Connecting CF Resources with Community Needs

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What is Cystic Fibrosis?

Cystic fibrosis (CF) is a genetic disease that affects the respiratory, digestive and reproductive systems. Thick mucus blocks small passageways in the lungs, intestines and other organs. This mucus also traps bacteria, leading to serious infections, progressive lung damage and other complications. With the implementation of newborn screening programs, most people are diagnosed at a young age. Early treatment, which may include nutritional and respiratory therapies, medications and exercise, has a significant impact on the quality of life of those with CF. Until recently, children with CF rarely survived childhood. While innovative research, new medications, improved therapies and lung transplantation are prolonging and enhancing the lives of those with CF, it remains a life-threatening disease for which there is no cure.

Executive Director's Note

Dear Friends,

On behalf of CFRI's Board of Directors, and the cystic fibrosis community we serve, I am delighted to share that 2019 marked another successful year of programmatic growth. Thanks to the generous support of our individual donors, corporate sponsors and foundation funders, our innovative research, education, advocacy, and psychosocial support programs continued to expand to meet the needs of our diverse community.

As shared in this Annual Report, we made significant progress in 2019 to advance our strategic goals and objectives. We are mission-driven and determined to advance research in pursuit of a cure, while providing meaningful programs to our national – and international – CF community.

Impacting approximately 31,000 people in the United States, cystic fibrosis is often a low priority when it comes to research funding and drug development. We have strengthened our relationships with other CF and rare disease groups to ensure a strong voice. Thank you for joining us to raise awareness and advocate for access to quality medical care and therapies for those living with cystic fibrosis.

CFRI seeks to improve and enhance the lives of those with CF, now and into the future. CFRI's accomplishments are only possible thanks to the support of our community, which is passionately committed to the search for a cure.

Warm regards,

Siri Vaeth
Executive Director & Mother of an Adult Daughter with CF

cfri Cystic Fibrosis Research Inc.

Cystic Fibrosis Research, Inc.
1731 Embarcadero Road, Suite 210, Palo Alto, CA 94303
1.855.cfri.now (1.855.237.4669) toll free www.cfri.org

CFRI funds research, provides educational and personal support, and spreads awareness of cystic fibrosis, a life-threatening genetic disease.

cfri Cystic Fibrosis Research Inc.

Research for Living ~ Partners for Life

2019 Annual Report

EDUCATION

CFRI's Strategic Plan provides goals and objectives to create innovative and responsive education programs for the national cystic fibrosis (CF) community.

2019 Education Highlights

- Hosted and live streamed the 32nd National CF Education Conference where 17 renowned experts in the field of CF presented the latest in research and clinical practice to over 300 members of the global CF community (in-person and live-streamed), including adults with CF, CF parents, CF medical caregivers, researchers, and pharmaceutical and medical technology representatives. Evaluations found that ~85% of participants improved their knowledge of CF and treatment options.
- Through our *CF Community Voices* video podcast series, produced and posted 25 diverse podcasts that received over 28,000 combined views.
- Through our website, offered a dynamic resource for the global CF community (over 46,000 unique views). In addition, CFRI engaged its 9,000+ Facebook, Twitter and Instagram followers with breaking news, resources, and inspiring stories.
- Distributed 30,000 copies of the *CFRI Community* newsletter to homes and health centers across the globe. Distributed 6,000 copies of *CFRI Comunidad*, CFRI's Spanish-language newsletter, to CF centers with large Spanish-speaking patient populations.
- Provided updates on CF research, special events, advocacy efforts, and support programs through our weekly eNewsletter, distributed to over 15,000 subscribers.
- Distributed CFRI publications, including "Cystic Fibrosis in the Classroom" and "Fibrosis Quística en la Clase" to patients, families, health care providers and educators nationwide.

SUPPORT

CFRI's Strategic Plan provides goals and objectives to create innovative and responsive support programs for the national cystic fibrosis (CF) community.

2019 Support Highlights

- 114 adults with CF and CF caregivers participated in CFRI's online Mindfulness-Based classes; evaluations indicate a significant reduction in depression and anxiety symptoms.
- 50 people with CF and their family members participated in two "Yoga for CF Health" classes, with six sessions each. Classes were offered online and free of charge.
- 82 individuals with CF and/or their immediate family from 17 states received individual therapy underwritten by CFRI, resulting in a statistically significant reduction in depression and anxiety symptoms.
- 40 people attended the CF Summer Retreat, including adults with CF and their friends and families. Attendees participated in educational presentations, exercise, art, and support groups. Evaluations demonstrate a reduction in depression and anxiety symptoms among participants.
- 27 mothers of children/adults with CF attended Embrace, a weekend retreat providing resources, psychosocial support, and connection to their peers. Attendees experienced a measurable decrease in depression and anxiety symptoms.
- CFRI's Caregiver Support Group, facilitated by a CF social worker, was offered monthly to parents, spouses and partners of those with CF from across the U.S.
- CFRI's Online Support Group for Adults with CF, facilitated by a CF social worker, was offered monthly to those with CF.
- Support for the Spanish-speaking CF community was provided via print, DVD, and website resources, including a Spanish language version of CFRI's newsletter.

