CYSTIC FIBROSIS FOUNDATION®

YOUR IMPACT

The cystic fibrosis community has been an essential partner in the fight against CF for more than 65 years. We continue to make remarkable progress thanks to the steadfast support of thousands of CF champions around the country, like Angel, an adult with CF.

1955
1956
1957
1958
1959
1960
1961
1962
1963
1964
1965
1966
1967
1968
1969
1970
1971
1972
1973
1974
1975
1976
1977
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010
2011
2012
2013
2014
2015
2016
2017
2018
2019

2020 ANNUAL REPORT

“

When we started 65 years ago, no one had ever heard of this disease. I think the average lifespan then was 5 years old. **How unacceptable.** I turned to my family, to my friends, and I said, **‘We’ve got to go to work'…**

AND WE DID.

— **DORIS TULCIN,** FOUNDING PARENT

Dear Friends,

As we entered 2020, the Cystic Fibrosis Foundation looked forward to its 65th anniversary and celebrating more than six decades of transformative progress in the fight against CF – a journey which had reached new heights with the approval of Trikafta® just months before.

Building on that recent triumph, the Foundation set out our five-year strategic plan to chart the course for our next chapter. When the COVID-19 pandemic changed our way of life seemingly overnight, we refocused to ensure continued progress on our mission and found creative ways to advance our work in research, care, and community engagement. I am overwhelmed with pride and gratitude as I reflect on how the CF community responded to the challenges of last year.

There are many shining examples of how we met those obstacles head-on with the trademark grit and determination of the CF community, including the rapid shift to telehealth to ensure continuity of care, collaborating with our community to hold more than 950 virtual events to inspire and inform, and the continued progress in our pursuit of treatments and a cure for every person with CF.

In the past year, the Foundation funded more research into lifesaving treatments and care than ever before in our history, including significant investments in genetic-based therapies through our Path to a Cure. We also established innovative new strategies to draw the best science and technologies into CF. We celebrated the exciting results that many people with CF experienced in the first year following Trikafta's approval and laid important groundwork to address the changing needs of adults with CF.

We also confronted challenges unrelated to the pandemic, taking important steps to understand how race impacts life with CF and begin to address health disparities and build an inclusive community for every person with CF.

Despite the hardships of the past year, there is so much to celebrate.

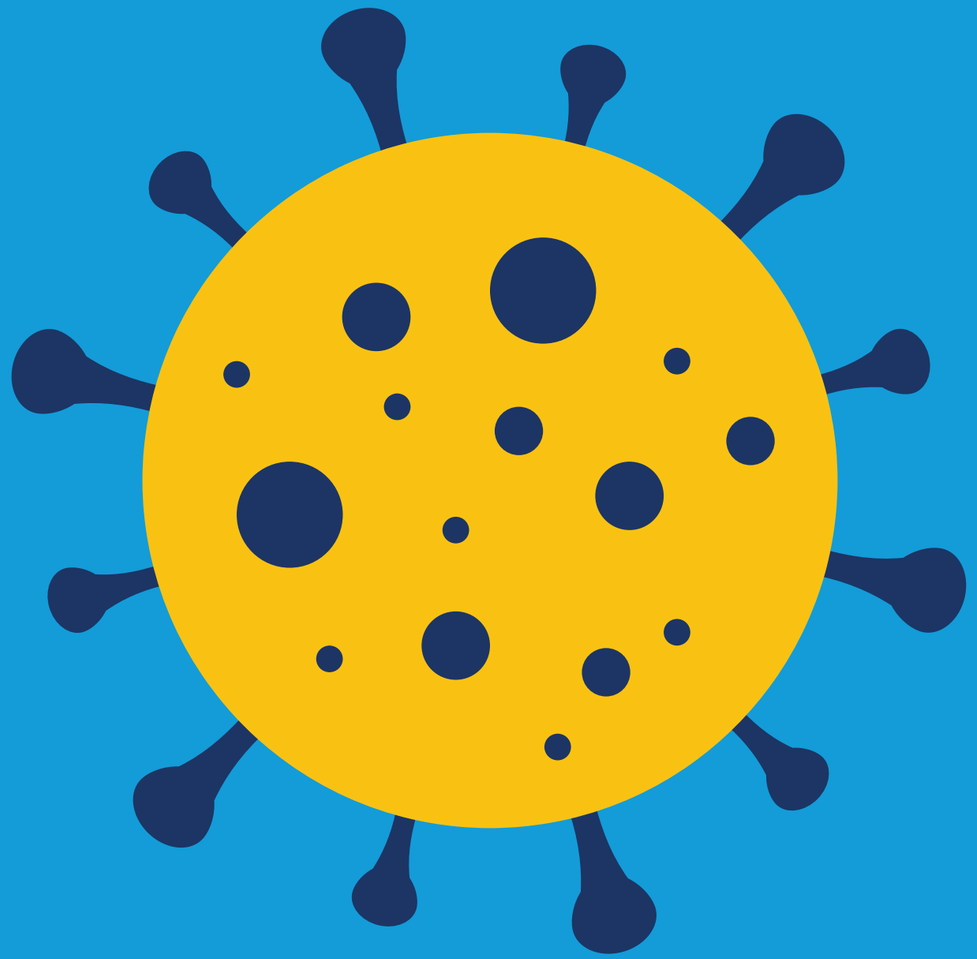
We came together as a community, more united than ever before. We advocated for people with CF and their families, chose connection over isolation, and kept sight of what really matters – meeting the urgent needs of people with CF today, while aggressively pursuing the breakthroughs of tomorrow.

As I write this, COVID-19 is still taking a toll on many communities in the U.S. and around the world, but we are beginning to see light at the end of the tunnel. In the face of uncertainty, our drive to find a cure and help all people with CF live long, fulfilling lives remains constant. Above all, I know that when we work together, we can overcome any challenge that comes our way – and we will emerge from the pandemic even stronger.

With gratitude,

Michael P. Boyle, MD
President and CEO

LOOKING BACK ON 2020



MEETING THE MOMENT

OUR RESPONSE TO COVID-19

At the start of 2020, the Cystic Fibrosis Foundation unveiled our vision for a new era in CF with the launch of a detailed five-year strategic plan. As concerns about a novel coronavirus grew, we quickly adjusted course to mount a response to this emerging threat – even as we continued to press forward on urgent priorities related to improving treatments and care for all people with CF. In February, weeks before COVID-19 infections spiked and cities and states began to lock down, the Foundation commenced an effort to help the CF community, clinicians, and researchers navigate what would soon become a worldwide pandemic. It was at that early stage we made the difficult decision to cancel all in-person events to protect the CF community and staff.

As months passed and the pandemic upended every aspect of daily life, we continually adapted to address emerging needs while remaining focused on our scientific mission. The Foundation established a mechanism to monitor and publish COVID-19 outcomes of people with CF; took important steps to preserve access to high-quality, specialized CF care; provided support for the practical and emotional challenges associated with life during the pandemic; and initiated new studies to better understand this novel disease – all while funding more research into lifesaving new therapies than at any other time in our history.

MEETING THE MOMENT

SAFEGUARDING THE HEALTH OF PEOPLE WITH CF

COVID-19 MEDICAL ADVISORY GROUP

⟶ The Foundation quickly convened a COVID-19 Medical Advisory Group made up of 29 CF clinicians, members of the CF community, and Foundation staff to discuss emerging information about the novel coronavirus, align on unique considerations for people with CF and care teams, and recommend actions to safeguard their health.

