in a single generation, making CF the greatest story in medicine.

SECTION 3

focusing on the future

We are working with great urgency to support the development of new therapies for people with CF whose mutations do not respond to current treatments, or who have pressing medical needs from their disease.

The CF Foundation's research portfolio in 2019 encompassed the largest and most diverse set of programs in our history, reflecting our belief that **our most important and challenging work is still ahead.**

PATH TO A CURE

On Oct. 30, 2019, against the backdrop of a historic North American Cystic Fibrosis Conference, the Foundation unveiled its *Path to a Cure* – an ambitious research agenda to accelerate the development of treatments for the underlying cause of the disease and a cure for every person with CF. We intend to allocate **$500 million** to the effort through 2025.

The *Path* builds on the Foundation's highly successful venture philanthropy strategy to stimulate industry investment in CF, and challenges potential collaborators to submit proposals centered around three core strategies to address the underlying cause of CF: repairing broken CFTR protein, restoring CFTR protein when none exists, and fixing or replacing the underlying genetic mutation.

With *Path to a Cure*, we seek to fund top innovators from around the world to develop the next generation of transformative breakthroughs in CF, accelerate treatments for individuals with the greatest need, and progress toward our goal of a cure for all.

PATH TO A CURE

many routes, one mission

START HERE

MUTATED CFTR GENE

WHAT DO WE NEED TO FIGURE OUT ?

REPAIR CFTR PROTEIN

WHAT'S THE PLAN?

CFTR MODULATORS

WE HAVE SOME. WE NEED MORE.

NONSENSE-SPECIFIC TREATMENTS

MRNA THERAPY

SHORT NUCLEOTIDE THERAPIES

OUR WORK CONTINUES...

TREATMENT FOR ALL

PEOPLE WITH CF WILL NEED ONGOING TREATMENTS

RESTORE CFTR PROTEIN

WHAT'S THE PLAN?

FIX OR REPLACE CFTR GENE

WHAT'S THE PLAN?

GENE EDITING

GENE TRANSFER

IN ORDER TO DO THIS, WE NEED TO...

SOME TRICKY STUFF TO FIGURE OUT HERE

TARGET THE CORRECT CELLS

DELIVER DNA

IT'S A LONG ROAD, BUT WE WON'T STOP UNTIL...

CF STANDS FOR CURE FOUND

RESEARCH WE FUND

Our total research investment in 2019 was **$160 million**, including **$150 million** in research awards and **$10 million** in funding for our one-of-a-kind, CF-focused lab just outside of Boston.

TOTAL RESEARCH SPENDING

TREATING CF MANIFESTATIONS
$65M

CLINICAL RESEARCH SUPPORT
$24M

CFTR MODULATION
$19M

CURE
$17M

NONSENSE AND RARE MUTATIONS
$13M

LABORATORY RESEARCH SUPPORT
$12M

CF FOUNDATION THERAPEUTICS LAB
$10M

TOTAL
$160M

Our funding priorities in 2019 included developing therapies with the potential to benefit individuals not yet helped by modulators and working to address the most pressing challenges facing people with CF today, from infection to transplant.

PORTFOLIO SNAPSHOT

322 studies to understand and address manifestations of CF including infection, inflammation, mucus clearance, CF-related diabetes, gastrointestinal issues, and advanced lung disease

64 studies to explore additional modulators and to study and expand the current therapeutic options

18 studies to focus on restoring CFTR for individuals who have two nonsense or rare mutations

65 studies to focus on genetic-based therapeutic approaches that could cure CF*

* *These studies also encompass some of the most promising strategies to address rare and nonsense mutations.*

DAVID
AGE 42

David is a husband and father of three. He and his kids like to stargaze and hike around their farm. David is on a modulator, but still experiences other manifestations of CF, like CF–related diabetes (CFRD). The Foundation is funding research into studying CFRD and other manifestations of the disease to help people like David live better lives today.

FOCUS ON MANIFESTATIONS

Improved treatments and care are driving continued gains in life expectancy, yet each success is accompanied by new questions and opportunities. Even with the widespread use of modulators, we expect that many people with CF will continue to require treatment for conditions associated with CF disease progression, with new challenges continuing to emerge in adults. This is a key area of concern for the CF community, and advancing new therapies to address the many manifestations of CF remains a critical area of focus.

INFECTION
$24M
150 Studies

INFLAMMATION
$10M
27 Studies

MUCUS & AIRWAY HYDRATION
$6M
34 Studies

GASTROINTESTINAL
(nutrition, liver disease, GI symptoms, GI microbiome)
$7M
29 Studies

ENDOCRINE
(CFRD, bone, reproductive health)
$3M
25 Studies

ADVANCED LUNG DISEASE
(lung transplant, exacerbations, lung microbiome, lung disease progression)
$13M
42 Studies

OTHER
$2M
15 Studies

DRUG DEVELOPMENT PIPELINE

To advance drug development and the search for a cure, Cystic Fibrosis Foundation has contractual agreements with several companies to receive royalties related to drugs that are developed as a result of CFF funding, see *"How Drugs Get on the Pipeline."* Any royalties we receive are used in support of our mission.

