

The Challenges of Cystic Fibrosis

One in 31 people reading this is likely to be a carrier of the gene that causes cystic fibrosis (CF), a rare disease currently diagnosed in over 40,000 people in the United States and more than 100,000 people worldwide. If two carriers have a child, there is a one in four chance that their child will have CF.

Managing CF requires time-consuming respiratory therapy, daily medications, regular clinic visits, and frequent hospitalizations. The physical, financial and emotional burden placed on those with CF – as well as their families – is immense.

While most people associate CF with lung disease, it impacts every organ system. A defective exchange of fluids across cells, caused by a mutation in the gene for the CFTR protein, causes thick mucus to block small ducts in the respiratory, reproductive and digestive systems. This leads to chronic infections, malnutrition and progressive lung damage.

CF impacts people of all races and ethnicities, and early diagnosis is vital. Newborn screening for CF has helped to identify new cases at an early age, but these tests often fail to identify rare mutations more common among people of color.

New exciting therapies are available to many with cystic fibrosis – including CFTR modulators – but they are not a cure. The median age of death for those living with CF is in the early-to-mid thirties. CFRI needs your support to improve and extend the lives of those facing this extremely challenging disease.



Mission

To be a global resource for the cystic fibrosis community while pursuing a cure through research, education, advocacy, and support.

Vision

To find a cure for cystic fibrosis while enhancing quality of life for the CF community.

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CFRI is Your Partner in Living!

Founded in 1975, CFRI serves the national and international cystic fibrosis (CF) community by funding innovative CF research, and providing vital educational and psychosocial support programs. We actively advocate at the regional, state and federal levels to raise awareness of cystic fibrosis and the need for improved therapies and access to care. We welcome participation in our programs! Together we are a strong community.

Cutting-Edge Research

Extraordinary advances are being made in CF treatment options yet there is more to be done. While median life expectancy continues to increase, the median age of death remains in the early-to-mid thirties and there is still no cure. **Research is the key to new therapies, and ultimately, a cure.**

CFRI funds innovative CF research projects through the **Elizabeth Nash Memorial Fellowship Program** for post-doctoral fellows, and the **New Horizons Program** for principal investigators conducting CF research at distinguished academic and medical institutions nationwide.

Scientific discoveries by CFRI-funded researchers have laid the groundwork for promising therapies that move us closer to a cure.



Educational Programs and Resources

CFRI's annual **National Cystic Fibrosis Education Conference** brings together individuals with CF, families, clinicians, and scientists for an exciting weekend of information and activities.

Our **CF Community Voices video podcast** series addresses a diverse range of CF topics, and provides information as well as inspiration via CFRI's YouTube and podhosting sites.

CFRI's **weekly eNewsletter** provides 15,500 digital subscribers with the latest information on research, programs and events, while the printed newsletters, **CFRI Community** and **CFRI Comunidad**, are distributed around the globe.

Psychosocial Support and Community

As part of the Partners in Living Initiative / CF Quality of Life Program: A Living Legacy of Peter and Kathy Judge, CFRI provides financial support for **individual counseling** to those with CF and their family members.

CFRI offers monthly online **CF Support Groups** to caregivers, adults and teenagers with CF, lung transplant recipients, those who are bereaved, and those whose first language is Spanish.

CFRI offers free **online wellness classes including Mindfulness and Yoga** for individuals with CF and CF caregivers nationwide.

CFRI's **Retreats for Adults with CF** provide support, information and recreation for people with CF, their friends and families. CFRI's annual weekend **"Embrace" Retreat** for mothers of children and adults with CF provides women with respite, resources, and support.



Advocacy

Through the **Many Voices ~ One Voice CF Advocacy and Awareness Program**, CFRI spearheads advocacy efforts to educate and engage our community. We raise awareness of the diversity of our community, and seek to ensure our voices are heard at the state and federal levels on issues that impact access to quality CF healthcare and therapies.

We seek your engagement and participation!

Please visit www.cfri.org to learn more about our research, education, advocacy, and support programs. CFRI is a partner in living with the CF community.