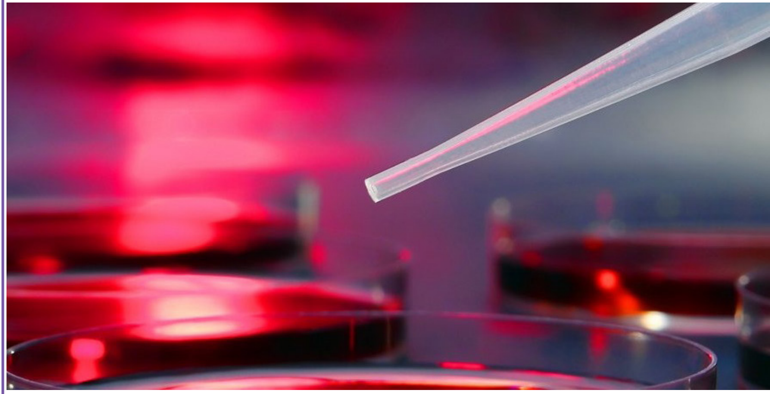
ADVOCACY

CFRI's Strategic Plan provides goals and objectives to engage the national cystic fibrosis (CF) community, industry and funders in advocacy and awareness efforts that increase quality of life.

2019 Advocacy and Awareness Highlights

- Sent multiple action alerts and partnered with other rare disease groups to engage our community, resulting in thousands of messages to elected officials at the state and federal level.
- Produced a "Faces of CF" Awareness and Advocacy video featuring members of the CF community; the video had over 1,500 online views.
- Coordinated campaign to declare May as CF Awareness Month in California by State Senate Resolution 108; hosted CF advocacy day in Sacramento including meetings between elected representatives and CFRI advocates.
- Met with federal legislators in Washington, DC to discuss issues impacting the health and quality of life for those with CF, including access to care.
- Strengthened ties and alliances with our cystic fibrosis organizational partners in the Cystic Fibrosis Engagement Network, as well as with other rare disease groups through national rare disease organizations and alliances.
- Released the "Voice of the Cystic Fibrosis Patient" Report, a summary of CFRI's Externally-Led Patient Focused Drug Development meeting on CF held with the FDA in late 2018. Credited with impacting FDA's rapid review and approval of triple-combination CFTR modulator.
- Participated in diverse activities to raise awareness of the discriminatory use of Quality Adjusted Life Year (QALY) to assess drug pricing and value for rare disease drugs.
- CFRI's Executive Director becomes member of American Thoracic Society Public Advisory Roundtable which brings patient voice to research and clinical practice.

RESEARCH



CFRI's Strategic Plan provides goals and objectives to ensure that research will continue toward a cure.

2019 Research Highlights

In line with its Strategic Plan, CFRI continued its research programs in 2019, funding 7 cystic fibrosis research projects at universities and medical facilities throughout the United States.

2019 New Horizons Researchers

Martina Gentzsch, PhD
University of North Carolina at Chapel Hill
Physiological Models of Cystic Fibrosis Airway Cultures that Mimic the In Vivo Environment for Therapeutic Testing

Lucas Hoffman, MD, PhD
Univ. of Washington, Seattle and Seattle Children's Hospital
Bacterial Community-Level Susceptibility Testing for Cystic Fibrosis Lung Infections

Elizabeth Kramer, MD, PhD
Cincinnati Children's Hospital Medical Center
The Role of TGF in Driving Airway Hyperresponsiveness and Smooth Muscle Dysfunction in Cystic Fibrosis

Kenichi Okuda, MD
University of North Carolina Chapel Hill
Regional Regulation of CFTR and Ionocyte Expression in Airways

Forest Rohwer, PhD
San Diego State University
Development of tailocins against microbial infections in cystic fibrosis lungs

2019 Elizabeth Nash Memorial Fellowship Researchers

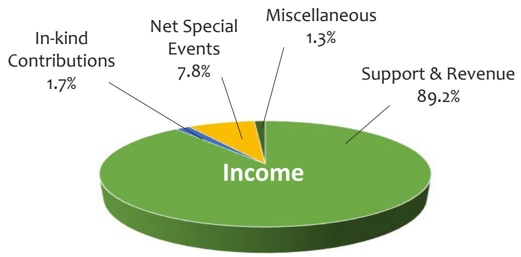
Emily Cope, PhD & Keehoon Lee, PhD
Northern Arizona University
A Multi-'Omic Approach to Evaluate Concurrent Sinus and Pulmonary Disease in Cystic Fibrosis

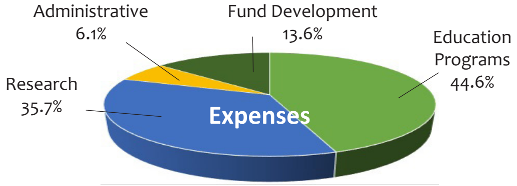
Forest Rohwer, PhD & Cynthia Silveira, PhD/ Ana Cobian, PhD
San Diego State University
Bacteriophage-Mediated Spread of Virulence Factors in Cystic Fibrosis

FINANCIAL SUMMARY

INCOME		
Support & Revenue	$1,318,124	89.2%
In-kind Contributions	$25,000	1.7%
Net Special Events	$115,018	7.8%
Miscellaneous	$18,715	1.3%
Total Income*	**$1,476,857**	**100.00%**

EXPENSES		
Education Programs	$610,809	44.6%
Research	$489,957	35.7%
Administrative	$84,202	6.1%
Fund Development	$185,774	13.6 %
Total Expenses*	**$1,370,742**	**100.00%**





As outlined in CFRI's Strategic Plan, CFRI seeks to create sustainable funding to remain a strong and viable agency.

CFRI is independently audited by Wheeler Accountants LLP.

CFRI is registered as a 501 (C)(3) charity: EIN #51-0169988.

* Final 2019 Audit approved by CFRI Board of Directors.