THERAPIES AVAILABLE TO PATIENTS

4

+ Elexacaftor + Tezacaftor + Ivacaftor (Trikafta®)
+ Ivacaftor (Kalydeco®)
+ Lumacaftor + Ivacaftor (Orkambi®)
+ Tezacaftor + Ivacaftor (Symdeko®)

2

+ Dornase Alfa (Pulmozyme®)
+ Hypertonic Saline

1

+ Ibuprofen

5

+ Amikacin Liposome Inhalation Suspension (Arikayce®)
+ Azithromycin
+ Aztreonam (Cayston®)
+ Inhaled Tobramycin
+ Tobramycin Inhaled Powder (TOBI® Podhaler™)

3

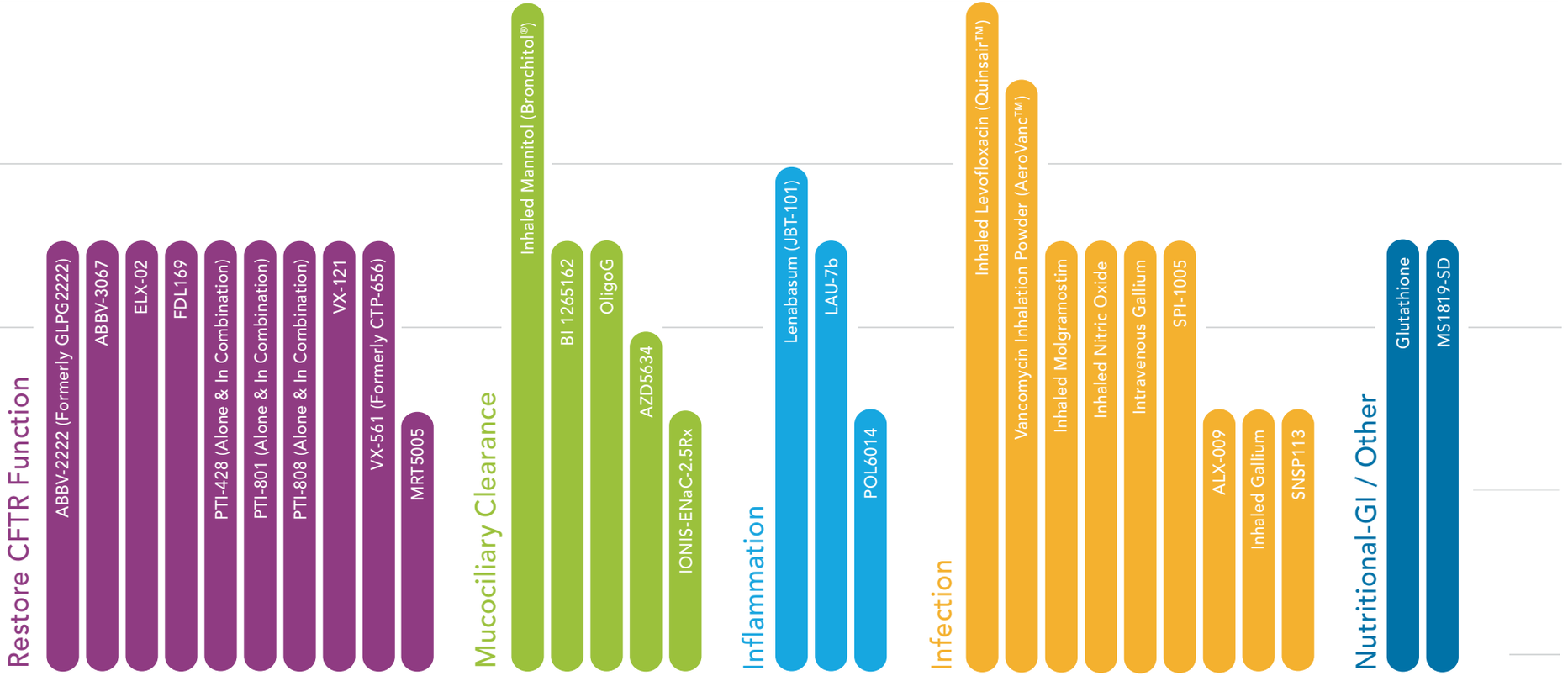
+ AquADEKs
+ Pancrelipase Enzyme Products
+ RELiZORB®

