ENTERING a new era IN CF
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.
MADDE
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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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
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)
effectively transformed a genetic disease in a single generation, making CF the greatest story in medicine.

together, we have

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.
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.

WILL
AGE 22

Will is passionate about wildlife – he just completed his thesis on research into big cats. Will’s dream for the future is that, someday, CF can be cured as soon as someone is diagnosed, so no one must suffer through it. The Foundation is investing in our Path to a Cure to help make this dream come true.
PATH TO A CURE
many routes, one mission

START HERE
MUTATED CFTR GENE

WHAT DO WE NEED TO FIGURE OUT?

REPAIR CFTR PROTEIN
RESTORE CFTR PROTEIN
FIX OR REPLACE CFTR GENE

GENE EDITING
GENE TRANSFER

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

WHAT’S THE PLAN?

WHAT’S THE PLAN?
WHAT’S THE PLAN?

CFTR MODULATORS
NONSENSE-SPECIFIC TREATMENTS
MRNA THERAPY
SHORT NUCLEOTIDE THERAPIES

OUR WORK CONTINUES...

TARGET THE CORRECT CELLS

DELIVER DNA

SPECIFIC ORGANS
ENTIRE BODY

DURATION
DELIVERY ROUTE
VEHICLE

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

CF STANDS FOR CURE FOUND

CF T STANDS FOR CURE FOUND

FOCUSING ON THE FUTURE • 21
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.

<table>
<thead>
<tr>
<th>Research Area</th>
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<tr>
<td>TREATING CF MANIFESTATIONS</td>
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<td>NONSENSE AND RARE MUTATIONS</td>
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<td>CLINICAL RESEARCH SUPPORT</td>
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<td>LABORATORY RESEARCH SUPPORT</td>
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<td><strong>TOTAL</strong></td>
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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.
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.

**Focus on Manifestations**

**Gastrointestinal**
- $7M
- 29 Studies

**Advanced Lung Disease**
- $13M
- 42 Studies

**Infection**
- $24M
- 150 Studies

**Inflammation**
- $10M
- 27 Studies

**Endocrine**
- $3M
- 25 Studies

**Mucus & Airway Hydration**
- $6M
- 34 Studies

**Infection**
- $10M
- 27 Studies

**Other**
- $2M
- 15 Studies

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.

**Infection**
- $24M
- 150 Studies

**Endocrine**
- $3M
- (CFRD, bone, reproductive health)

**Advanced Lung Disease**
- $13M
- (lung transplant, exacerbations, lung microbiome, lung disease progression)

**Mucus & Airway Hydration**
- $6M
- 34 Studies

**Other**
- $2M
- 15 Studies

**Inflammation**
- $10M
- 27 Studies

**Endocrine**
- $3M
- (CFRD, bone, reproductive health)

**Advanced Lung Disease**
- $13M
- (lung transplant, exacerbations, lung microbiome, lung disease progression)

**Gastrointestinal**
- $7M
- 29 Studies

**Other**
- $2M
- 15 Studies
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.

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**DRUG DEVELOPMENT PIPELINE**

### THERAPIES AVAILABLE TO PATIENTS

1. **Phase 3**
   - Definitive Trial
   - **Inflammation**
     - Ibuprofen
   - **Infection**
     - Amikacin Liposome Inhalation Suspension (Arikayce®)
   - **Nutritional-GI/Others**
     - Azithromycin
     - Aztreonam (Cayston®)
     - Inhaled Tobramycin
     - Tobramycin Inhaled Powder (TOBI® Podhaler®)

2. **Phase 2**
   - Human Safety & Efficacy Trial
   - **Inflammation**
     - Dornase Alfa (Pulmozyme®) + Hypertonic Saline
   - **Infection**
     - Inhaled Levofloxacin (Quinsair™)
     - Vancomycin Inhalation Powder (AeroVanc™)
     - Inhaled Molgramostim
     - Inhaled Nitric Oxide
     - Intravenous Gallium

