

Connecting CF Resources with Community Needs

2021 BOARD OF DIRECTORS

William Hult, President
 Jessica Martens, Vice President
 Zoe Davies, NP, Secretary
 Oscar Flamenco, CPA, Treasurer
 Francine Bion
 Julie Desch, MD
 Colleen Dunn, MS, RT, CCRD
 Elyse Elconin Goldberg
 Jean Hanley, MD
 Doug Modlin, PhD
 Richard B. Moss, MD
 Arek Puzia, CFP, CPA
 Ahmet Uluer, DO, MPH

2021 COMMITTEE CHAIRS

William Hult
 Audit & Compliance
 Oscar Flamenco, CPA
 Finance
 Julie Desch, MD
 Research Advisory
 Isabel Stenzel Byrnes, LCSW, MPH
 National CF Education Conference

Jessica Martens
 CF Summer Retreat
 Bridget Barnes
 Newsletter
 Siri Vaeth, MSW
 Adult Advisory Committee
 Robin Modlin, MA
 Embrace Mothers' Retreat
 Siri Vaeth, MSW
 CF Diversity and Inclusion Advisory
 Committee
 Ann Robinson
 Mothers' Day Celebration

2021 STAFF

Siri Vaeth, MSW
 Executive Director
 Sue Landgraf
 Chief Financial Officer
 Mary Convento
 Programs & Finance Supervisor
 Sabine Brants, MA
 Programs & Outreach Associate
 Leeya Kannankunni
 Programs Assistant
 Stacie Reveles
 Advocacy & Outreach Associate
 Danielle Mandella
 Social Media Outreach Associate

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, pancreas and other organs, while trapping bacteria that create serious infections, progressive lung damage and other complications. Cystic fibrosis impacts people of all races and ethnicities. 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 reached adulthood. 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 ongoing challenging times, 2021 marked another year of programmatic growth for CFRI, as we addressed the emerging needs of the CF community.

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, in 2021 we made significant progress realizing our goals and objectives. While only 40,000 people in the United States have been diagnosed with cystic fibrosis, it is our belief that many more people remain misdiagnosed or undiagnosed. Funding innovative CF research, raising awareness of the disease, creating resources to address emerging needs, and maintaining public focus on the need for increased research funding and access to care remain key goals of our strategic plan.

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.

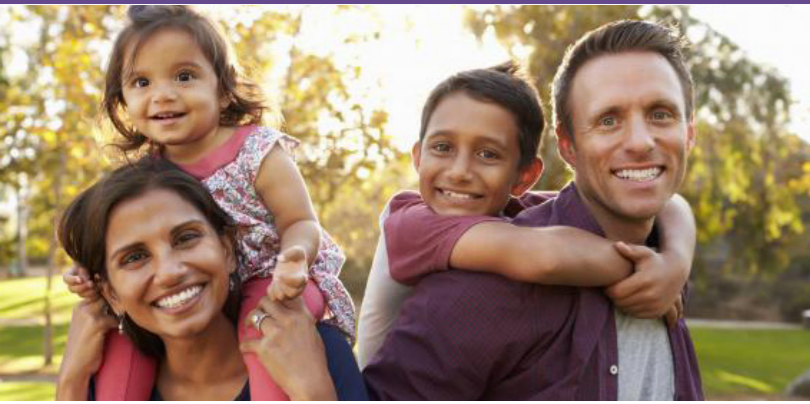


Our vision is to find a cure for cystic fibrosis while enhancing quality of life for the CF community.

CFRI Cystic Fibrosis
 Research Institute
 RESEARCH · EDUCATION · ADVOCACY · SUPPORT

2021
 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 and global 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 and global CF community; developing and strengthening national and global partnerships with community, industry and funders.