PHASE 3
Definitive Trial

PHASE 2
Human Safety & Efficacy Trial

PHASE 1
Human Safety Trial

PRE-CLINICAL
Initial Testing in Laboratory



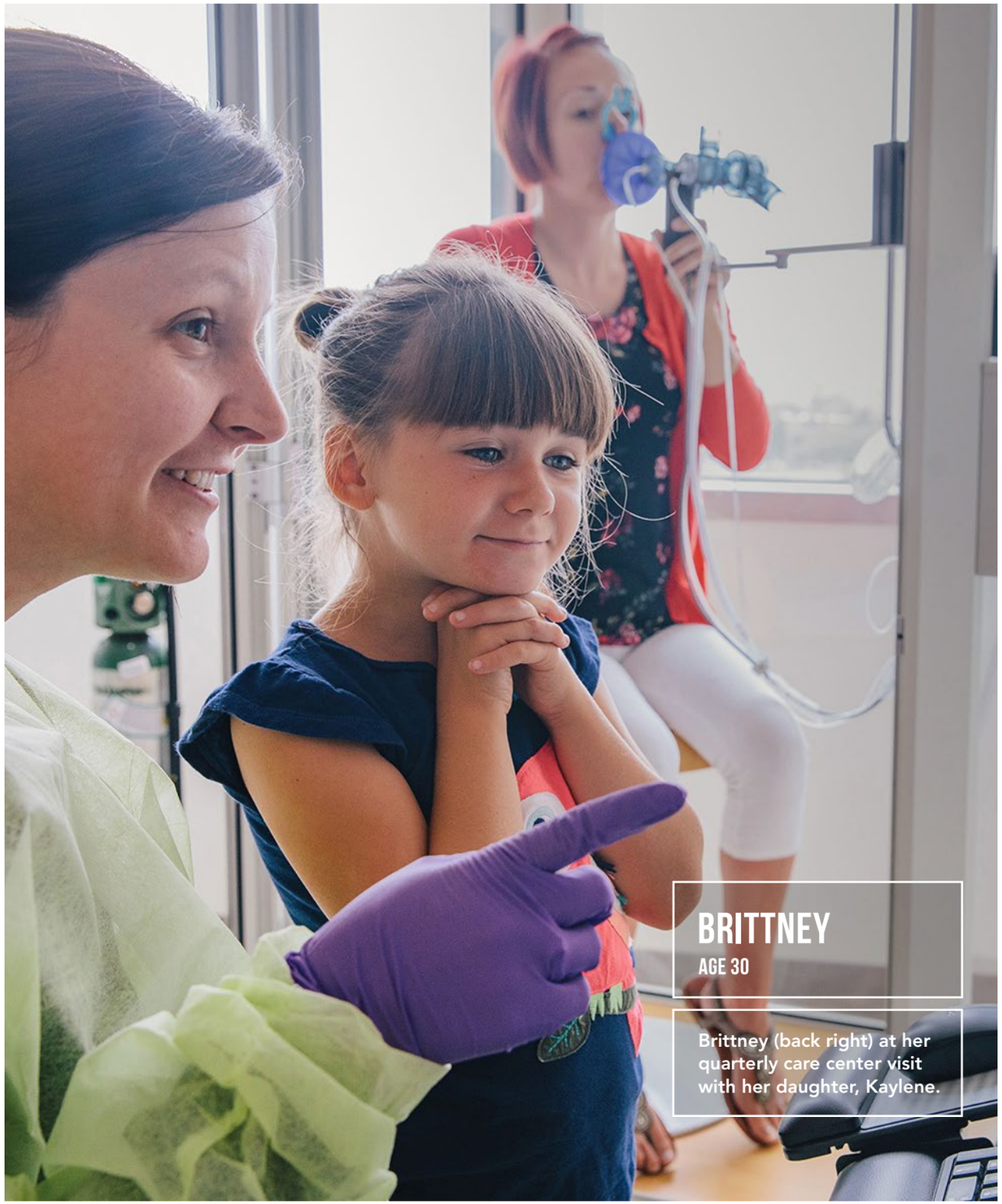
PIPELINE AS OF DEC. 31, 2019

INFECTION RESEARCH INITIATIVE UPDATE

In the first year following the launch of the Infection Research Initiative – a sweeping effort that committed $100 million to address chronic and intractable infections in people with CF – the Foundation provided funding to support 150 studies aimed at improving outcomes through enhanced detection, diagnosis, prevention, and treatment.

INFECTION RESEARCH TOPIC AREAS

- NONTUBERCULOUS MYCOBACTERIA
- PSEUDOMONAS AERUGINOSA
- BACTERIOPHAGE
- MICROBIOME
- VIRAL INFECTIONS
- BURKHOLDERIA CEPACIA
- STAPHYLOCOCCUS AUREUS
- FUNGI
- ANTI–MICROBIAL TOXICITY



BRITTNEY
AGE 30

Brittney (back right) at her quarterly care center visit with her daughter, Kaylene.

FIVE–YEAR STRATEGIC PLAN 2020–2024

Working alongside the CF community for the past 65 years, we have achieved unparalleled advances in the treatment and care of cystic fibrosis and generated unprecedented momentum in research. In 2019, we reflected on the last six decades of progress and what those advances mean for people with CF. We also considered how the needs of people with CF and those who care for them will change in the coming years as the treatment landscape continues to evolve.

The resulting strategic plan defines key areas of focus for the next five years as we advance our *Path to a Cure*, meet emerging challenges in care, and explore new ways to partner with and support the CF community. Hundreds of people with CF and their circles of support, as well as leading clinicians and researchers, helped to shape this vision.

CARMEN
AGE 55

Carmen is a mother and grandmother who enjoys making jewelry. Like many people with CF, Carmen takes dozens of medicines and does hours of treatments each day, including wearing her vest.

CURE

We will bring the best scientific minds and technology into CF research and catalyze the next generation of transformative CF therapies.

KEY AREAS OF FOCUS

- Drive progress toward treating the underlying cause of CF for all people with the disease and delivering a cure
- Advance new and improved treatments to address the many manifestations of CF, including challenges associated with advanced disease

CARE

We will apply the principles of our pioneering care model to optimize health for people with CF in the changing CF treatment landscape.

KEY AREAS OF FOCUS

- Support the best possible CF treatment and care delivery by generating high-quality data and evidence
- Evolve and support the CF care model and network to meet the future needs of people with CF across their life span and ensure clinicians and researchers are equipped to meet the changing needs of people with CF

COMMUNITY

We are seeking new and meaningful ways to engage the community, enhance our support for life with CF, and expand the reach of our programs and services to those in need.

KEY AREAS OF FOCUS

- Support people with CF in living their best possible life no matter where they are on their CF journey
- Engage the CF community to shape Foundation programs and stimulate fundraising to achieve our mission
- Expand the reach of programs and services to benefit more individuals across the CF community

our most important and *challenging* work is still ahead

RUBY

AGE 19

Ruby is majoring in biology at college and enjoys running. Ruby has two rare CFTR genetic mutations, which means she is not currently eligible for a modulator. The Foundation is aggressively pursuing research so that every person with CF will have a treatment for the underlying cause of their disease.

SECTION 4

living better today

Thanks to improvements in treatments and care, many people with CF are living longer, healthier lives than ever before. Yet, we recognize that life with CF continues to grow more complex, and individual experiences with this disease are becoming more diverse.

The Foundation is committed to delivering support and resources for people with CF to live the longest, healthiest lives possible, wherever they are in their journey. The median life expectancy for a person with CF is now in the mid-40s. While still not nearly long enough, this represents a dramatically different outcome than prior generations could expect.

