

# Connecting CF Resources with Community Needs

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## What is Cystic Fibrosis?

Cystic fibrosis (CF), a genetic disease that impacts people of all races and ethnicities, affects the respiratory, digestive and reproductive systems. Thick mucus blocks small passageways in the lungs, intestines and other organs, while trapping bacteria that create serious infections, progressive lung damage and other complications. With the implementation of newborn screening programs, most people are diagnosed at a young age – though newborn screening often misses mutations more frequently found in people of color. 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.



## Note from CFRI's Board President and Executive Director

Dear Friends,

On behalf of CFRI's Board of Directors, we hope this finds you safe and well. Despite these challenging times, 2020 marked another year of programmatic growth for CFRI, as we addressed the emerging needs of the CF community in response to the pandemic.

Cystic fibrosis impacts people of all races and ethnicities. As an organization, we hold principles of equity, diversity and inclusion at the forefront in all that we do. 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.

As shared in this Annual Report, we made significant progress realizing our goals and objectives. Our updated name, logo and mission statement better reflect our strategic focus. Impacting only 30,000 people in the United States, cystic fibrosis is often a low priority when it comes to research funding. 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,

Bill Hult  
 President of the Board

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

**CFRI's mission is to be a global resource for the cystic fibrosis community while pursuing a cure through research, education, advocacy, and support.**



**CFRI** Cystic Fibrosis  
 Research Institute

RESEARCH · EDUCATION · ADVOCACY · SUPPORT

**2020  
 Annual  
 Report**

# EDUCATION



CFRI's Strategic Plan outlines priorities that guide our program development and delivery. Our priorities are rooted in our commitment to diversity, inclusion and equity for all community members and include: ensuring research will continue toward a cure; engaging the national CF community in advocacy and awareness efforts that increase access to therapies, research funding and quality of life; creating innovative and responsive education and support programs for the national CF community; developing new – while strengthening existing – national partnerships with community, industry and funders.

## 2020 Education Highlights

- Hosted the fully virtual 33rd National CF Education Conference, where 17 renowned experts in the field of CF presented the latest in research and clinical practice to over 500 members of the global CF community. Evaluations found that 85% of participants improved their knowledge of CF and treatment options.
- Produced and posted 27 podcasts through our CF Community Voices podcast series, with over 8,000 combined views.
- Responded to COVID-19: Hosted COVID-19 town hall meeting at the onset of the pandemic; released regular COVID-19 and CF podcast sessions with Rick Moss, MD; created COVID-19 resource section on website and in weekly eNewsletter.
- Updated our website to provide a more dynamic resource for the global CF community. In addition, CFRI engaged its 12,000+ 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 nearly 10,000 informational brochures about cystic fibrosis and CFRI's services.

# SUPPORT

## 2020 Support Highlights

- Underwrote individual therapy sessions for 74 individuals with CF from 18 states and/or their immediate family, resulting in a statistically significant reduction in depression and anxiety symptoms.
- Offered free online CF-Specific Yoga, Strength-Building, Mindfulness and Physical Therapy classes which were attended by over 260 people with CF and their family members.
- Hosted two virtual retreats: a CF Summer Retreat, attended by 50 adults with CF and their friends and families; and a retreat for 25 mothers of children/adults with CF. Both provided resources, psychosocial support and connection to peers; evaluations showed measurable decrease in symptoms of depression and anxiety.
- Offered a weekly virtual Support Group for CF and COVID-19 related stress and anxiety. Facilitated by a CF psychiatrist, the group was attended by 90 people from across the U.S. and globe.
- Provided three monthly virtual Support Groups facilitated by CF social workers: a group for Adults with CF; a group for Caregivers of children with CF; a group for parents/spouses/partners of adults with CF. Participants were from across the U.S. and globe.
- Increased support for the Spanish-speaking CF community via print, DVD, and website resources, including a Spanish language version of CFRI's newsletter.



# ADVOCACY

## 2020 Advocacy and Awareness Highlights

- Sent multiple action alerts and partnered with other rare disease groups to engage our community on issues emerging from COVID-19, including discriminatory State and Federal Emergency Plans /Health Crisis Standards that would de-prioritize those with advanced lung disease and/or CF should medical rationing be necessary.
- Joined with other disease groups to support push for federal expansion of paid family medical leave for people with chronic conditions and their caregivers; continued coverage for telehealth services, and prohibition of co-pay accumulator programs and surprise medical billing.
- Produced a "CF Advocacy in the Face of COVID-19" video and "Faces of CF" Awareness and Advocacy video featuring members of the CF community.
- Held in-person and virtual meetings with state and federal legislators to discuss issues impacting the health and quality of life for those with CF, including access to care.
- Pursued efforts to create state Rare Disease Advisory Councils through coalition building with rare disease groups.
- 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.
- Strengthened ties and alliances with our cystic fibrosis organizational partners in the Cystic Fibrosis Engagement Network, with national rare disease organizations, disability groups, and with our partner organizations in the American Thoracic Society Public Advisory Roundtable.

# RESEARCH



## 2020 Research Highlights

In 2020, the following researchers conducted research with the support of CFRI:

### New Horizons

- Martina Gentsch, 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*
- Xiaopeng Li, PhD**  
Michigan State University  
*Targeting V-type ATPase in Human Small Airways for CF Lung Disease Treatment*
- 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*

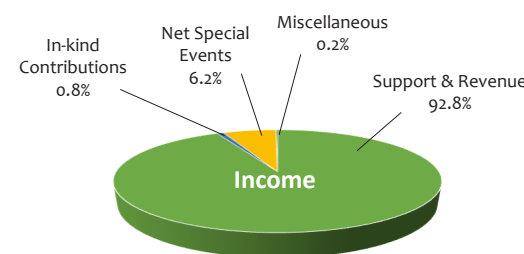
### Elizabeth Nash Memorial Fellowship

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

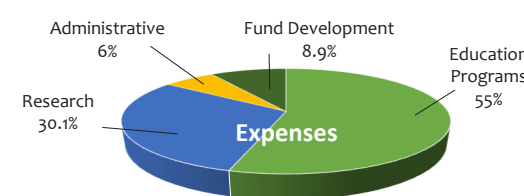
**Forest Rohwer, PhD (PI) and Ana Cobian, PhD (Post-Doctoral Fellow)**  
San Diego State University  
*Bacteriophage-Mediated Spread of Virulence Factors in Cystic Fibrosis Microbiomes*

## FINANCIAL SUMMARY

INCOME		
Support & Revenue	\$1,214,231	92.8%
In-kind Contributions	\$10,000	0.8%
Net Special Events	\$81,789	6.2%
Miscellaneous	\$2,201	0.2%
<b>Total Income*</b>	<b>\$1,308,221</b>	<b>100.00%</b>



EXPENSES		
Education Programs	\$590,808	55%
Research	\$328,269	30.1%
Administrative	\$65,524	6%
Fund Development	\$96,099	8.9%
<b>Total Expenses*</b>	<b>\$1,080,700</b>	<b>100.00%</b>



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 2020 Audit approved by CFRI Board of Directors.