CFRI community
51 Years of Research, Education, Advocacy, & Support
Spring 2026

The Diagnosis That Gave Me Back My Life

Devanshi Dubey

For most of my childhood, I knew something about my body was not right, but I didn't have the language, diagnosis, or support to make sense of it. Growing up in India, where awareness of rare diseases like cystic fibrosis (CF) is limited, my symptoms were often explained in ways that didn't fully capture what I was experiencing. At one point my chronic cough, frequent infections, and episodes of hemoptysis led to a diagnosis and treatment for tuberculosis; a path not uncommon in my native country. But in my case, it wasn't TB.

Alongside this, there was a quieter narrative that followed me: that maybe I just wasn't doing enough. That if I were stronger, more disciplined, or more careful, I wouldn't be this sick. I was a child. It wasn't outright dismissal. It was misunderstanding, and at times, subtle blame. And over time, I internalized that.

I didn't know what was wrong, why it kept happening, or how to fix it. By my early teen years, that uncertainty had turned into a quiet but overwhelming hopelessness. I became deeply pessimistic. I struggled to imagine a future where I felt healthy, or even stable. I felt so exhausted, physically and emotionally, that I questioned whether I wanted to keep going. And then I decided that…I did not.

This mindset followed me through my teenage years and into early adulthood. It shaped how I showed up in the world. Socially, I often felt different, constantly negotiating my energy, symptoms, and limits while others seemed to move through life with ease. In subtle but cumulative ways, I missed out on events and things that slowly took away a meaningful part of my childhood.

Everything shifted when I moved to the United States for college and was diagnosed with CF at the age of 19. The diagnosis brought clarity, but also a flood of emotions. There was relief in finally understanding my body, but also grief, fear, and the weight of a lifelong condition.

Finishing a half marathon

However, for the first time, I had access to specialized care, accurate treatment, and a support system that truly understood what I was going through.

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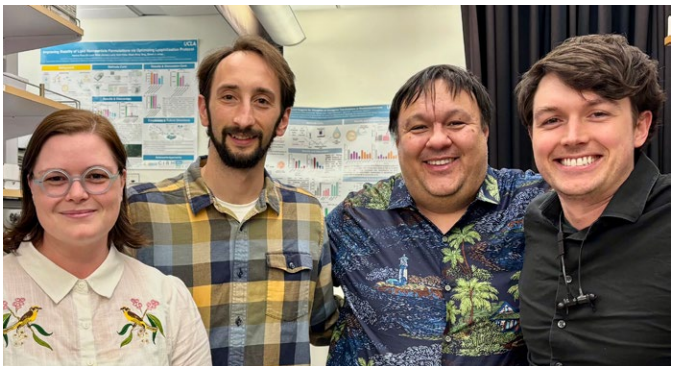
Advancing Delivery of Cystic Fibrosis Gene Therapies

Steven Jonas, MD, PhD and Ruby Sims, PhD

Mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene are the root cause of cystic fibrosis (CF).



Senior members of the Jonas lab; from left to right: Ruby Sims, PhD, William Fisher, PhD, Steven Jonas, MD, PhD, and Noah Zachary Laird, PhD.

Errors in the chloride ion channel encoded by the CFTR gene result in impaired mucociliary clearance in a patient's airway, chronic infection, and progressive lung damage. UCLA scientists in the laboratories of Drs. Steven J. Jonas, Brigitte Gomperts and Donald Kohn are working together to develop an advanced nano-scale toolkit to investigate gene therapy strategies for restoration of CFTR function toward a universally curative therapy for CF. To achieve this goal, three key nanotechnologies are being developed to edit the genome of airway stem cells, deliver these editing reagents to these cells, and ways to test these therapies outside the body.

To enable rapid, scalable screening of these treatments in vitro (in a culture dish), researchers in the Gomperts research group had to first establish advanced human airway submucosal gland organoid models that mimic key structural and functional aspects of the airway. These tissue-engineered models enable the research

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CFRI Community
Spring 2026

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Greetings from the President of the Board and the Executive Director

Dear CFRI Community,

CFRI is an organization by and for the cystic fibrosis community. Members of the Board of Directors recently completed CFRI's new Strategic Plan, which reaffirms our commitment to funding innovative research, providing responsive educational and psychosocial support programs, and advancing advocacy and awareness efforts to ensure improved access to early diagnosis and quality care. To learn more about our strategic goals and objectives, please visit our website: **www.cfri.org/about us**.