People with CF also have markedly higher lung function and body mass index (BMI) compared to the prior decade, which are key indicators of health.

The milestones that people with CF are reaching in their daily lives are perhaps the best, most important indication of progress.

bachelor's degree or higher

5,675

people with CF

married or living together

6,993

people with CF

full-time or part-time work

8,919

people with CF

53%

of adults meet BMI goals

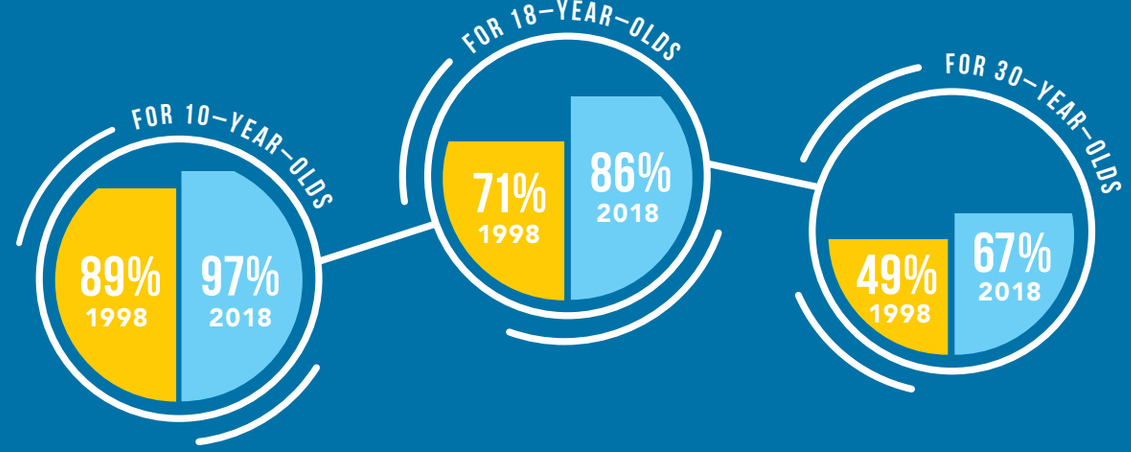
Over age 20, the body mass index (BMI) goal for people with CF is 23 for men and 22 for women.

median BMI percentile for 2–19 is

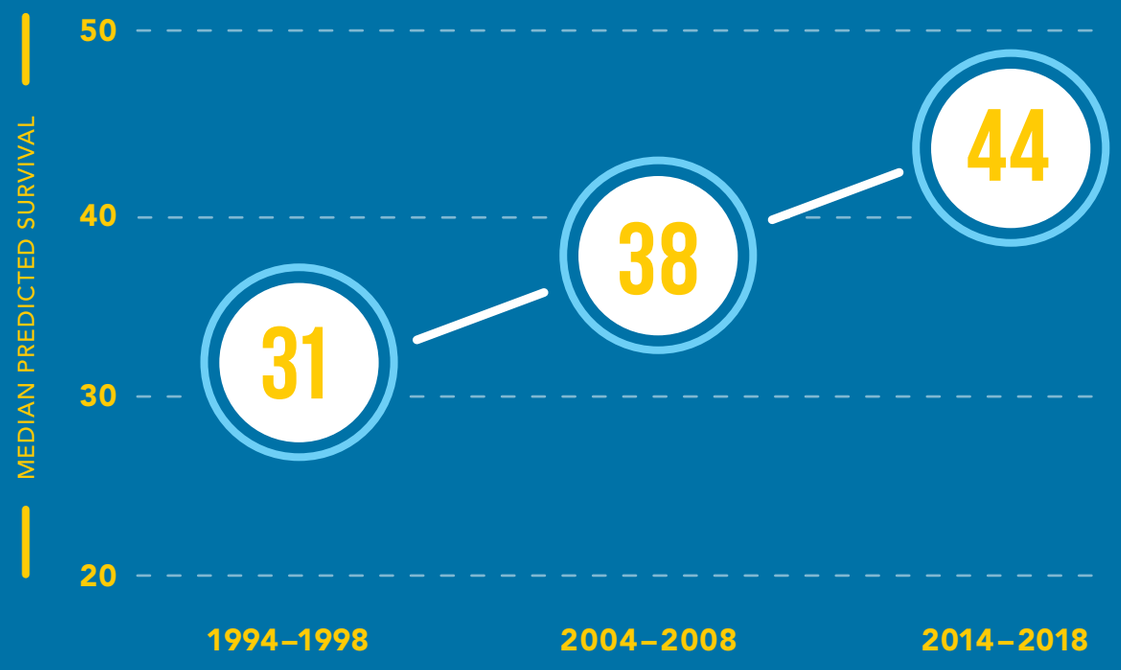
58

The BMI percentile goal is 50 or greater for children and adolescents with CF.