COVID-19 TOWN HALLS

⟶ The Foundation connected thousands of people with CF and their families with experts to help deal with the uncertainty of life during the pandemic, understand rapidly evolving public health guidelines, and make informed decisions about their health. Mental health professionals discussed proactive ways to maintain emotional well-being during a time of unprecedented anxiety at *Emotional Wellness and COVID-19*; *School Reopening and Cystic Fibrosis* focused on the uncertainty surrounding decisions related to in-person learning; and the *COVID-19 Vaccines Community Town Hall* explained the science behind authorized vaccines and demystified the allocation process.

7
NATIONAL VIRTUAL EVENTS ON COVID-19

1,650
QUESTIONS SUBMITTED

4,915
TOTAL ATTENDEES

As the pandemic continues, more information is needed to understand how people with cystic fibrosis may be infected by – or respond to – the novel coronavirus that causes COVID-19. In December, the Foundation committed $2.76 million to fund 11 studies that will evaluate CF and COVID-19.

CYSTIC FIBROSIS REGISTRY HARMONIZATION GROUP

⟶ The Cystic Fibrosis Foundation Patient Registry – established decades ago to identify trends related to the health status of people with CF – became an indispensable tool to inform CF care providers and the community about our evolving understanding of how COVID-19 affects people with CF in the U.S. The data collected enabled the Foundation to issue weekly reports on the latest data to CF care teams. The Foundation also helped lead the Cystic Fibrosis Registry Harmonization Group, an international collaboration established to monitor outcomes of adults and children with CF who contracted COVID-19. This global effort published three manuscripts in the *Journal of Cystic Fibrosis* that offered the first insights into the impact of COVID-19 on people with CF. While more data are needed, the findings painted a reassuring picture of outcomes for people with CF that was less severe than initially anticipated.

SPOTLIGHT

Noor · 31

Noor is a volunteer teacher who struggled with isolation during the pandemic. Living with family members who were essential health care workers meant she had to isolate even within her home to protect her health. In April, she discovered Beam, an online exercise, education, and well-being program for people with cystic fibrosis that the Foundation made available to people with CF at no cost throughout the pandemic. The experience also helped her become more involved with the CF community. In June, Noor led a FamilyCon session with her sister, Ella, about the power of resilience.

MEETING THE MOMENT

ENSURING CONTINUITY OF CARE

As care teams and people with CF weighed the risk of in-person clinic visits during the pandemic against the importance of regular monitoring and care, telehealth emerged as a critical vehicle for maintaining vital connections without risking exposure to COVID-19.

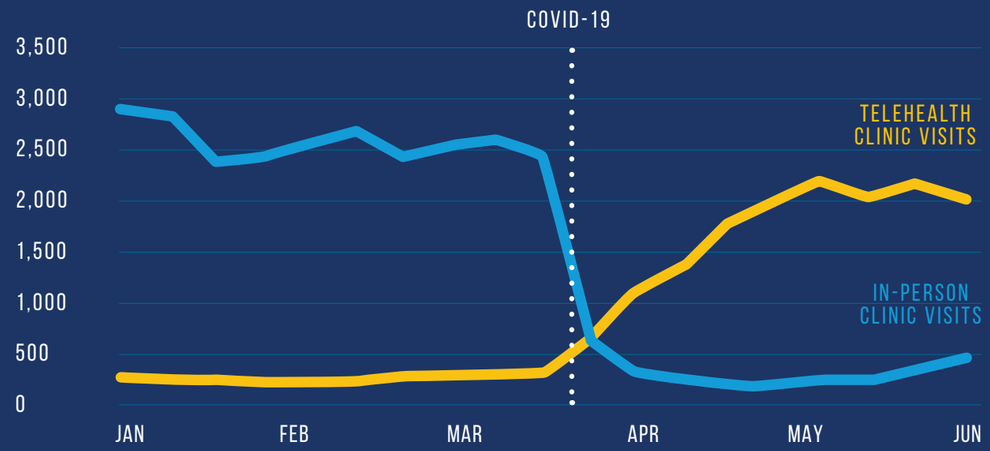
> **The Foundation advocated in all 50 states for changes to reimbursement and licensing policies to enable this shift. In addition, we funded and facilitated delivery of more than 17,000 home spirometers for patients and families across the country – ensuring that people with CF and their care teams could monitor pulmonary function, a key indicator of health, without an in-person visit.**

While people with CF faced heightened risks to their health due to COVID-19, CF care centers also grappled with new issues. Hospitals cut and furloughed skilled clinicians as the pandemic brought severe financial pressure to health systems across the U.S., and many care providers were redeployed to treat COVID-19 patients. The Foundation provided flexibility for centers to direct grant funding where resources were most urgently needed to support CF care, enabling care centers to continue a multidisciplinary team approach that incorporated mental health professionals and social workers as part of a patient's care team.

Conscious of the significant mental and emotional strain facing care teams working on the front lines, the Foundation offered events and resources to bolster mental health and well-being to help ensure those caring for others also had the tools to care for themselves. We continue to help address the mental health impacts of the pandemic through events focused on mental health, grants for mental health coordinators, and ongoing community support.

RAPID SHIFT TO TELEHEALTH

→ Telehealth visits across the CF care center network increased fivefold in 2020. This rapid adoption was aided by the CF Foundation's Telehealth Index, a continuously updated compendium of best practices related to remote care available to care teams, as well as robust advocacy in all 50 states for policies that would enable coverage of telehealth services. With its potential to reduce the significant financial and logistical burdens associated with regular in-person clinic visits, we expect that telehealth will continue to play a role in CF care long after the pandemic is over.



50
ADVOCATED FOR TELEHEALTH IN ALL 50 STATES

17,000
HOME SPIROMETERS

+400%
INCREASE IN TELEHEALTH VISITS

MEETING THE MOMENT

ADVOCATING FOR THE NEEDS OF THE CF COMMUNITY

Like countless Americans, many members of the CF community were forced to make the painful choice between placing their or their loved one's health at risk by going to work or losing their income altogether. The Foundation advocated to Congress for expanded paid leave, and CF advocates made their voices heard through constituent meetings and more than 31,000 messages to members of Congress about the need for this critical protection.

SPOTLIGHT

Kat · 39

Kat is an adult with CF who worked as a nurse practitioner in a surgical ICU in Tennessee. When her hospital unit began to reopen in June, she was faced with the prospect of returning to work after co-workers tested positive for COVID-19. Kat ultimately decided to quit her job to protect her health. She shared her story with The Tennessean to help bring attention to the struggle that people with CF and their families, as well as frontline workers everywhere, faced throughout the pandemic: how to return to work safely.

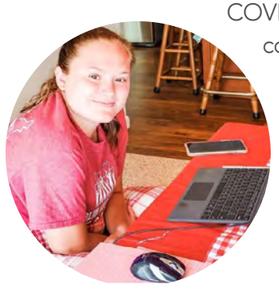
At the state level, the Foundation focused on preserving programs that people with CF and their families rely on for continued access to treatments and care. Fighting for these vital resources throughout the country will remain a priority as many states face budget issues that threaten Medicaid and state CF programs.

