

# 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, 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, more 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, 2022 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 the principles of equity, diversity, justice, 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 2022 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.



**2022  
Annual  
Report**



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# 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.

## 2022 Education Highlights

- Hosted the fully virtual 35th 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 95% of participants improved their knowledge of CF and treatment options.
- Produced and posted 22 podcasts through our *CF Community Voices* podcast series, with over 2,800 combined views.
- Maintained our website as a dynamic resource - available in multiple languages - 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

## 2022 Support Highlights

- Underwrote individual therapy sessions for nearly 100 individuals with CF and/or their immediate family members from 20 states, resulting in a statistically significant reduction in depression and anxiety symptoms.
- Offered free online CF-specific Yoga, Strength-Building, Mindfulness and Physical Therapy classes, attended by over 200 people with CF and their family members.
- Hosted four retreats for our global CF community: two virtual CF Retreats for adults with CF; and virtual and in-person retreats for mothers of children/adults with CF. All events provided educational resources, psychosocial support and connection to peers.
- Provided seven monthly virtual Support Groups facilitated by social workers and offering peer-to-peer support: Adults with CF; Caregivers of Children with CF; Parents/Spouses/Partners of Adults with CF; Those who are Bereaved; Adults with CF Post-Transplant; Spanish-Speaking CF Community Members; and Teens with CF. 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

## 2022 Advocacy and Awareness Highlights

- Advanced awareness of the CF community's racial and ethnic diversity through the creation of films and podcasts. 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.
- Produced annual 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 impacting our community, including access to care, the need for copay accumulator bans, greater support for research, and addressing the antimicrobial resistance crisis.
- Held over 25 virtual meetings with state and federal legislators to discuss issues impacting the health and quality of life for those with CF.
- 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) methodologies 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



## 2022 Research Highlights

In 2022, 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*

#### Carlos Milla, MD

Stanford University  
*Improving CF Airway Mucociliary Clearance: Toward Transition from Animals to Humans*

#### Kenichi Okuda, MD

University of North Carolina Chapel Hill  
*Pathways Maintaining Basal Mucin and CFTR-Mediated Fluid Secretion in the Human Distal Airway*

#### Matthew Porteus, MD, PhD

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

#### Zachary Sellers, PhD

Stanford University  
*Targeting IRBIT to Correct Bicarbonate Secretory Defects in Cystic Fibrosis*

### Elizabeth Nash Memorial Fellowship

#### Paul Bollyky, MD, PhD (Principal Investigator)

Nina Pennetzdorfer, PhD (Postdoctoral Fellow)  
Stanford University  
*Targeting Bacterial Resistance to Phage Therapy 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*

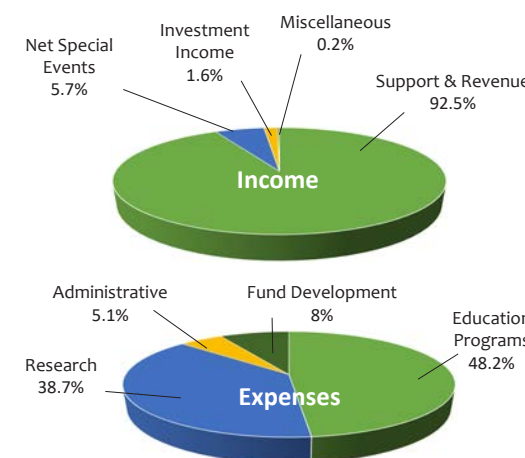
## FINANCIAL SUMMARY

### INCOME

Support & Revenue	\$1,249,309	92.5%
Net Special Events	\$76,867	5.7%
Investment Income	\$21,420	1.6%
Miscellaneous	\$2,700	0.2%
<b>Total Income</b>	<b>\$1,350,296</b>	<b>100.00%</b>

### EXPENSES

Education Programs	\$735,516	48.2%
Research	\$590,000	38.7%
Administrative	\$77,631	5.1%
Fund Development	\$122,788	8%
<b>Total Expenses*</b>	<b>\$1,525,935</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's Board of Directors voted to utilize excess reserve funds to expand research funding in 2022.

CFRI is independently audited by BryMar CPA, LLP.

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