median FEV_1 percent predicted



survival

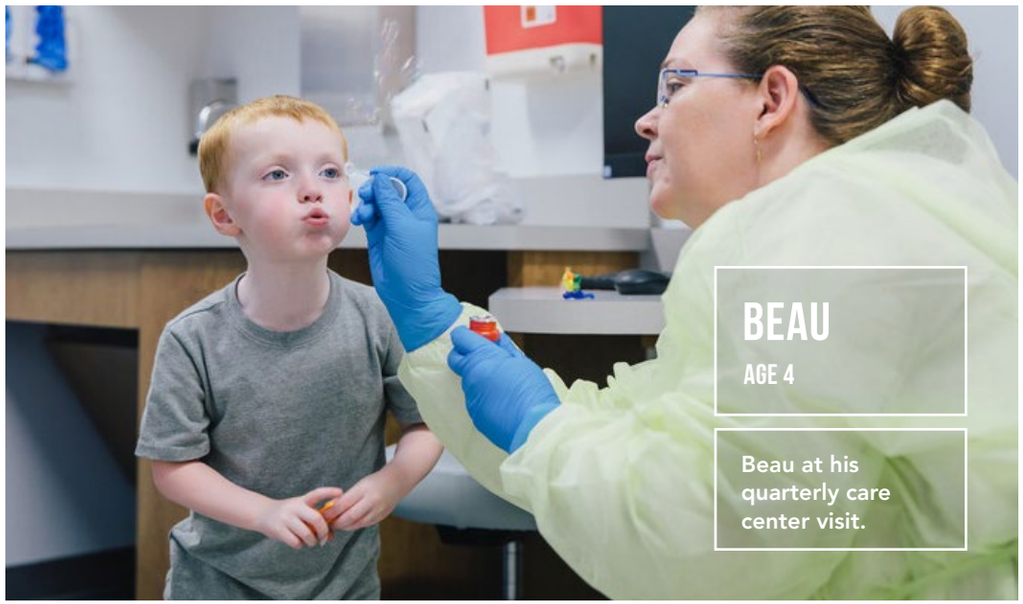


CONTINUED INVESTMENT IN CARE

Highly specialized care has added decades of life for people with CF and remains the backbone of our efforts to improve the health and daily lives of people with CF.

The Foundation is a critical source of funding for a network of accredited CF care centers, which in 2019 included 118 adult and 128 pediatric programs. These grants provide vital support for multidisciplinary care teams, ensuring that people with CF experience coordinated care by a range of specialists.

These funds also included workforce development grants – such as our PACE, ENVISION, and DIGEST programs – that are aimed at recruiting and training leading adult care providers, endocrinologists, and gastroenterologists, and other programs to encourage pharmacists and physical therapists to focus on CF.



BEAU
AGE 4

Beau at his quarterly care center visit.

THE MULTIDISCIPLINARY CARE TEAM

REQUIRED TEAM MEMBERS

- SOCIAL WORKER
- PHYSICIAN
- NURSE
- PROGRAM COORDINATOR
- RESPIRATORY THERAPIST
- DIETITIAN

RECOMMENDED TEAM MEMBERS

- PSYCHOLOGIST
- RESEARCH COORDINATOR
- PHYSICAL THERAPIST
- PHARMACIST

UNDERSTANDING ADVANCED LUNG DISEASE

The Foundation has undertaken a concerted effort to improve care for individuals with advanced lung disease, most notably through our Lung Transplant Initiative – a comprehensive effort to maximize the opportunity for transplant as a life-sustaining therapy and extend post-transplant survival for people with CF.

Addressing chronic rejection is a critical area of focus as we work to improve transplant outcomes. In 2019, the Foundation awarded $4 million across seven research grants focused on Chronic Lung Allograft Dysfunction, (CLAD), a common post-transplant complication related to organ rejection. The Foundation also initiated development of a lung transplant registry and advanced plans for a biorepository to collect samples from individuals after transplant.

In addition to driving new scientific understanding of transplant outcomes, the Foundation held the first-ever CF Lung Transplant Surgery Workshop and a transplant quality improvement summit, which connected CF care teams with transplant teams to partner and improve the transplant journey for people with CF.

REUBEN

AGE 33

Reuben received a lung transplant in 2019. Part of his post-transplant care is having regular check-ups with his transplant team. The CF Foundation's Lung Transplant Initiative is focusing on learning more about advanced lung disease and improving outcomes for people with CF who have undergone transplant.

FOSTERING CONNECTIONS ACROSS THE CF COMMUNITY

We recognize the power of tapping into the unique experiences of people with CF and their families, and work alongside them to design programs that facilitate meaningful connections and opportunities to learn and share.

In 2019, the Foundation held four virtual events designed by adults with CF, family, clinicians, and researchers – including the first-ever ResearchCon, which focused on infection. More than 1,500 attendees participated in these forums, including many who had never before engaged with the Foundation. Additionally, 134 individuals found personal connections through our peer-mentoring program, which matches participants to someone from the CF community – an adult with CF or a parent, partner, or spouse – who has had a similar experience, such as dating and going to college, adjusting to a child's new diagnosis, or considering a lung transplant.

SUPPORT FOR DAY-TO-DAY CHALLENGES

Living with CF requires a complex and time-consuming daily care regimen, as well as frequent visits to a multidisciplinary care team. People with CF often face insurance, financial, and practical challenges to sustaining their care in the midst of daily life. CF Foundation *Compass* is a personalized, one-on-one service that provides support for people with CF, their families, and their care teams – regardless of their income or insurance status.

Following the approval of Trikafta, *Compass* provided a vital source of support for individuals and families as they navigated barriers to accessing this important therapy.

Compass can help

more than

11,000

conversations

nearly

6,000

cases handled

37 PEOPLE

supported with transplant-related needs

we're committed to helping people with CF

no matter where they are on *their journey*

JESSE

AGE 38 AND HIS WIFE, YVETTE

As people with CF live longer, they are reaching new milestones – like completing degrees, starting careers, getting married, and having families of their own. As living with CF grows more complex, the Foundation remains committed to supporting and providing resources for people with CF and their families.

SECTION 5

advancing our mission

The CF community continues to bring power and energy to our mission – particularly as a new generation of adults with CF steps forward to shape our priorities.

We will continue to seek meaningful ways to engage the CF community and to become a place where all people with CF and their circles of support feel welcome and can make a difference.