As vaccine development progressed, the Foundation urged policymakers to prioritize people with CF for COVID-19 vaccination, sending more than 50 letters to national and state health officials and ensuring rare disease expertise was represented on public health committees developing distribution frameworks. We also presented the community's needs in written and public testimony to the Center for Disease Control's Advisory Committee on Immunization Practices and the National Academy of Medicine.

As we advocated for these and other pandemic-related issues with lawmakers, CF Foundation *Compass* case managers fielded more than 9,000 calls to help individual members of the CF community deal with the financial and logistical hardships related to COVID-19 as well as ongoing needs associated with CF.

TEEN ADVOCACY DAY

⟶ This year, Teen Advocacy Day went virtual, enabling teens with CF to join their family and friends in advocating for the first time ever. Sydney Willig was among the 100 young people with CF who made their voices heard in 2020. Sydney's parents had to return to in-person work during the COVID-19 pandemic so Sydney could continue taking Trikafta, despite the risk that COVID-19 infection posed to their daughter. She shared her story with members of Congress to help advocate for expanded Family and Medical Leave.



COMPASS

⟶ *Compass* case managers helped address 9,000 calls on issues including:

Financial Hardship

Connected callers with national and local resources to help alleviate financial burdens.

Food Insecurity

Received specialized training to connect families with food assistance programs.

Health Insurance Coverage

Helped people with CF and their families compare available health insurance plans.

MEETING THE MOMENT

COMING TOGETHER AS A COMMUNITY

"Social distancing" became fundamental to containing the pandemic, with billions of people around the globe now experiencing one of the major difficulties many people with CF face every day – how to maintain relationships with friends and loved ones from a distance.

While virtual events were already a mainstay of life with CF, the pandemic prompted remarkable ingenuity as people with CF sought ways to stay connected, support one another, and raise funds to advance the Foundation's mission.

The Foundation and community held more than 950 virtual events and raised more than $73 million for the fight against CF, demonstrating the CF community's talents and commitment to connecting with one another and fueling our shared mission as they weathered the pandemic.

GRAMPIONS STORY TIME

CF Grampions – "grandparent champions" who are passionate about helping people with CF live their best lives – knew that families with young children needed a little brightness during the pandemic. Story Time, born in the kitchen of Martin and Annelle Tanner of Alexandria, La., was initially planned as a one-time event but has grown into a bi-weekly series with themes, costumes, and even magic tricks. These virtual gatherings have garnered hundreds of views and at least that many smiles – and have inspired other Grampions to host story times of their own.

HAPPINESS HOUR

At the very beginning of nationwide lockdowns, the Foundation's Adult Advisory Council made it their mission to bring a little bit of joy into people's lives during an otherwise unsettling time. The Council rallied together for a Happiness Hour – a virtual event organized by adults with CF. These informal events complemented other points of connection for people with CF, including the annual BreatheCon and ResearchCon virtual meetings.

ROSE UP

Adults with CF encouraged the community to ROSE UP for CF through a new virtual fundraising initiative. Inspired by the strength of the CF community, the event raised money and awareness by encouraging people to support the Foundation's mission in ways that reflected their unique passions and creativity. Created and led by a planning committee including Marissa Benchea, Somer Love, and KC White, more than 1,300 people across the CF community participated, raising more than $100,000. Highlights included Nick Kelly, an adult with CF who danced to a poem he wrote called "Fighter."

GET SALTY COMEDY SHOW

Tomorrow's Leaders are young professionals who are passionate about making a difference for people with CF. The *Get Salty* comedy show, a star-studded event typically held at a club in L.A., was reimagined this year as the 2020 Tomorrow's Leaders National Signature Event. During the virtual comedy show hosted by Richelle Meiss, a Foundation volunteer and sister of a person with CF, a celebrity line-up performed at a studio in L.A. in front of an interactive screen of Foundation donors. The CF community raised $53,000 during this special event.

MAINTAINING THE MOMENTUM

PROGRESS IN RESEARCH AND CARE

While COVID-19 tested the strength of the CF community in new and unexpected ways, we continued our work to advance the next generation of transformative CF therapies and address the most pressing needs facing people with CF today.

As we look toward the future, it is clear that we have entered a new era in CF. Trikafta has had a profound impact on the health of people with CF in the first year following its approval, and today more people than ever before are on a highly effective modulator. Yet progress comes with new challenges, as people with CF increasingly face complications associated with their disease and many people with CF are still waiting for their breakthrough.

RESEARCH WE FUND

Top research priorities in 2020 included progressing treatments for the underlying cause of disease for all people with CF, addressing the manifestations of CF – including infections, CF-related diabetes, GI and liver complications, and others – and understanding the impact of highly effective modulators.

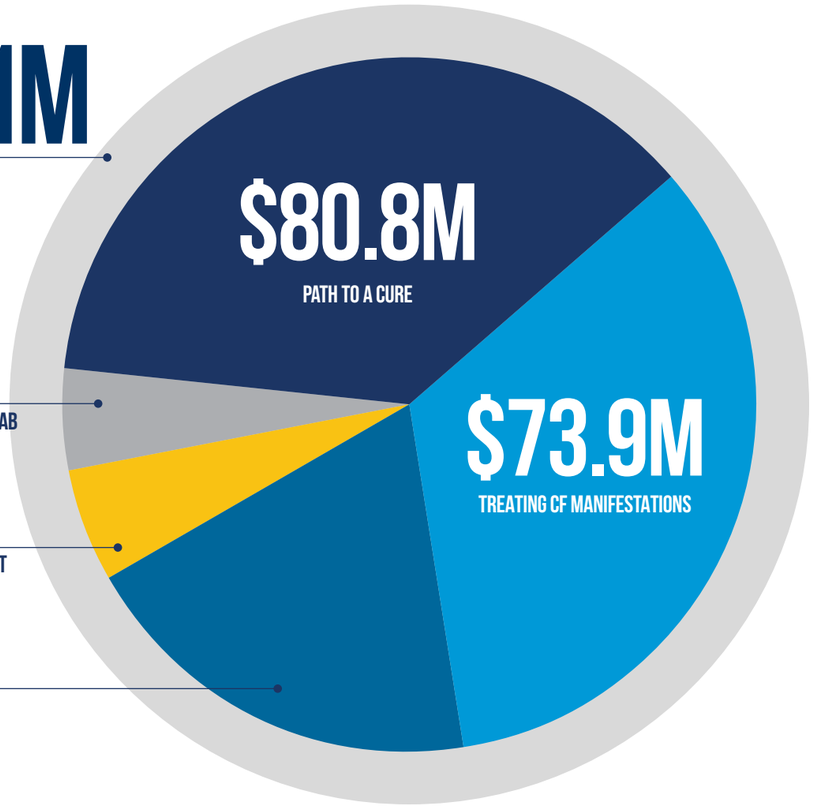
The Foundation provided $258 million of funding for research and care, including work at the CF Foundation Therapeutics Lab – more than at any other time in our history.

$218.1M
TOTAL INVESTMENT ACROSS OUR RESEARCH PORTFOLIO

$10.1M
CF FOUNDATION THERAPEUTICS LAB

$11.3M
LABORATORY RESEARCH SUPPORT

$42M
CLINICAL RESEARCH SUPPORT



TREATING CF MANIFESTATIONS

As people with CF live longer, they face increasingly complex manifestations of their disease. The Foundation is committed to accelerating new treatments that are needed today, as we pursue tomorrow's cure.