In 2026, CFRI will provide research awards to 10 brilliant scientists at universities and medical institutions across the country. Currently, members of our Research Advisory Committee are reviewing proposals; the recipients will be announced in late May.

There is a great deal of work still to be done. Approximately 10% of our community members cannot use CFTR modulators. Lung transplant recipients need better therapies. Disparities in diagnosis and care remain. Adults with CF face increased comorbidities, including high rates of cancer. Our mission-driven Board, staff and volunteers remain focused on addressing the diverse needs of our community now and into the future.

This is Julie and Siri's first letter together. After 16 years of dedicated and impactful leadership as Board President, Bill Hult handed the presidential reins to Julie. Julie has decades of involvement with CFRI. A retired pathologist and adult living with CF, Julie is a Member of the Board, former chair and current member of the Research Advisory Committee, and leader of our Mindfulness sessions. We wish to recognize Bill, and also Jessica Martens, who served as Vice-President for the past 16 years. We are grateful for their service, and that both remain on the Board!

Each one of us plays a part in the search for improved therapies and a cure. Working collaboratively, we can improve longevity and quality of life. We thank you for being a part of this engaged and caring community.

Julie Desch, MD | *President, CFRI Board of Directors*
Siri Vaeth, MSW | *Executive Director*

Learn and Be Inspired: CF Community Voices Has Something for Everyone

Created by and for the CF community, CFRI's video podcast program *CF Community Voices* shares information and insights about a wide variety of topics as well as inspirational stories from within the CF community. Recent episodes address issues including cancer screenings, nutritional recommendations for people with CF, IEP and 504 plans for students with CF, and intimate partner violence. In addition, there are videos from our Diversity and Inclusion Initiative. Many of the episodes are available with Spanish and Hindi subtitles, as well as captioning in English for the hearing impaired. New episodes are released monthly and can be downloaded on CFRI's podhosting site: **cfri.podbean.com**. You can also watch on CFRI's YouTube channel: **https://tinyurl.com/39kfd3ws**. We look forward to sharing our community's diverse voices.

CFRI's 2026 CF Community Voices is made possible to date with support from Viatris, and Vertex Pharmaceuticals.

The Many Faces of CF

The mistaken belief that cystic fibrosis only impacts people of European descent persists. This false narrative—partially perpetuated by outdated information and inadequate newborn screening programs—has exacerbated the physical, mental, and emotional burden of many people of color living with the disease. As a partner in living to all people with CF, CFRI remains steadfast in our commitment to ensuring that timely diagnoses, supportive care, developing therapies, useful resources, and opportunities for connection are made accessible for all.

Honoring our commitment to this vision, CFRI's Faces of CF Diversity and Inclusion Program is led by an active and engaged Advisory Committee, comprised of individuals with CF, family members, and healthcare professionals. This dynamic team helps guide the vision of many of CFRI's programs, utilizing their lived experiences to ensure equity and belonging are centered throughout.

In November 2025, CFRI released its fourth-annual CF Care Team Survey—a tool developed by the Diversity and Inclusion Advisory Committee to identify gaps in resources witnessed by CF care team providers across the country. Results yielded useful information. While 68% of respondents were confident that their CF centers meet the language and cultural needs of their patients and families, respondents noted additional tools and resources that might benefit their patients and families. CFRI aims to advance language accessibility for our community, translating documents and captioning videos into Spanish and Hindi, offering a monthly virtual support group for the Spanish-speaking CF community, and providing live captioning in a plethora of languages at our annual CF education conference.

Other insights from the survey included workshop topics suggested by CF social workers and clinicians to advance their efforts to provide culturally responsive and appropriate care. This year, CFRI is continuing the popular Faces of CF Diversity Workshop Series that began in 2025. Topics, including social determinants of health, access to mental health treatment, and unconscious bias, will be explored by people with CF, family members, and care team providers in an inclusive virtual setting.

Together, we can raise awareness, share experiences, and improve the quality of life for all those living with CF. For more information about CFRI's Faces of Diversity and Inclusion Program, please visit **www.cfri.org/diversity-and-inclusion**.

CFRI's Faces of CF Diversity and Inclusion Program is supported through grants from Genentech and Viatris.

CFRI's Online CF Wellness Classes: Get Moving and Improve Your Physical and Mental Health!