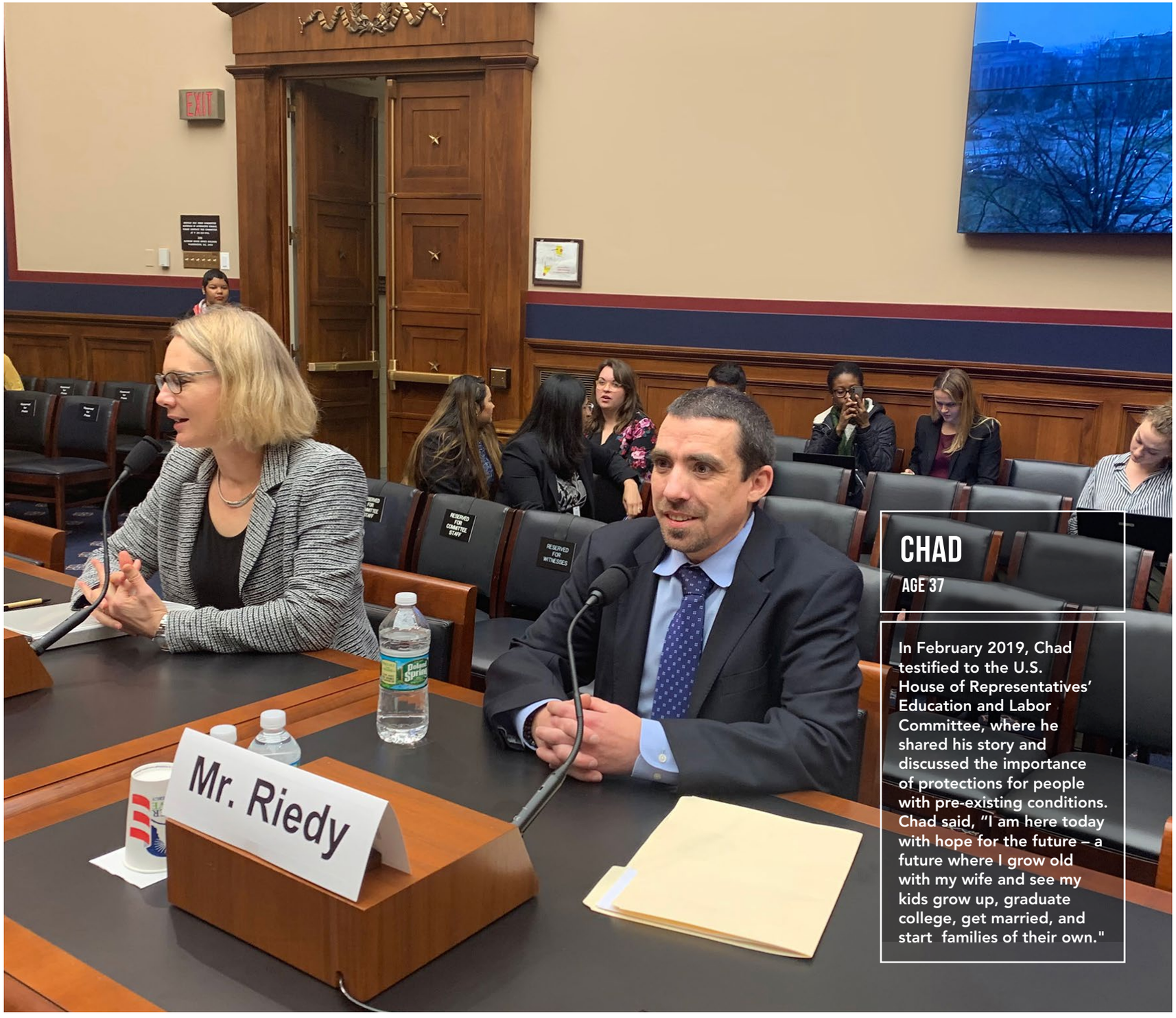
SHAPING OUR WORK

Community Voice remains a key mechanism for people with CF and their family members to actively shape research and programs. In 2019, more than **980 individuals** shared their perspective and insights through participation in **67 different** surveys, focus groups, or committees.

KATIE

AGE 37

Katie loves photography, traveling, and going to modern art museums. Katie is a member of Community Voice, which provides opportunities for people with CF and their families to actively shape research and programs. Katie and others who help to shape our work are essential partners in the fight against CF.