Funding for Research into CF Manifestations — $73.9M
380 studies total

- **Infection** — $34.4M
  162 studies
- **Inflammation** — $11.1M
  30 studies
- **Mucus & Airway Hydration** — $4.6M
  43 studies
- **Digestive System** — $7.1M
  Nutrition, liver disease, GI
  33 studies
- **Endocrine** — $3.1M
  CFRD, bone, reproductive health
  31 studies
- **Advanced Lung Disease** — $8.4M
  Pulmonary exacerbations, lung microbiome, lung disease progression
  43 studies
- **Other** — $5.2M
  38 studies

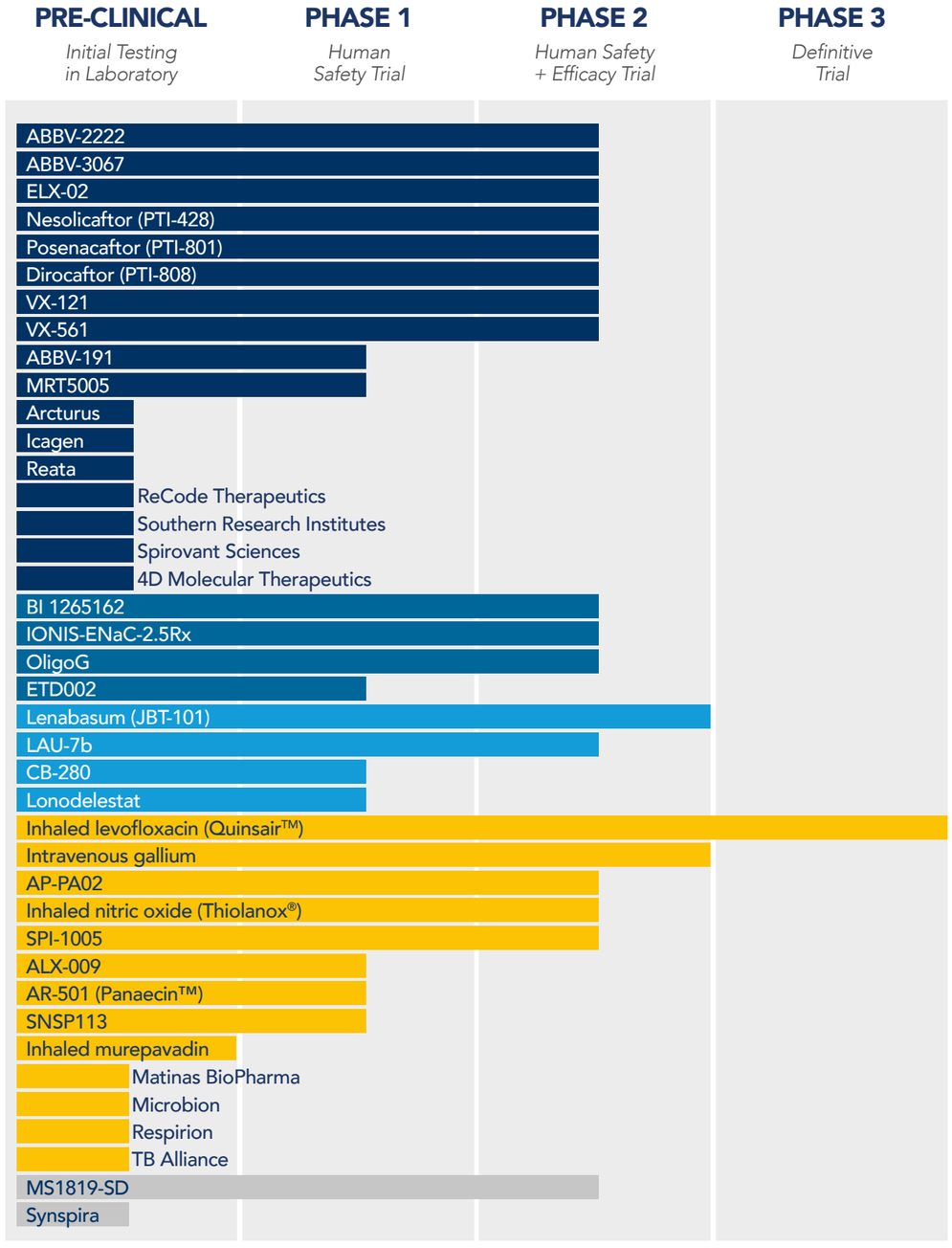
DRUG DEVELOPMENT PIPELINE

CF drug development continued to progress in 2020. Four programs for complications entered the clinic, while three others moved closer to pivotal studies and a new therapy for CF was approved by the U.S. Food and Drug Administration: Bronchitol®, a treatment to help thin sticky mucus in the lungs. Other highlights include the initiation of the first-ever controlled clinical study of phage treatment for CF and new preclinical programs to explore treatments that will benefit all people with CF regardless of their mutations – including an ongoing Phase 1 study of mRNA therapy.

2020 PIPELINE PROGRESS

Restore CFTR Function	• **ABBV-191** (AbbVie) added in preclinical and advanced to Phase 1
Mucociliary Clearance	• **INHALED MANNITOL (BRONCHITOL) APPROVED** • **ETD002** (Genentech) advanced from preclinical to Phase 1
Inflammation	• **CB-280** (Calithera) added in Phase 1
Infection	• **Matinas BioPharma** added in preclinical • **Microbion** added in preclinical • **Inhaled Murepavadin** (Polyphor) added in Phase 1 • **AP-PA02** (Armata) added in Phase 2 • **Intravenous Gallium** (CF Foundation) advanced through Phase 2
Nutrition/GI/Other	• **Non-porcine enzyme replacement** (Synspira) added in preclinical

To advance drug development and a search for a cure, the Cystic Fibrosis Foundation (CFF) has contracts with several companies to help fund the development of potential treatments and/or cures for cystic fibrosis. Pursuant to these contracts, CFF may receive milestone based payments, equity interests, royalties on the net sales of therapies, and/or other forms of consideration. Resulting revenue received by CFF is used in support of our mission. See "How Drugs Get on the Pipeline" at **www.cff.org/howdrugsgetonthepipeline** for more.



As of December 31, 2020. To view the current pipeline, visit **cff.org/trials/pipeline**

Bronchitol is a registered trademark of Pharmaxis, Ltd. Thiolanox is a registered trademark of Novoteris, LLC. Quinsair is a trademark of Horizon Orphan LLC. Panaecin is a trademark of Aridis Pharmaceuticals Inc.