CFRI's wellness program was developed in recognition of the positive impact of movement and exercise upon one's physical and mental health. All our wellness classes are free, fun and interactive. Anyone with CF, as well as their parents, spouses, partners and siblings from across the country and globe are welcome to join. Boost your physical and mental health! Work out in a supportive online environment with your CF community peers. Classes are held on the first and third Saturdays of every month at 9:00 am PT / 12:00 pm ET. We offer a range of activities, from Slow Flow Yoga and Mat Pilates to U-Jam, strength building, and Qi Gong. You only need to register once to attend as many classes as you like. You will receive a reminder with a link within 24 hours of the launch of each class.

No experience is required; all abilities and mobilities are welcome!

For the complete schedule and to register, go to **cfri.org/wellness-classes/**.

CFRI's CF Wellness Classes are sponsored by Vertex Pharmaceuticals and Viatris, with additional support from individual donors through CFRI's Dance Like a Fool event.

Embrace ~ *A Retreat for Mothers of Children and Adults with CF*

CFRI will host its 12th Embrace Mothers Retreat from May 1 – 3 at the beautiful Vallombrosa Retreat Center in Menlo Park, California. Through art, yoga, writing and advocacy workshops, the retreat offers an opportunity for women who share the CF path to connect and rejuvenate. The theme of this year's Embrace event is "Building Strength from Within."

The Embrace Retreat was created to address the high rates of depression and anxiety that have been documented among mothers of children with cystic fibrosis. Sustained stress is emotionally and physically damaging, and this can directly impact their children's outlook and adherence to their medical regimen. Women travel from across the United States to attend, and through the years a supportive network has been created. Evaluations of Embrace participants show that the retreat is extremely effective in lowering symptoms of depression and anxiety.

For more information, please visit our website at **www.cfri.org**.

Embrace Mothers Retreat is generously sponsored by Vertex Pharmaceuticals.

The Diagnosis That Gave Me Back My Life

Continued from Cover

As my physical health began to improve, my mental health began to noticeably shift as well. Having a diagnosis replaced years of uncertainty with understanding. Feeling physically stronger gave me a new sense of control. And perhaps most importantly, being supported - by doctors who listened and people who believed me - helped me slowly unlearn the idea that my illness was somehow my fault.

Having answers changed how I saw myself and everything about this life. The constant instability, confusion, and hopelessness that had defined my life began to fade. I started to experience something I hadn't felt in years: HOPE.

Socially, I began to open up. It became easier to explain my experiences, to advocate for myself, and to let people in.

But healing did not erase the past. The years of being misunderstood, treatment for a condition I did not have, and the internalized belief that I was to blame left a lasting impact. Prolonged uncertainty and incorrect treatment lead to medical trauma that lingers even after things improve. Even now, there are moments when that history resurfaces.

At the same time, my life today looks very different from what it once did. There was a time when illness, known or unknown, felt like it controlled everything. It shaped how I thought, how I interacted, and how I imagined my future. In many ways, I am now living a life that once felt completely out of reach, better than anything I ever allowed my younger self to imagine. I have a new sense of hope, purpose, and direction. I can experience joy without it being overshadowed by constant uncertainty. I feel more grounded in my body and more connected to my life.

If anything, my experience has taught me the deep interconnection between physical health, mental health, and social wellbeing. When illness is misunderstood or misdiagnosed, the impact goes far beyond the body. It shapes identity, self-worth, and the ability to hope. Mental health must be an essential part of CF care… not just after diagnosis, but throughout the journey. No one should have to navigate years of uncertainty. No one should grow up believing their illness is their fault.

Today, one of my strongest motivations is to ensure that others do not go through what I experienced. Whether through advocacy, storytelling, or simply speaking openly about the mental health side of a chronic illness like CF, I want to help create a space where patients feel understood; not just physically, but emotionally.

CF may always be part of my life. Some days, it still takes up more space than I would like. But it no longer defines me. It's just one part of a much larger story. And that story is no longer about survival. It's about truly living and making sure others have that chance too.

CFRI's Patrick Nash Fellows Training Program – Aging in the New Era of CF: Advancing Multidisciplinary Research and Care

As adults with cystic fibrosis age, other health issues develop or worsen, including cancer, osteoporosis, diabetes, liver disease and cardiovascular complications. Now in its third year, the Patrick Nash Fellows Training Program, Aging in the New Era of Cystic Fibrosis, seeks to advance collaborative research and care by clinicians in multiple disciplines to address these multifaceted impacts of CF and aging.

