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, intestines and other organs. This mucus also traps bacteria, leading to serious infections and progressive lung damage. With the implementation of nationwide newborn screening programs, most people are diagnosed at a very 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 2018 marked another successful year of 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 2018 to advance our strategic goals and objectives. In addition to our many successful longstanding programs, CFRI was honored to host an Externally-Led Patient-Focused Drug Development Meeting on Cystic Fibrosis to bring the patient voice to representatives of the Food and Drug Administration (FDA). The day-long meeting was live-streamed and viewed by over 900 people, and the resulting published report serves as an enduring testament to the complex and devastating impact of CF.

Impacting only 30,000 people in the United States, cystic fibrosis is often a low priority when it comes to research funding and access to medications. 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 funds research, provides educational and personal support, and spreads awareness of cystic fibrosis, a life-threatening genetic disease.
CFRI's Strategic Plan provides goals and objectives to ensure that research will continue toward a cure. 

2018 Research Highlights

- In line with its Strategic Plan, CFRI continued its research programs in 2018, funding 7 CF research projects at universities and medical facilities throughout the United States.

2018 New Horizons Researchers

Martina Gentzsch, PhD
University of North Carolina at Chapel Hill

Lucas Hoffman, MD, PhD
Univ. of Washington, Seattle and Seattle Children’s Hospital

Elizabeth Kramer, MD, PhD
Cincinnati Children’s Hospital Medical Center

AKM Shamsuddin, PhD
UC San Diego

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 #51-0165988.

* Final 2018 Audit approved by CFRI Board of Directors.

EDUCATION

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

2018 Education Highlights

- Hosted and live-streamed the 31st CF National Education Conference where 14 renowned experts in the field of CF presented the latest in research and clinical practice to 345 members of the global CF community. Event evaluation found that over 90% of participants improved their knowledge of CF and treatment options.
- Through our CF Community Voices video podcast series, produced and posted 27 diverse podcasts that received over 6,200 combined views.
- Through a grant from the Taproot Foundation, revamped our website to be a more dynamic resource for the global CF community. 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 newsletter, distributed to over 15,000 subscribers.
- Provided updates on CF research, special events, advocacy efforts, and support programs through our weekly newsletter, distributed to over 15,000 subscribers.
- Distributed over 5,000 copies of CFRI publications, including “Cystic Fibrosis in the Classroom” and “Fibrosis Quistica en la Clase” to patients, families, healthcare providers, and educators.

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.

2018 Advocacy and Awareness Highlights

- Hosted an Externally-Led Patient-Focused Drug Development Meeting for representatives of the Food and Drug Administration (FDA), so as to bring the CF patient voice to the FDA and other interested parties, expand understanding of disease impacts, and the need for priority FDA review of CF therapies.
- Through our Many Voices – One Voice CF Awareness and Advocacy Campaign, generated to Action Alerts resulting in over 23,453 CFRI constituent letters to elected officials, raising CF awareness and addressing legislative items impacting the CF community such as access to medications and care.
- Produced two Many Voices – One Voice CF Awareness and Advocacy Campaign videos featuring members of the CF community; the videos have had over 1,200 views.
- Coordinated campaign to declare May as CF Awareness Month in the state of California by State Senate Resolution 108.
- Testified on behalf of CFRI and member organizations of the Cystic Fibrosis Engagement Network at the Institute for Clinical and Economic Review’s (ICER’s) Midwest Comparative Effectiveness Public Advisory Council to express collective concern about ICER’s flawed methodology in assessing the value of CFTR modulators.
- CFRI met with Missouri representatives and senators in Jefferson City to raise CF awareness; CFRI was honored on the senate floor.
- Met with state and national legislators to discuss issues that impact the health and quality of life of those with CF.
- Strengthened ties and alliances with our Cystic Fibrosis organizational partners in the Cystic Fibrosis Engagement Network, as well as with Rare Disease advocacy groups.

RESEARCH

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

2018 Research Highlights

In 2018, CFRI supported 20 research projects in 2018, funded 7 CF research projects at universities and medical facilities throughout the United States.

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University of North Carolina at Chapel Hill

Lucas Hoffman, MD, PhD
Univ. of Washington, Seattle and Seattle Children’s Hospital

Elizabeth Kramer, MD, PhD
Cincinnati Children’s Hospital Medical Center

AKM Shamsuddin, PhD
UC San Diego

Jeff Wine, PhD and Nam Soo Joo, PhD
University of North Carolina at Chapel Hill

Richard Boucher, MD and Kenichi Okuda, MD
University of North Carolina, Chapel Hill

Forest Rohwer, PhD and Cynthia Silveira, PhD
San Diego State University

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