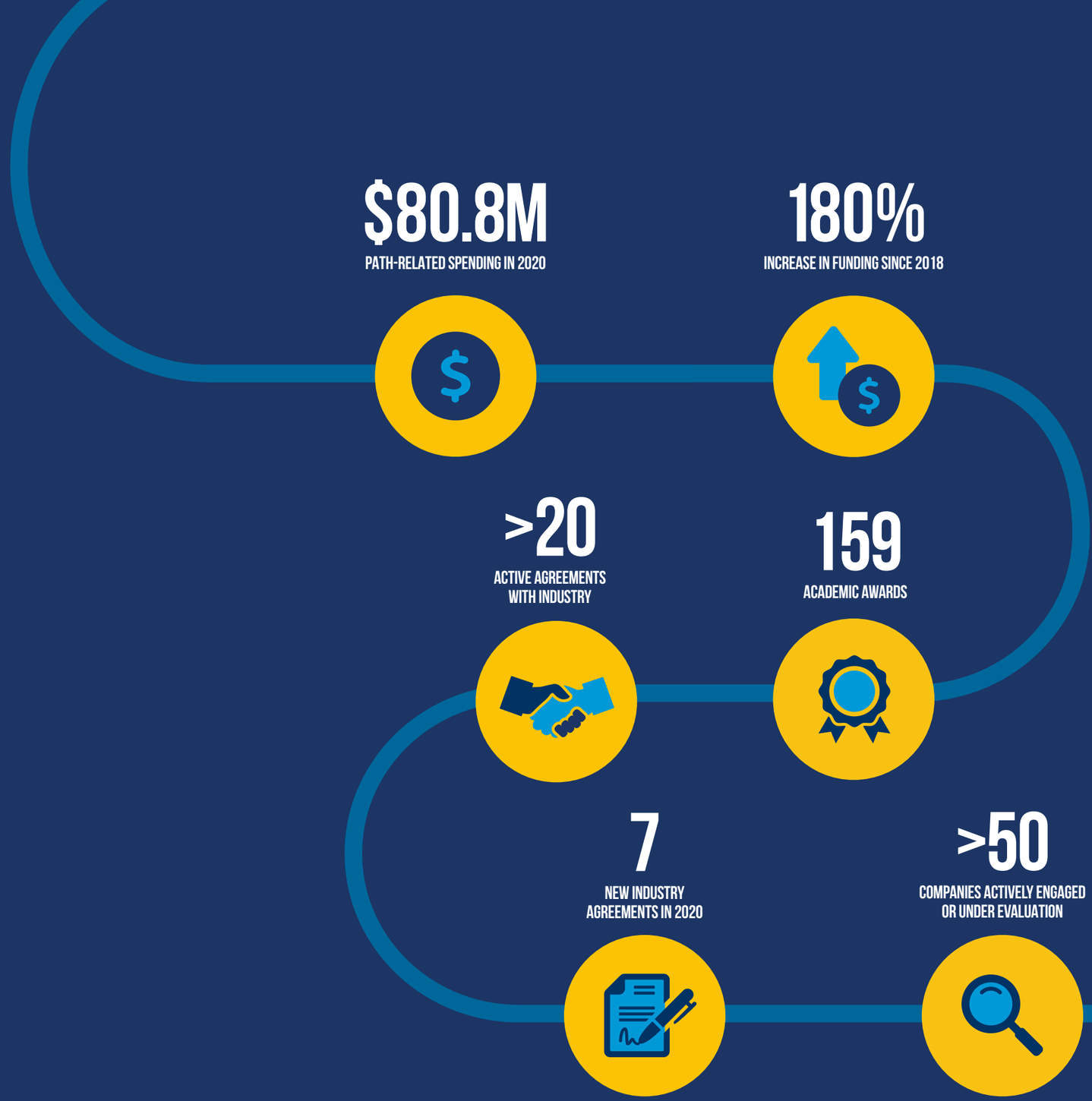
PROGRESSING OUR PATH TO A CURE

The CF Foundation's $500 million Path to a Cure centers on 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 to address the root cause of CF. Each approach requires a different set of scientific tools and knowledge. The Foundation is using its resources to bring researchers and industry leaders from a range of disciplines together to advance multiple areas of research in parallel.

CONTINUING TO INNOVATE THROUGH VENTURE PHILANTHROPY

→ The CF Foundation's pioneering venture philanthropy model spurred the development of almost every medicine approved to treat CF, adding decades of life for people with CF and transforming the role that people with CF play in driving medical and scientific breakthroughs. In 2020, the Foundation took important steps to adapt and evolve our approach in order to bring new scientific minds and technologies into CF.

In August, the Foundation announced a collaboration with Longwood Fund, a biotech-focused venture capital firm. Together, we established a CF-focused incubator to build companies from the ground up that prioritize the needs of people with CF. This approach will enable the Foundation to play a more active role in shepherding promising early technologies from academia to industry and bringing companies into CF earlier in their formation.

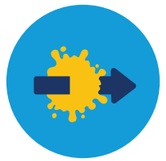


ADDRESSING THE CHALLENGES ASSOCIATED WITH GENE DELIVERY

Delivery is a critical component of potential gene editing or gene replacement therapies, ensuring that healthy genes or gene editing tools can be delivered to the correct cells. Developing an effective delivery method remains one of the biggest hurdles in advancing treatments for all people with CF because of the lungs' aggressive defense mechanisms. In 2020, we entered into agreements with three companies pursuing novel strategies to deliver a healthy CFTR gene into the lungs of people with CF.

4D Molecular Therapeutics

Customized gene delivery vehicle that is uniquely able to target cells in the lung.



enGene Inc.

Non-viral approach to make gene delivery vehicles more effective at penetrating mucus.

Splice Bio

Platform capable of modifying gene therapy delivery vehicles to better target specific cells.

SPOTLIGHT

Sapphire + Emerald · 3

Sapphire and Emerald are identical twins, who are bubbly and full of life – never missing an opportunity to sing and dance in their family's kitchen. Both have nonsense mutations, which means they are still waiting for treatments to address their underlying mutations. The Foundation announced its Path to a Cure for Sapphire, Emerald, and others with CF who are still waiting for a breakthrough. We will not stop until we reach our goal.

ADVANCING NEW STRATEGIES TO ADDRESS INFECTIONS

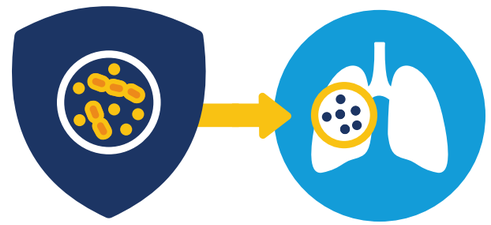
Chronic, hard-to-treat infections remain a daily challenge for most people with CF – more than 60% of people with CF culture positive for at least one microorganism even at a very young age; that figure climbs to nearly 80% among adults with CF. The treatment landscape for infections is becoming more challenging as antimicrobial resistance (AMR) increases. The Foundation is allocating significant resources to combat this issue in the lab, in the clinic, and on Capitol Hill.

> **Since launching the Infection Research Initiative in 2018, the Foundation has awarded more than $79 million for infection-related research, including more than 120 awards in 2020 to understand and improve outcomes for difficult-to-treat infections. As research develops and promising science comes into reach, we are prepared to go further.**

In addition to research funding, the Foundation has become a leading voice in conversations about antimicrobial resistance. In July, President and CEO Michael Boyle, MD, spoke alongside international scientific and industry leaders to help launch the global AMR Action Fund, a collective venture expecting to invest over $1 billion into development of novel antibiotics.