Patrick Nash

The program honors Patrick Nash, an inspirational adult with CF who lost his battle with pancreatic cancer in 2022. Clinician researchers from diverse specialties are selected from a national pool of applicants to participate in an intensive symposium and quarterly discussions to advance understanding of CF non-pulmonary comorbidities, accelerate collaborative research, and ultimately, improve CF care models for adults. Fellows receive ongoing mentorship from leaders in the field and opportunities to collaborate. To date, 30 fellows, representing 22 institutions and 13 medical disciplines have participated, and are now pursuing exciting and impactful research and projects.

The application for the third-year cohort is now open with a deadline of June 8th. CFRI covers the cost of attendance at the three-day symposium, which will be held this year in Dallas, November 12 – 14. We encourage fellows and early career professionals up to two years post fellowship to apply. For more information, go to **www.cfri.org/research/funding-opportunities/**.

CFRI thanks Viatris, Vertex Pharmaceuticals, and the family of Patrick Nash for the grants and donations that make the 2026 program possible.

CFRI Funds Cutting-Edge Research to Move Us Closer to a Cure

At the core of CFRI's mission is to pursue a cure for cystic fibrosis by supporting innovative research. CFRI is committed to ensuring that research will continue toward a cure. We invest in the highest quality scientific research that will increase understanding of the disease, broaden treatment options, improve quality of life, and expand the search for a cure. Members of CFRI's Research Advisory Committee (RAC) are in the process of reviewing research proposals for the 2026-2028 funding cycle. RAC recommendations guide CFRI's Board of Directors' award decisions. Awardees will be announced in late May.

CFRI-funded researchers are pursuing work that includes diverse gene editing and repair strategies, phage therapies, the role of ionocytes, stem cell strategies, and addressing bacterial resistance. Currently funded researchers are listed below.

New Horizons Award Program

(For Principal Investigators)

- **Ashley Cooney, PhD** / University of Iowa
- **Daria Van Tyne, PhD** / University of Pittsburgh
- **Ruobing Wang** / Boston Children's Hospital
- **Daniel Wolter, PhD** / University of Washington
- **Feng Yuan, PhD** / University of Alabama at Birmingham

Elizabeth Nash Memorial Fellowship Program

(For Post-Doctoral Fellows)

- **Paul Bollyky, MD, PhD, *Principal Investigator***
  Saumel Rodriguez Perez, PhD, MS, *Postdoctoral Fellow*
  Stanford University
- **Steven Jonas, MD, PhD, *Principal Investigator***
  Ruby Sims, PhD, *Postdoctoral Fellow*
  University of California Los Angeles
- **Ron Kopito, PhD, *Principal Investigator***
  Celeste Riepe, PhD, *Postdoctoral Fellow*
  Stanford University
- **Sriram Vaidyanathan, PhD, *Principal Investigator***
  Brodie Ranzau, PhD, *Postdoctoral Fellow*
  The Research Institute at Nationwide Children's Hospital
- **Katrine Whiteson, PhD, *Principal Investigator***
  Sage Dunham, PhD, *Postdoctoral Fellow*
  University of California Irvine

All the researchers listed above will present their work at CFRI's 39th annual National Cystic Fibrosis Education Conference, which will be held July 24 to 26, 2026.

These promising projects are made possible through generous contributions from the community. Thank you to all whose support is advancing innovative cystic fibrosis research.

May is CF Awareness Month

Help Us Flood Social Media With Purple Purpose & Power Up CF Awareness

How to Participate

1. **Follow & Learn**
   Visit CFRI's social channels all May long to explore daily CF facts & Purple Power posts. And for our followers—weekly CF sticker & swag giveaways you won't want to miss.
2. **Share the Power**
   Like, comment & share our posts—or use our downloadable graphics to create your own Purple Power content to help us spread awareness.
3. **Take Action & Support**
   Tag **@CFRI.cureCF**, use **#CFRIPurplePower** & support CF by engaging, donating (if you're able) & spreading awareness. *Every action makes an impact!*

https://curecf.cfri.org/PurplePower2026

PURPLE POWER FOR CYSTIC FIBROSIS

Sponsored to date by
Viatris, Vertex Pharmaceuticals
and ***Sionna Therapeutics***

Tributes

Our *"In Memory of"* and *"In Honor of"* pages provide the opportunity to honor a person, or family, or to remember a loved one. If you want your donation to honor or remember someone special, please include the person's name and address with your donation.