CHAD

AGE 37

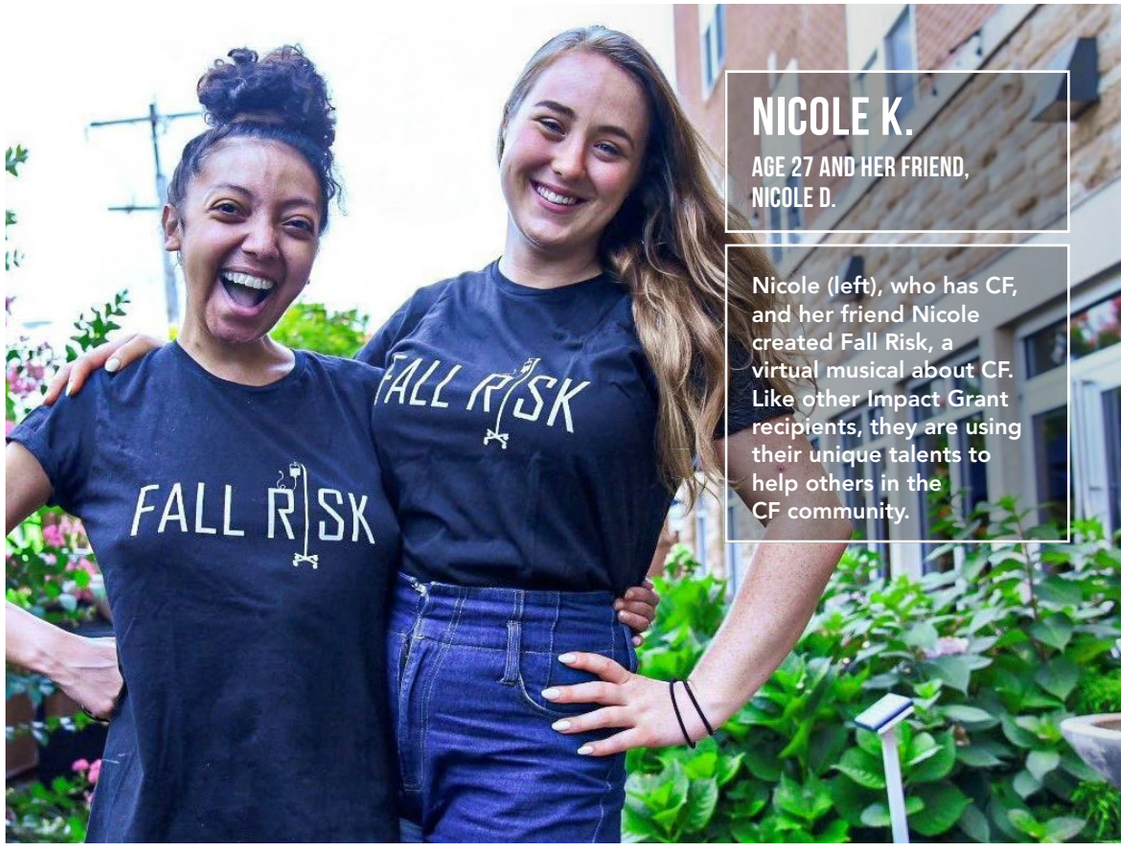
In February 2019, Chad testified to the U.S. House of Representatives' Education and Labor Committee, where he shared his story and discussed the importance of protections for people with pre-existing conditions. Chad said, "I am here today with hope for the future – a future where I grow old with my wife and see my kids grow up, graduate college, get married, and start families of their own."

SHARING YOUR VOICE

People with CF also shared their voices to drive change outside of the Foundation in 2019, advocating for their and their loved ones' needs with policymakers. Nearly **350 advocates** traveled to Washington, D.C., for our March on the Hill and Teen Advocacy Day events, with countless others writing letters and making phone calls to tell their representatives what matters most to them.

USING YOUR PASSION TO SUPPORT OTHERS

People with CF remain one another's greatest champions and channel their passion and creativity to help others in the CF community. It's the Foundation's privilege to support this work through annual Impact Grants, which provide up to $10,000 per year to community-led programs and services for people affected by CF.



NICOLE K.
AGE 27 AND HER FRIEND, NICOLE D.

Nicole (left), who has CF, and her friend Nicole created Fall Risk, a virtual musical about CF. Like other Impact Grant recipients, they are using their unique talents to help others in the CF community.

2019 impact grant recipients

THE SALTY LIFE
a cystic fibrosis magazine

Print magazine dedicated to shining a light on important topics and sharing perspectives from children, adults, and families affected by CF

CYSTIC ARTS
by khloe's hope

Art therapy YouTube channel to help people with CF and their caregivers of all ages work through emotions related to CF

Seven prior Impact Grant awardees received ongoing funding in 2019 based on their proven success.

FALL RISK
the CF musical comedy

CF-based musical comedy bringing people with CF together virtually in musical theatre

HEALTH ADVOCACY SUMMIT

Virtual conference that provides young adults with chronic and rare diseases skills to self-advocate

SINGSPIRE
virtual choir

Virtual choir where people with CF receive music and voice assignments, connect through online rehearsals, and record a unified choral piece

ABIGAIL AND JACK

AGES 5 AND 6

In 2019, brother and sister Abigail and Jack joined thousands of CF community members across the country to lace up and walk for a cure. Their family walked in Omaha, one of more than 450 walks and events that raised more than $80 million to advance our mission.

VOLUNTEERS AND DONORS MAKING A DIFFERENCE

The unprecedented progress we have made in the fight against CF would not be possible without partnership with the CF community.

There are numerous ways that individuals are rolling up their sleeves to help us find a cure for CF and make a meaningful difference in the lives of every person affected by this disease.

Some have raised funds by walking, dancing, hiking, cycling, golfing, and skiing, and through countless passion fundraisers as unique and diverse as the CF community. Others have made outright gifts in response to annual and major gift appeals. In the end, every donor and volunteer who supported the Foundation helped propel the mission forward, raising more than **$109 million** in 2019.

With your continued support, we will not stop until CF stands for Cure Found.

Thank you.

CF Foundation supporters are the heart of our organization, and the generosity of individuals who have made personal gifts at any level is helping to accelerate progress in our mission. We celebrated the 30th anniversary of the gene discovery and the milestones we've reached since then alongside many of these tireless donors at the North American Cystic Fibrosis Conference.

As just one example of our many volunteer programs, Tomorrow's Leaders, including this group from South Carolina, are young professionals across the country gaining leadership skills and networking while they make a difference in the lives of those with cystic fibrosis. While some of our 1,600 Tomorrow's Leaders are siblings, partners, or friends of people with CF, others support the Foundation's mission without any direct connection to CF. Tomorrow's Leaders raised more than $3 million to advance our mission in 2019.

Bonnee is an active CF Foundation volunteer fighting for a cure for her granddaughter, Delaney. She is one of the Foundation's Grampions – grandpersons who are passionate about helping those with cystic fibrosis live their best life.