NOVEL APPROACHES TO COMBAT ANTIMICROBIAL RESISTANCE

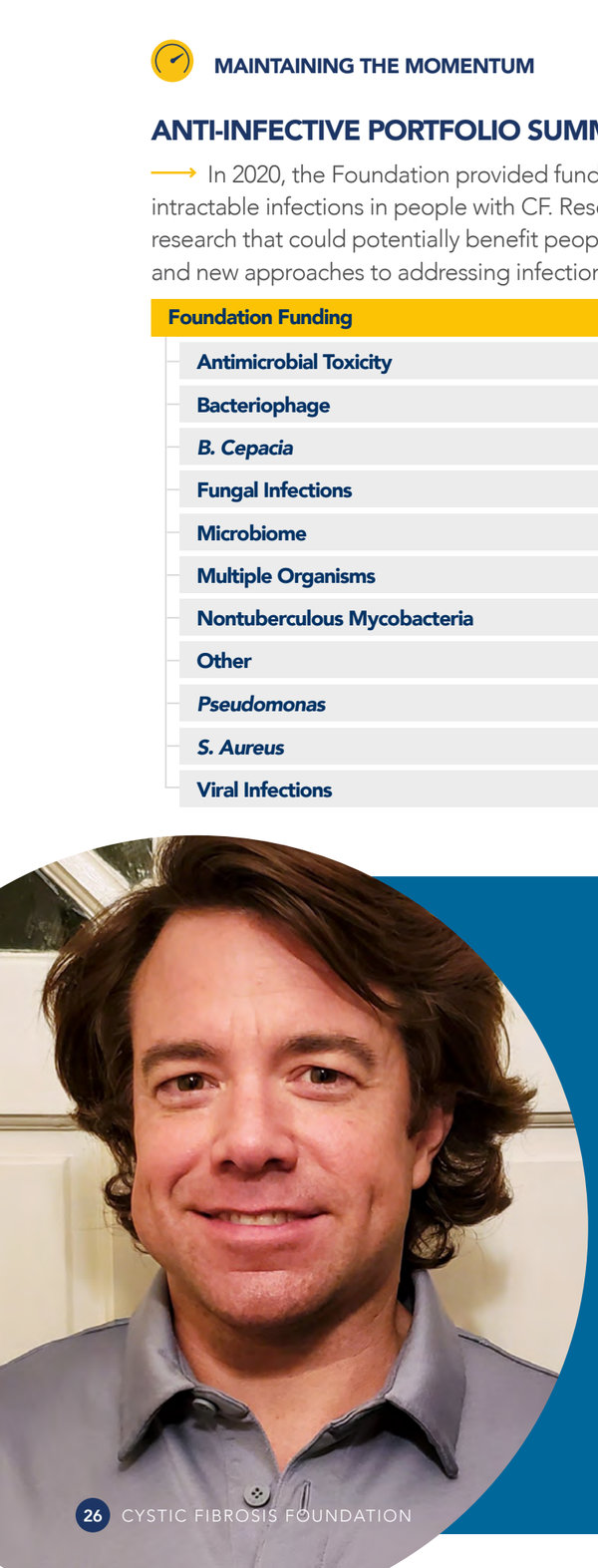
Antimicrobial resistance to many standard treatments has increased the need for research into new types of therapies. This year, the Foundation funded the first-ever controlled clinical study in CF of phage therapy – specialized viruses that kill very specific bacterial strains.



ANTI-INFECTIVE PORTFOLIO SUMMARY

In 2020, the Foundation provided funding for 162 studies to address chronic and intractable infections in people with CF. Research topic areas include pathogen-specific studies, research that could potentially benefit people who culture for multiple types of organisms, and new approaches to addressing infection:

Foundation Funding	162 studies total
Antimicrobial Toxicity	1 study
Bacteriophage	8 studies
B. Cepacia	7 studies
Fungal Infections	4 studies
Microbiome	1 study
Multiple Organisms	30 studies
Nontuberculous Mycobacteria	30 studies
Other	5 studies
Pseudomonas	59 studies
S. Aureus	8 studies
Viral Infections	9 studies



SPOTLIGHT

Seth · 38

For more than 20 years, Seth has been fighting pseudomonas infections – with some more resistant to antibiotics than others. When he found a treatment that worked for him for a particular strain, he developed an allergy that forced him off the medication. In addition to funding critical research into potential new infection treatments for people like Seth, the Foundation is urging policymakers to invest in solutions to ensure access to antibiotics that work both now and in the future.

IMPROVING TREATMENT OPTIONS FOR ADVANCED DISEASE

As people with CF continue to live longer, their needs are becoming more varied and complex. The Foundation continues to expand its research into manifestations, including CF-related diabetes, gastrointestinal issues, and sinus disease. This work also includes efforts to standardize and optimize care for individuals with advanced lung disease, such as the publication of guidelines focused on improving quality of life and survival. These recommendations were developed over a period of two years by a multidisciplinary team convened by the Foundation.

LUNG TRANSPLANT INITIATIVE

A cornerstone of these efforts remains our Lung Transplant Initiative – a comprehensive effort established in 2016 to maximize the opportunity for transplant as a life-sustaining therapy and extend post-transplant survival for people with CF. We continued to invest in the research support and infrastructure needed to improve the transplant journey for hundreds of people with CF each year, including designating Cleveland Clinic as a Biorepository Coordinating Center – a center that will store samples contributed by sites in the U.S. and Canada – and building a patient registry of lung transplant recipients to store clinical data related to the stored samples. These samples and data will be used to help better understand mechanisms and risk factors associated with chronic lung allograft dysfunction, the most common, life-limiting post-transplant complication related to organ rejection.

Additionally, more than 40 CF care centers have been working with lung transplant centers to improve communication, education, and relationships – ultimately improving the transplant journey for people with CF.

MAXIMIZING THE IMPACT OF CFTR MODULATORS

CFTR modulators continue to transform daily life for many people with CF. To help those eligible for modulators live even healthier lives, we are supporting continued research into additional therapeutic options and broader access to currently approved therapies.

UNDERSTANDING THE REAL-WORLD IMPACT OF MODULATORS

→ To help ensure people with CF and their care providers know as much as possible about Trikafta, we are currently supporting several large clinical studies that will assess the longer-term impact of this important new therapy.

PROMISE

Explore effects on lung function, GI symptoms, pancreatic function, diabetes, and other manifestations of CF.