At your request, we will send an acknowledgment of your gift to the person you designate.

Please mail your contributions to:
CFRI — 1731 Embarcadero Road, Suite 210, Palo Alto, CA 94303
Or go to **www.cfri.org** to make a donation online.

DONATE LIFE

www.donatelife.net

In Honor of

October 16, 2025 — March 15, 2026

Alexander Adams
Micah Baker
Thomas Bardenfleth
Lucy Larkin Barnes
Jennifer Belken
Marodean Bitbadal
Edesa Bitbadal
Terri Boskovich
Robert Boswell
The Britting Children
Lucas Buchanan
Naomi Burks
Gavin C
Gabriela Castillo
The Amazing CFRI Staff
John Christie
Patricia Cline
Mary Convento
Lauren Colonna Cooper
Cameron Cornell
Tim Crose
Barbara and Jim Curry
Stacy Dean
Julie Desch
Chuck and Edna Devore
The DeVore Family
Mackenzie Dondanville
Tess Dunn
Daniel Ellett
Everyone with CF
Alanah Rosenbloom Fink
Oscar Flamenco
The Flynn Family
Kathleen Flynn
The Frisbee Family
Zaylee Fults
Sean Gallagher
Cheri Geoghegan
Kathryn L Giebenhain
Todd Giebenhain
Larissa Giuliano
Elyse and Craig Goldberg
Michelle Goodlad
Emily Gorsky-Bonanno
Alma Graf
Pete Greenberg
Bonnie Grossman
Gianna Gutierrez-Serrato
Brendan Harrigan
Carrie Harwood
Melanie Henshaw
Niall Hibbard
Elli Hill
Susan Hoffman
Joshua Holdaway
Anna Modlin Holyoak
Thomas Horal
Erinn Hoyt
Margaux and Ryan Hughes
Clark Hummel
Michelle Jones
Joy Jubu
Cary and Ralph Kelly
Jeremy Kharrazi
Franny Kiles
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Michael Livingston
Joseph Arthur Lopez
Dyana Louet
Emily Fredrick Lucas
Larissa Marocco
Patty McCallister
Rachael and Rebecca McMullen
Carly McReynolds
Dillon Michael
Hannah Mitchell
Rebecca Mueller
Austin Murray
Jessica Nett
Tristan O'Neill
Aly, Maddie and Killian O'Reilly
Molly Pam
Niraj Patel
Kent Peterson
Lucy Phillipson
Natalie Puzia
Michael Reuscher
Megan Reveles
The Reynolds Family
Rebecca Roanhaus
Elizabeth Rogers
Corey Sarkis
Sebastian Sharpe
Janice Shaul
Ethan Spain
Simone Svikhart
Brian Tacke
Tara
Dr. Varsha Taskar
Ian Terrell
The Thibault Family
Roxanna and Jason Thomas
Adam Thompson
Jeremiah Travis
Robert Turk-Bly
Siri Vaeth
William Vogt
Matt and Melissa Weiner
The Wine Family
Jonathan Witczak

In Memory of

October 16, 2025 — March 15, 2026

Sonya Lyn Akister
Gianna Altano
Joe Anderson
Jay Archibald
Jessica Arvidson
Ann and Ronald Baldwin
Cara Baysinger
Anne Beltrame
Brett and Kitsy Bennett
Mary Auer Bolt
Theresa Boujie
Rebecca Boyer
Aggie Obeso Bradley
Greg Brazil
Cheri Brower
Jared Bulthuis
Jerry Christopher Burch
Kyle Butler
Isabel Stenzel Byrnes
Andrew Carl
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Carol Conrad
Michelle Rae Cowin-Gantz
John Cunningham
Neva DeVore
Anthony Di Profio
Jason Dolan
Pat and Sharon Dunn
Maxine Eggerth
Susie Ellerson
Caitlin Femmel
Victoria Flamenco
Yvonne and Barry John Florenza
Michael and Patricia Flynn
Jessie Marie Franks
Robert Franz
Jessica Fredrick
A Friend
Jade Frota
Laura Gale
Albert Ghan
Jenise Giuliano
Mark Glisson
Ray Goldstein
Diana Goodman
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Donald Yanik
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CFRI's Retreats for Adults with CF: Keeping the Community Connected

The CF Spring Retreat provided five days of connection for adults with cystic fibrosis (CF), along with family and friends. The event was held in a hybrid fashion from April 6 to April 10, 2026. Those attending in person enjoyed the tranquil beauty of the El Retiro Retreat Center in Los Altos, California, while participating in a wide array of health-related and psychosocial support programs and activities. Those participating online were able to connect with each other, as well as those attending in person.