3. **Phase 1**
   - Human Safety Trial
   - **Inflammation**
     - Lenabasum (JBT-101)
     - LAU-7b
   - **Infection**
     - SPI-1005
   - **Nutritional-GI/Others**
     - AquADEKs
     - Pancrelipase Enzyme Products
     - RELIZORB®

4. **Pre-Clinical**
   - Initial Testing in Laboratory
   - **Inflammation**
     - AZD5634
     - IONIS-ENaC-2.5R
     - Mucociliary Clearance
     - VX-561 (Formerly CTI-656)
   - **Infection**
     - A720221 (Formerly GLPG2222) + Aztreonam (Cayston®)
     - ABBV-3067
     - ELX-02
     - FDL169
     - MRT5005
   - **Nutritional-GI/Others**
     - A7306
     - BI1265162
     - OligoG
     - POL6014
     - VX-121
     - VX-809 (Alone & In Combination)
     - VX-808 (Alone & In Combination)
     - VX-120 (Alone & In Combination)

5. **Non-Clinical**
   - **Inflammation**
     - Elexacaftor + Tezacaftor + Ivacaftor (Trikafta®)
     - Ivacaftor (Kalydeco®)
     - Lumacaftor + Ivacaftor (Orkambi®)
     - Tezacaftor + Ivacaftor (Symdeko®)
   - **Infection**
     - Dornase Alfa (Pulmozyme®)
     - Hypertonic Saline
   - **Nutritional-GI/Others**
     - Amikacin Liposome Inhalation Suspension (Arikayce®)
     - Azithromycin
     - Aztreonam (Cayston®)
     - Inhaled Tobramycin
     - Tobramycin Inhaled Powder (TOBI® Podhaler®)
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
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.

**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
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.
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

For 10-year-olds:
- 1998: 89%
- 2018: 97%

For 18-year-olds:
- 1998: 71%
- 2018: 86%

For 30-year-olds:
- 1998: 49%
- 2018: 67%

Survival

LIVING BETTER TODAY
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.

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.
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.

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 people with CF, their families, and their care teams – regardless of their income or insurance status.

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
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.
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.

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.”
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.

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.

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.

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.

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

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

2019 Impact Grant Recipients

Advancing Our Mission
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.

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.
Thank you.

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.

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.
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

Gold

Bronze

American Airlines

AbbVie

Choate Construction Company


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

Top National Corporate Team

Rising Star National Corporate Team

Choate Construction Company

MC Companies – Sharing the Good Life Foundation
*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

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<td></td>
<td><strong>$4,476,511,082</strong></td>
<td><strong>$4,013,935,956</strong></td>
</tr>
</tbody>
</table>
## Statements of Activities

For the years ended December 31, 2019 and 2018

### Revenue

#### Support Received From the Public

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special Event Revenue</td>
<td>96,255,420</td>
<td>95,743,556</td>
</tr>
<tr>
<td>Direct Benefit Expenses</td>
<td>(15,820,602)</td>
<td>(14,813,644)</td>
</tr>
<tr>
<td>Net Special Event Revenue</td>
<td>80,434,818</td>
<td>80,929,912</td>
</tr>
<tr>
<td>General Contributions</td>
<td>28,586,267</td>
<td>27,217,734</td>
</tr>
<tr>
<td><strong>Total Support Received From the Public</strong></td>
<td><strong>109,021,085</strong></td>
<td><strong>108,147,646</strong></td>
</tr>
<tr>
<td>Other</td>
<td>55,976,109</td>
<td>27,456,695</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td><strong>164,997,194</strong></td>
<td><strong>135,604,341</strong></td>
</tr>
</tbody>
</table>

### Expenses

#### Program Services

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Programs</td>
<td>245,607,343</td>
<td>237,133,914</td>
</tr>
<tr>
<td>Public and Professional Information and Education</td>
<td>17,584,009</td>
<td>15,998,432</td>
</tr>
<tr>
<td>Community Services</td>
<td>22,103,810</td>
<td>20,043,322</td>
</tr>
<tr>
<td><strong>Total Program Services</strong></td>
<td><strong>285,295,162</strong></td>
<td><strong>273,175,668</strong></td>
</tr>
</tbody>
</table>