SIMPLIFY

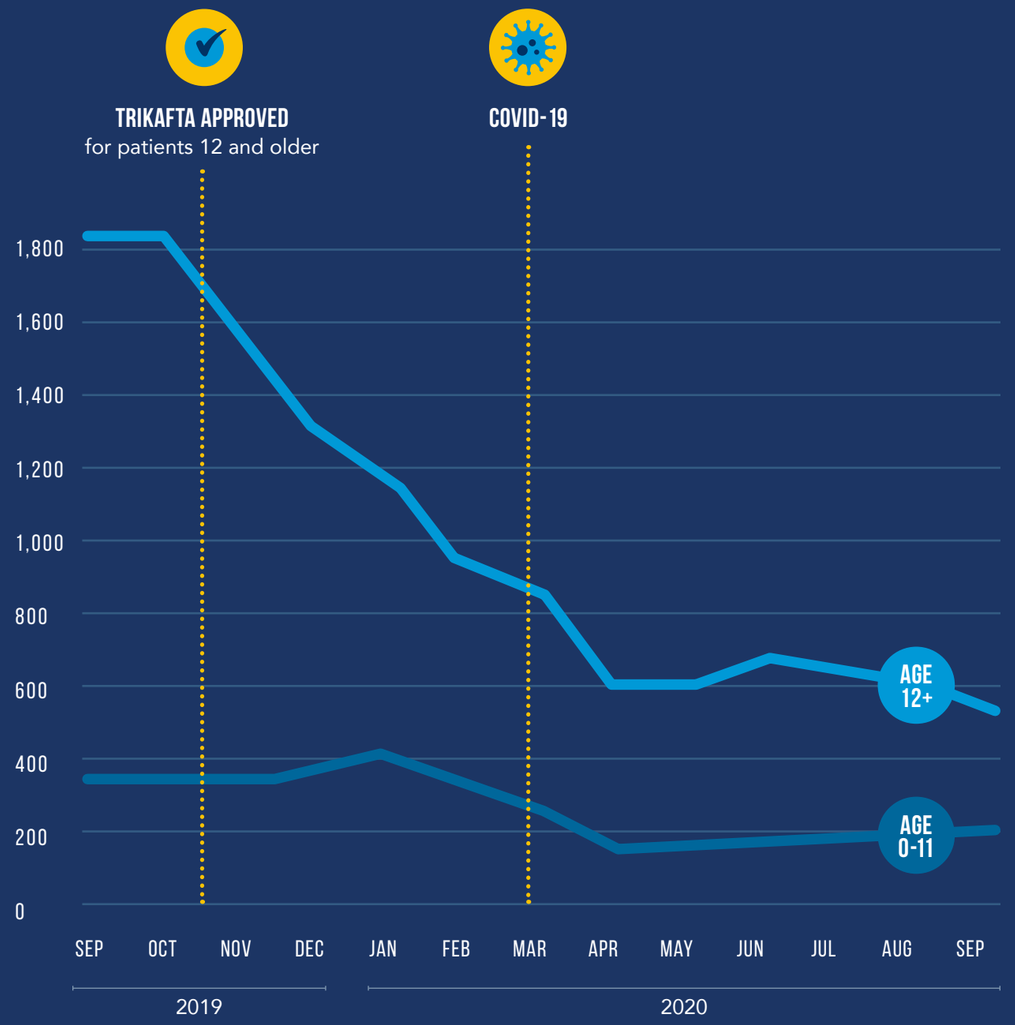
Determine if it is possible to safely reduce the daily treatment burden of CF.

BEGIN

Evaluate the ongoing impact of modulators on young children and infants.

TRIKAFTA MAKES AN IMPACT

→ Highly effective CFTR modulators are known to have a transformative effect on the health and wellbeing of many people with CF. In the future, expanding access to younger ages may have an even bigger impact in slowing or preventing irreversible lung damage. We observed a marked drop in the number of IV-treated pulmonary exacerbations in the year following the approval of Trikafta.



BRINGING MODULATORS TO MORE PEOPLE WITH CF

→ **September** | **FDA approved access to Kalydeco®** for infants as young as 4 months with certain mutations. Early access to modulator therapies may help slow – or even prevent – the irreversible progression of cystic fibrosis, dramatically altering the course of the disease over time.

→ **December** | **FDA expanded its approval of Kalydeco, Symdeko®, and Trikafta** to include 183 additional rare mutations, enabling more than 600 people with CF to access treatments for the underlying cause of their disease for the first time.

SPOTLIGHT

Hillary · 25

In the year since its approval, Trikafta has fundamentally changed the lives of so many people with CF. That could not have been more true for Hillary. Less than two months after starting Trikafta, Hillary found out that she was pregnant. She gave birth to her son, Christian, in 2020.

ADDRESSING HEALTH DISPARITIES AND BUILDING AN INCLUSIVE COMMUNITY

The Foundation took important steps to better understand and acknowledge the profound impact that race and ethnicity have on all aspects of the CF experience. According to the CF Foundation Patient Registry, approximately 15% of people with CF are Black, Hispanic, or other people of color. These individuals are more likely to receive a late diagnosis, are underrepresented in clinical studies, are less likely to have a modulator therapy approved for their mutations, and are at increased risk of poor outcomes from CF and following a transplant. We are focused on engaging and listening to Black members of the CF community and other people of color with CF, like Lauren, 22:

> **"Black people's voices have struggled to be heard for years, especially in the medical field. More than ever before, I think it is extremely important for the CF community to be educated about different races and cultures that are affected by CF. All our stories deserve to be heard."**

We are also working with leading researchers to address these health disparities and build an inclusive community for all people with CF. Early efforts to acknowledge and celebrate diversity within CF included awarding an Impact Grant to the National Organization of African Americans With Cystic Fibrosis, focusing on inclusivity and community at BreatheCon 2020, and supporting a symposium on culturally competent CF care at the North American Cystic Fibrosis Conference.

MARKING THE MILESTONE

65 YEARS OF PROGRESS IN CF

The Cystic Fibrosis Foundation has led the way in the fight against CF for 65 years. Working alongside the CF community, we have invested billions of dollars into research and care, fostered the development of more than a dozen CF treatments, and helped add decades of life for those living with this disease. Together, we are transforming the day-to-day reality of CF for many people with this disease and providing the CF community with more hope than ever before.

To celebrate our collective impact throughout the first 65 years of our mission, and to raise funds to further accelerate our progress, we launched the 65 Roses Challenge: a broad-reaching fundraising effort with a goal of raising $65 million – an audacious aim in a year when the full financial impact of the pandemic was still unknown. Through hundreds of virtual events and programs – including virtual Great Strides walks, climbs, cycles, and galas; Chapter Board Challenges; passion fundraisers throughout the CF community; and individual gifts and corporate sponsorships – we surpassed this bar, raising $73 million and bringing us closer to a cure for every person with this disease. Hundreds of members of the CF community joined Together: Now, an online celebration to launch this effort; and our Breath of Life Celebration to mark its success.

All of our progress in 2020 – and in the 65 years prior – was made possible through the support of the CF community. Your support and partnership will continue to be vital as we continue in our shared mission to make CF stand for Cure Found. Thank you.

1955 1956 1957 1958 1959 1960 1961 1962 1963 1964 1965 1966 1967 1968 1969 1970 1971 1972 1973 1974 1975 1976 1977 1978 1979 1980 1981 1982 1983 1984 1985 1986 1987

0 FDA-Approved Therapies

0 Medicines in the Pipeline

$0 Funding For Research

NO Specialized Care

NO Hope

THEN

IT ALL STARTED IN 1955 WITH PARENTS WORKING TOGETHER

⟶ Since then, we have effectively transformed a genetic disease in a single generation, making CF one of the most amazing stories in medicine.

1988 1989 1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020

16 FDA-Approved Therapies

40 Treatments in the Pipeline

BILLIONS Invested Into Research + Care

130+ Accredited Care Centers

56% Of People With CF Are Adults

NOW

YOUR IMPACT DRIVES US ONWARD TOWARD A CURE

⟶ Our most important work is still ahead. Together we'll make CF stand for Cure Found.

CORPORATE SUPPORTERS

Curing cystic fibrosis and caring for people with CF is a community effort and takes many resources. We are grateful for the generosity of our National Corporate Champions, who provide direct support of $100,000 or more to support our search for the cure and efforts to improve the lives of people with CF.