2021 Education Highlights

- Hosted the fully virtual 34th National CF Education Conference, where 25 speakers - including renowned experts in the field of CF, patient panelists, and CF researchers - presented the latest in research and clinical practice to over 500 members of the global CF community. Evaluations found that over 85% of participants improved their knowledge of CF and treatment options.
- Produced and posted 26 podcasts through our *CF Community Voices* podcast series, with over 3,500 combined views.
- Continued response to COVID-19: released podcast sessions with Rick Moss, MD, on COVID-19 and CF, with focus on vaccine rollout; provided up-to-date COVID-19 resources on website, social media and in eNewsletter.
- Maintained our website as a 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 nationwide.
- 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

2021 Support Highlights

- Underwrote individual therapy sessions for 81 individuals with CF from 21 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 300 people with CF and their family members.
- Hosted three virtual retreats for our global CF community: a CF Spring Retreat and Summer Retreat for adults with CF; and a retreat for mothers of children/adults with CF. All events provided resources, psychosocial support and connection to peers; evaluations showed measurable decreases 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 five monthly virtual Support Groups facilitated by CF social workers: Adults with CF; Caregivers of children with CF; parents/spouses/partners of adults with CF; people who lost a loved one to CF; CF and COVID-19 related stress and anxiety. Participants were from across the U.S. and globe.
- Increased support for the Spanish-speaking CF community via print, social media, and website resources, including a Spanish language version of CFRI's newsletter.



ADVOCACY

2021 Advocacy and Awareness Highlights

- Advanced awareness of the CF community's racial and ethnic diversity through the creation of five films. Created a series of informational sheets in multiple languages to raise awareness and offer resources; expanded Hindi and Spanish language offerings on our YouTube channel; provided captioning and subtitles for conference attendees; made CFRI website accessible in multiple languages.
- Continued to work with other disease groups to support 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 Awareness and Advocacy video featuring members of the CF community to inspire greater engagement in advocacy activities.
- Sent multiple action alerts and partnered with other rare disease groups to engage our community on issues that emerged during the pandemic, including the rejection of discriminatory State and Federal Emergency Plans /Health Crisis Standards that would de-prioritize those with advanced lung disease and/or CF.
- Held over 25 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.
- Continued alliances with our CF 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



2021 Research Highlights

In 2021, the following researchers conducted research with the support of CFRI:

New Horizons

Stephen Aller, PhD

University of Alabama at Birmingham
Role of CFTR Arginine-933 in Folding, Gating and Potentiator Drug Binding

Steven Jonas, MD, PhD

University of California Los Angeles
Developing Nanotechnology-Enabled Gene Therapy Solutions to Correct CFTR Mutations in Airway Stem Cells: Toward a One-Time Cure for 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

Matthew Porteus, MD, PhD

Stanford University
Identifying Biomaterials that Enable the Transplantation of Gene Corrected Airway Stem Cells to Treat Cystic Fibrosis

Forest Rohwer, PhD

San Diego State University
Development of tailocins against microbial infections in cystic fibrosis lungs

Elizabeth Nash Memorial Fellowship

Emily Cope, PhD (Principal Investigator) Keehoon Lee, PhD (Postdoctoral Fellow)

Northern Arizona University
A Multi-Omic Approach to Evaluate Concurrent Sinus and Pulmonary Disease in Cystic Fibrosis

Suzanne Fleiszig, OD, PhD (Principal Investigator) Naren Kumar, PhD (Postdoctoral Fellow)

University of California Berkeley
Characterizing the Intracellular Diversification of Pseudomonas aeruginosa in Chronic Lung Infections

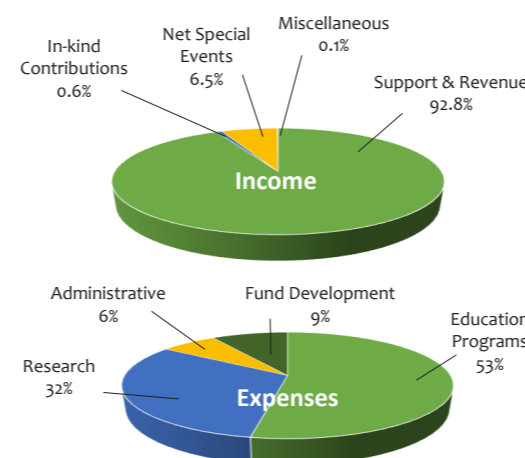
FINANCIAL SUMMARY

INCOME

Support & Revenue	\$1,486,790	92.8%
In-kind Contributions	\$10,000	0.6%
Net Special Events	\$104,160	6.5%
Miscellaneous	\$1,349	0.1%
Total Income*	\$1,602,299	100.00%

EXPENSES

Education Programs	\$614,489	53%
Research	\$366,929	32%
Administrative	\$76,123	6%
Fund Development	\$102,413	9%
Total Expenses*	\$1,159,954	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.