#### Supporting Services

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management and General</td>
<td>25,897,119</td>
<td>22,963,205</td>
</tr>
<tr>
<td>Fundraising</td>
<td>28,709,962</td>
<td>26,896,581</td>
</tr>
<tr>
<td><strong>Total Supporting Services</strong></td>
<td><strong>54,607,081</strong></td>
<td><strong>49,859,786</strong></td>
</tr>
</tbody>
</table>

### Other Changes in Net Assets

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net Nonoperating Investment Income (Loss)</td>
<td>636,250,409</td>
<td>(231,391,480)</td>
</tr>
<tr>
<td>Increase (Decrease) in Net Assets</td>
<td><strong>$461,345,360</strong></td>
<td>$(418,822,593)</td>
</tr>
</tbody>
</table>

### 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.

### 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.
## BOARD OF TRUSTEES AND CORPORATE OFFICERS

### TRUSTEES AND ADVISORS

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catherine C. McLoud</td>
<td>Chair</td>
</tr>
<tr>
<td>Michael L. Beatty, Esq.</td>
<td>Nonvoting, Leadership Council Chair</td>
</tr>
<tr>
<td>Michael P. Boyle, MD</td>
<td></td>
</tr>
<tr>
<td>James R. Butler, II</td>
<td>Nonvoting, Advisor</td>
</tr>
<tr>
<td>Dominic J. Caruso</td>
<td>Nonvoting, Advisor</td>
</tr>
<tr>
<td>Louis A. DeFalco</td>
<td>Vice Chair</td>
</tr>
<tr>
<td>Teresa L. Elder</td>
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<tr>
<td>Richard J. Gray, Esq.</td>
<td>Vice Chair</td>
</tr>
<tr>
<td>Carole B. Griego, MD</td>
<td></td>
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<tr>
<td>Susan L. Hook</td>
<td></td>
</tr>
<tr>
<td>Peter J. Mogayzel Jr., MD, PhD</td>
<td>Nonvoting, CF Care Center Representative</td>
</tr>
<tr>
<td>Chad T. Moore</td>
<td></td>
</tr>
<tr>
<td>David A. Mount</td>
<td>Treasurer</td>
</tr>
<tr>
<td>Robert H. Niehaus</td>
<td>Vice Chair</td>
</tr>
<tr>
<td>Eric R. Olson, PhD</td>
<td></td>
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<tr>
<td>Eric C. Schneider, MD</td>
<td>Nonvoting, Advisor</td>
</tr>
<tr>
<td>Steven Shak, MD</td>
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<tr>
<td>Eric J. Sorscher, MD</td>
<td>Nonvoting, Medical Advisory Council Chair</td>
</tr>
<tr>
<td>Theodore J. Torphy, PhD</td>
<td>Vice Chair</td>
</tr>
<tr>
<td>Doris F. Tulcin</td>
<td>Nonvoting, Chair Emeritus</td>
</tr>
<tr>
<td>John S. Weinberg</td>
<td>Executive Vice Chair</td>
</tr>
<tr>
<td>Paul W. Whetsell</td>
<td></td>
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<tr>
<td>KC Bryan White</td>
<td>Adult Advisory Council Chair</td>
</tr>
</tbody>
</table>

### CORPORATE OFFICERS

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michael P. Boyle, MD</td>
<td>President and CEO</td>
</tr>
<tr>
<td>Marc S. Ginsky</td>
<td>Executive Vice President and COO</td>
</tr>
<tr>
<td>Vera H. Twigg</td>
<td>Executive Vice President and CFO</td>
</tr>
</tbody>
</table>
with you by our side, we won’t stop until CF stands for Cure Found
our focus is firmly on the future and the work that lies ahead.