Platinum

American Airlines

Gold

AbbVie | Choate

Silver

BJ's Restaurants, Inc.
Genentech, Inc.
Gilead Sciences
Seibels
Snellings Walters Insurance Company
Vertex Pharmaceuticals

Bronze

- Alaska National Insurance Company
- Alliance RX/Walgreens
- Bank of NY Mellon
- CARSTAR
- Chiesi USA
- Citigroup
- Costco Wholesale
- Corbus Pharmaceuticals
- Deloitte
- Duke Energy
- FedEx
- G2 Secure Staff
- Hyatt Hotels
- Mastercard International
- MC Companies and Sharing the Good Life Foundation
- Merrill A Bank of America Company
- Quantum
- Samsung Electronics
- Sprint
- Tito's Handmade Vodka
- Truist Bank
- UPMC/UPMC Health Plan
- Valvoline Instant Oil Change
- Viatris
- Wells Fargo

SPOTLIGHT

American Airlines

Since its inception, American Airlines Celebrity Ski has helped raise more than $42 million to support the pursuit of a cure for cystic fibrosis. 2020 marked the 35th anniversary of this hallmark event, which raised $1.3 million. This was the last time we gathered as a community before masks and social distancing became the norm, making memories of the gathering even more special.

BOARD OF TRUSTEES AND CORPORATE OFFICERS

TRUSTEES AND ADVISORS

Catherine C. McLoud
Chair

Michael L. Beatty, Esq.
Nonvoting, Leadership Council Chair

Jessica H. Boyd, MD, MPH

Michael P. Boyle, MD

James R. Butler, II
Nonvoting, Advisor

Dominic J. Caruso
Nonvoting, Advisor

Louis A. DeFalco
Vice Chair

Teresa L. Elder

Richard J. Gray, Esq.
Vice Chair

Carole B. Griego, MD

Susan L. Hook

Peter J. Mogayzel Jr., MD, PhD
Nonvoting, CF Care Center Representative

Chad T. Moore

David A. Mount
Treasurer

Robert H. Niehaus
Vice Chair

Eric R. Olson, PhD

Eric C. Schneider, MD
Nonvoting, Advisor

Steven Shak, MD

Eric J. Sorscher, MD
Nonvoting, Medical Advisory Council Chair

Theodore J. Torphy, PhD
Vice Chair

Doris F. Tulcin
Nonvoting, Chair Emeritus

John S. Weinberg
Executive Vice Chair

Paul W. Whetsell

KC Bryan White
Adult Advisory Council Chair

CORPORATE OFFICERS

Michael P. Boyle, MD
President and CEO

Marc S. Ginsky
Executive Vice President and COO

Vera H. Twigg
Executive Vice President and CFO

As of December 31, 2020

STATEMENTS OF FINANCIAL POSITION

Condensed Financial Information*
As of December 31, 2020 and 2019

	2020	2019
ASSETS		
Cash and cash equivalents	$ 69,557,739	$ 69,364,201
Investments	5,201,460,415	4,331,314,555
Program-related investments	26,512,601	–
Due from investment managers	11,155,925	29,206,032
Receivables, net	47,664,844	29,154,940
Other assets	5,799,425	6,356,702
Fixed assets, net	7,848,712	11,114,652
Total assets	**$ 5,369,999,661**	**$ 4,476,511,082**
LIABILITIES AND NET ASSETS		
Accounts payable and other liabilities	$ 34,541,037	$ 42,933,110
Awards payable	236,465,610	196,869,140
Total liabilities	**271,006,647**	**239,802,250**
NET ASSETS		
Without donor restrictions	5,089,568,156	4,226,469,269
With donor restrictions	9,424,858	10,239,563
Total net assets	**5,098,993,014**	**4,236,708,832**
Total liabilities and net assets	**$ 5,369,999,661**	**$ 4,476,511,082**

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

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, 2020 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, 2020 were $2,156,142,525 in Level 1 assets, $1,538,236,334 in Level 2 assets, and $8,307,617 in Level 3 assets. Level 2 assets include $44,675,709 which are part of cash equivalents in the statement of financial position. Investments totalling $1,569,962,249, which are measured at fair value using net asset value as a practical expedient, have not been categorized in the fair value hierarchy.

PROGRAM-RELATED INVESTMENTS

The Foundation makes program-related investments in companies with cystic fibrosis-related projects. These include direct equity investments, investments in equity funds, and a convertible promissory note. Equity investments are stated at fair value using quoted market prices or net asset value (NAV) as a practical expedient. The promissory note is recorded at net realizable value and included in receivables, net on the statement of financial position. There are unfunded capital commitments of $32,265,356 related to program-related investments.

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 renewal criteria at the beginning of each award period. Awards are expensed at the time the Foundation unconditionally commits to fund the grant or, for those contracts with measurable performance milestones, when the milestone has been met. As of December 31, 2020, in addition to awards payable, the Foundation has medical scientific grant commitments of approximately $117,387,000 which extend through 2026. 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 $123,444,000. 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, 2020 are $3,751,646,058. 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

Condensed Financial Information*
For the years ended December 31, 2020 and 2019

	2020	2019
REVENUE		
SUPPORT RECEIVED FROM THE PUBLIC		
Special event revenue	$ 48,066,235	$ 96,255,420
Direct benefit expenses	(3,754,416)	(15,820,602)
Net special event revenue	44,311,819	80,434,818
General contributions	28,976,537	28,586,267
Total support received from the public	73,288,356	109,021,085
Proceeds of sale of intangible rights under drug discovery agreement	571,461,652	–
Other	50,042,692	55,976,109
Total revenue	**694,792,700**	**164,997,194**
EXPENSES		
PROGRAM SERVICES		
Medical programs	282,175,539	245,607,343
Public and professional information and education	24,580,646	17,584,009
Community services	20,822,084	22,103,810
Total program services	**327,578,269**	**285,295,162**
SUPPORTING SERVICES		
Management and general	23,803,901	25,897,119
Fundraising	21,579,521	28,709,962
Total supporting services	**45,383,422**	**54,607,081**
Total expenses	**372,961,691**	**339,902,243**
Increase (decrease) in net assets from operations	321,831,009	(174,905,049)
OTHER CHANGES IN NET ASSETS		
Net nonoperating investment income	540,453,173	636,250,409
Increase in net assets	$ **862,284,182**	$ **461,345,360**

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

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 interest and dividends and realized and unrealized gains or losses on nonoperating and program-related 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 donor-restricted support, 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 and2) the associated performance obligation has been satisfied. Licensing and royalty revenue are included in other revenue in the statement of activities. Amounts received in advance of the performance period are recorded as deferred revenue.

The Foundation retains legal rights to milestone payments and/or revenue generated by intellectual property developed under certain scientific grants and drug discovery agreements. At times, the Foundation may sell these 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 October 2020, the Foundation entered into an agreement to sell its rights to future revenue under a drug discovery agreement. Net revenue from the transaction was $571,461,652, which consists of gross proceeds of $575,000,000, net of $3,538,348 of transaction costs. The net proceeds from the transaction are classified in operating activities on the statement of cash flows.

LEASE COMMITMENTS

The Foundation is obligated under various operating leases for office space as of December 31, 2020. The approximate future minimum rental commitments, subject to escalation, are $37,947,000. The Foundation has entered into sublease agreements with tenants to occupy its former headquarters space. As of December 31, 2020, the approximate future minimum sublease rental payments due from sublease tenants are $2,509,000.

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.