

2023 BOARD OF DIRECTORS

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2023 COMMITTEE CHAIRS

*Note: We hold in our thoughts the memory of Ann Robinson and Isa Stenzel Byrnes, vital members of CFRI's organizational family whom we lost in 2023.*

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

2023 STAFF

*Note: We hold in our thoughts the memory of beloved staff member Danielle Mandella, whom we lost in 2023.*

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

# Connecting CF Resources with Community Needs

## 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. 2023 marked another year of programmatic

growth for CFRI, as we continue to expand programs to address 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 2023 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.



2023  
Annual  
Report



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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.

2023 Education Highlights

- Hosted the 36th National CF Education Conference as a hybrid event, where 28 speakers - including renowned experts in the field of CF, patient panelists, and CF researchers - presented the latest in research and clinical practice to over 100 in-person attendees and over 400 members of the global CF community virtually. 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 3,400 combined views.
- Maintained our website as a dynamic resource - available in multiple languages - for the global CF community. In addition, CFRI engaged its 18,000+ Facebook, Twitter and Instagram followers with breaking news, resources, and inspiring stories.
- Distributed 28,000 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.

2023 Support Highlights

- Underwrote individual therapy sessions for nearly 100 individuals with CF and/or their immediate family members from 23 states, resulting in a statistically significant reduction in depression and anxiety symptoms.
- Offered free weekly online CF-specific wellness classes – including strength training, yoga, pilates, dance, flexibility and stretching - which were attended by over 100 people with CF and their family members.
- Hosted four retreats for our national and global CF community: a virtual CF Spring Retreat and hybrid Summer Retreat for adults with CF; and an in-person Spring Retreat and virtual Fall 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.
- Provided eight 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; adults with CF post-transplant; teens with CF; Spanish-speaking CF community members; adults with a late CF diagnosis. 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.



2023 Advocacy and Awareness Highlights

- Advanced awareness of the CF community’s racial and ethnic diversity through the creation of podcasts and films, informational sheets and resource guides in multiple languages; provided captioning and subtitles for conference attendees; made CFRI website accessible in multiple languages.
- Pursued efforts to create state Rare Disease Advisory Councils (RDACs) through coalition building with rare disease groups; sent multiple action alerts and partnered with other rare disease groups to engage our community on issues that impact the rare disease community.
- Engaged with other disease groups to advocate on potential threats to CF community access to therapies, including co-pay accumulator programs, surprise medical billing, and state Prescription Drug Affordability Review Boards (PDABs).
- Produced a CF Awareness and Advocacy video featuring members of the CF community to inspire greater engagement in advocacy activities.
- Created English/Spanish language informational fliers to raise awareness of the significantly higher rates of colorectal cancer among those with CF; released podcasts on this topic.
- Held over 40 virtual and in-person meetings with state and federal legislators to discuss issues impacting the health and quality of life for those with CF, including access to care.
- 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 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.



2023 Research Highlights

In 2023, the following researchers conducted research with the support of CFRI:

Elizabeth Nash Memorial Fellowship Program

- **Paul Bollyky, MD, PhD (Principal Investigator), Kevin Qingquan Chen, PhD (Postdoctoral Fellow)** - Stanford University  
*Targeting Bacterial Resistance to Phage Therapy in Cystic Fibrosis*
- **Matthew Porteus, MD, PhD (Principal Investigator), Anaïs Amaya Colina, PhD (Postdoctoral Fellow)** - Stanford University  
*A Hybrid Gene Correction Strategy for Cystic Fibrosis*

New Horizons Program

- **Nadia Ameen, MD** - Yale University School of Medicine  
*Elucidating The Ion Transport Functions of CFTR High Expresser Cells (CHes) And Its Relevance To Intestinal Disease In Cystic Fibrosis*
- **Benjamin Chan, PhD** - Yale University School of Medicine  
*Optimization of Phage Therapy to Reduce Pseudomonas-Induced Inflammation in Cystic Fibrosis*
- **Carlos Milla, MD** - Stanford University  
*Improving CF Airway Mucociliary Clearance: Toward Transition from Animals to Humans*
- **Kenichi Okuda, MD, PhD** - University of North Carolina at Chapel Hill  
*Pathways Maintaining Basal Mucin and CFTR-Mediated Fluid Secretion in the Human Distal Airway*

- **Zachary Sellers, MD, PhD** - Stanford University  
*Targeting IRBIT to Correct Bicarbonate Secretory Defects in Cystic Fibrosis*
- **Katrine Whiteson, PhD** - University of California Irvine  
*Targeting Recalcitrant CF Pathogens with Phages, Antibiotics, And Small Molecule Adjuvants*

Special Circumstances Grant

- **Beate Illek, PhD** - University of California San Diego  
*CFTR mRNA Delivery to CF Airways*

FINANCIAL SUMMARY

INCOME		
Support & Revenue	*\$1,929,355	89%
Net Special Events	\$96,743	5%
Investment Income	\$94,720	4.5%
Miscellaneous	\$28,168	1%
Ed. Program & Collat	\$15,045	0.5%
<b>Total Income</b>	<b>\$2,164,031</b>	<b>100.00%</b>

EXPENSES		
Education Programs	\$728,556	45%
Research	\$641,900	40%
Administrative	\$109,348	7%
Fund Development	\$137,950	8%
<b>Total Expenses</b>	<b>\$1,617,754</b>	<b>100.00%</b>

\*includes \$500,000 bequest

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 BryMar CPA, LLP.

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