CORPORATE SUPPORTERS LEADING THE WAY

Businesses of all sizes play an important role in fueling our mission through fundraising events and sponsorship. National 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

CHOATE CONSTRUCTION
Reputation is Everything

THE COLLECTIVE C

Silver

BJ's Restaurants, Duke Energy, Genentech, Gilead, Mastercard International, Snellings Walters Insurance, Vertex

Top National Corporate Team

Choate Construction Company

Rising Star National Corporate Team

MC Companies – Sharing the Good Life Foundation

Bronze

Alaska National Insurance Company, AllianceRX/Walgreens, BB&T, CARSTAR, Chiesi, CISCO Systems Inc., Citigroup, Corbus Pharmaceuticals, Deloitte, FedEx, G2 Secure Staff, Hyatt Hotels, MC Companies – Sharing the Good Life Foundation, Merrill a Bank of America Company, Quantum, Samsung Electronics, Sprint, University of Pennsylvania Medical Center, Valvoline Instant Oil Change, Wells Fargo

SECTION 6

condensed financial information*

*The independently audited financial statements of the Cystic Fibrosis Foundation are available online at the Foundation's website, cff.org.

STATEMENTS OF FINANCIAL POSITION

As of December 31, 2019 and 2018

	2019	2018
ASSETS		
Cash and Cash Equivalents	$ 69,364,201	$ 82,921,497
Investments	4,331,314,555	3,869,931,266
Due From Investment Manager	29,206,032	33,757,653
Receivables, Net	29,154,940	12,264,592
Other Assets	6,356,702	3,515,006
Fixed Assets, Net	11,114,652	11,545,942
TOTAL ASSETS	**$ 4,476,511,082**	**$ 4,013,935,956**
LIABILITIES AND NET ASSETS		
Accounts Payable and Other Liabilities	$ 42,933,110	$ 41,689,767
Awards Payable	196,869,140	196,882,717
TOTAL LIABILITIES	**239,802,250**	**238,572,484**
NET ASSETS		
Without Donor Restrictions	4,226,469,269	3,764,331,282
With Donor Restrictions	10,239,563	11,032,190
TOTAL NET ASSETS	**4,236,708,832**	**3,775,363,472**
TOTAL LIABILITIES AND NET ASSETS	**$ 4,476,511,082**	**$ 4,013,935,956**

ORGANIZATION

The accompanying financial statements include the operations of the Cystic Fibrosis Foundation, including all of its field offices (the "Foundation").

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. Cash and cash equivalents that are held as part of the Foundation's investment portfolio are reported within investments.

INVESTMENTS

Investments as of December 31, 2019 included primarily fixed income securities, global public equity securities and interests in alternative investment funds. Authoritative guidance 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, 2019 were $2,206,184,052 in Level 1 assets, $1,159,281,990 in Level 2 assets and $7,442,396 in Level 3 assets. Level 2 assets include $41,397,526 which are part of cash equivalents in the statement of financial position. Investments totalling $999,803,643, 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, 2019, in addition to awards payable the Foundation has medical scientific grant commitments of approximately $104,175,000 which extend through 2023. These subsequent year awards are contingent upon renewal criteria, and therefore the costs and liabilities are not reflected in the financial statements. Certain agreements provide for future contracted drug discovery and development research payments amounting to approximately $145,746,000. 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, 2019 are $3,010,034,008. 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.

STATEMENTS OF ACTIVITIES

For the years ended December 31, 2019 and 2018

	2019	2018
REVENUE		
SUPPORT RECEIVED FROM THE PUBLIC		
Special Event Revenue	$ 96,255,420	$ 95,743,556
Direct Benefit Expenses	(15,820,602)	(14,813,644)
Net Special Event Revenue	80,434,818	80,929,912
General Contributions	28,586,267	27,217,734
Total Support Received From the Public	109,021,085	108,147,646
Other	55,976,109	27,456,695
TOTAL REVENUE	**164,997,194**	**135,604,341**
EXPENSES		
PROGRAM SERVICES		
Medical Programs	245,607,343	237,133,914
Public and Professional Information and Education	17,584,009	15,998,432
Community Services	22,103,810	20,043,322
TOTAL PROGRAM SERVICES	**285,295,162**	**273,175,668**
SUPPORTING SERVICES		
Management and General	25,897,119	22,963,205
Fundraising	28,709,962	26,896,581
TOTAL SUPPORTING SERVICES	**54,607,081**	**49,859,786**
TOTAL EXPENSES	**339,902,243**	**323,035,454**
Decrease in Net Assets From Operations	**(174,905,049)**	**(187,431,113)**
OTHER CHANGES IN NET ASSETS		
Net Nonoperating Investment Income (Loss)	636,250,409	(231,391,480)
Increase (Decrease) in Net Assets	**$ 461,345,360**	**$ (418,822,593)**

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

Contributions are recorded as revenue when received or when the donor has made an unconditional promise to give. Contributions received for future events are recorded as refundable advances and are recognized as revenue in the year in which the event takes place. 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 statement of activities as net assets released from restrictions.

Revenues from contracts with customers are recognized when or as performance obligations have been satisfied. Licensing revenue is recognized at a point in time for licenses issued to use intellectual property or over time for licenses granted to access intellectual property. Sales-based royalty revenue is recognized at the later of when 1) the sales occur and 2) the associated performance obligation has been satisfied. Licensing and royalty revenue are included in other in the statement of activities. Amounts received in advance of the performance period are recorded as deferred revenue.

LEASE COMMITMENTS

The Foundation is obligated under various operating leases for office space as of December 31, 2019. The approximate future minimum rental commitments, subject to escalation, are $44,738,000. The Foundation has entered into sublease agreements with tenants to occupy its former headquarters space. As of December 31, 2019, the approximate future minimum sublease rental payments due from sublease tenants are $3,340,000.

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with you by our side, *we won't stop* until CF stands for Cure Found

LAILA
AGE 10

Laila at the Great Strides walk in Chicago.

our focus is firmly on the future and the work that lies ahead.

CYSTIC FIBROSIS FOUNDATION®

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