Retreat provides a welcoming community for adults with CF looking for connection, information, and camaraderie with their peers. Participants heard from experts in the field on topics including nutrition, CF research advancements, and reproductive health. Art projects, yoga, qigong, support groups, a comedy workshop and talent show made this a full experience for all involved. New connections were forged, while old friends reunited in person and online.

CFRI's stringent cross-infection protocols were followed by all retreat participants. Attendees reported that the retreat offered new information about CF therapies and treatments, dramatically improved psychosocial health, and provided resources and strategies for coping with the daily challenges of CF.

The CF Adult Retreat Planning Committee is selling an array of clothing items in multiple colors and styles, with all proceeds supporting the Retreat. To shop, go to **https://curecf.cfri.org/LoveHeals2025**

The 2026 Virtual CF Summer Retreat will be held August 7-9.

CF Spring Retreat was generously sponsored by Vertex Pharmaceuticals, Devin Wakefield, and family bequests.

CF Quality of Life Programs: Supporting the Mental Health of Our Community

Those impacted by cystic fibrosis (CF) experience higher rates of depression and anxiety than the general population. With its unpredictability, daily treatment burden, and diverse symptoms, CF is a challenging disease for those diagnosed, as well as for those who love them. Studies show that depression and anxiety can negatively impact adherence to one's medical regimen. In response, CFRI offers a range of programs to address the psychosocial and mental health needs of our community.

Counseling Support: CFRI provides up to $125 per session for six sessions of counseling to individuals with CF (children and adults), and their family members with the licensed provider of their choice in their community. Participants must live in the U.S.

Support Groups: CFRI offers nine monthly online support groups for our diverse CF community members. Participants register once and then are able drop in monthly to connect with their peers. All groups are facilitated.

The following monthly groups are offered:

- *Caregivers/Parents of Children with CF;*
- *Caregivers/Partners/Spouses of Adults with CF;*
- *Adults with CF;*
- *Adults with CF Post-Transplant;*
- *Adults with a Late CF Diagnosis;*
- *CF Teen Connection;*
- *Conocimiento y Conexión;*
- *Navigating Grief to Growth;*
- *Those Who Cannot Benefit from CFTR Modulators*

Mindfulness: Shown to reduce anxiety and depression. CFRI offers quarterly workshops, each focused on different aspects of mindfulness and how it can offer positive coping skills for those living with CF. "Mindfulness to Manage Pain," focused on mindfulness and sleep, took place in March. The next session is scheduled for Tuesday, June 9. Open to those with CF and their family members, the workshops are taught by Julie Desch, MD, who lives with CF.

All groups and workshops are held via Zoom; participants log in from across the country and world. Please refer to our website for monthly meeting dates.

These programs are offered at no charge to our community members, thanks to our supportive sponsors. For more information, visit our website, or email Sabine Breon at sbreon@cfri.org.

Partners in Living Initiative – CF Quality of Life Programs are generously supported by Viatris, Vertex Pharmaceuticals, the Boomer Esiason Foundation, Genentech, and private donors, as well as contributions through CFRI's CF Quality of Life Program, a Living Legacy of Peter and Kathy Judge.

Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program

From conversations in the clinic setting to meetings held with representatives in Congress, CFRI engages the cystic fibrosis community to raise awareness of the ongoing physical, financial and emotional burdens of the disease. Through CFRI's Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program, progress is driven by and for the CF community. Year-long engagement of people with CF, family members, care team providers, researchers, and industry partners fuels change that directly impacts the health, well-being, and quality of life of those affected by the disease.

At the federal level, CFRI remains steadfast in supporting the passage of several bills that directly impact access to and the affordability of health care for individuals with CF. The HELP Copays Act (HR 6423) would make life-saving prescription medications more affordable for patients by requiring insurance companies and Pharmacy Benefit Managers (PBMs) to count the value of copay assistance they receive on a patient's behalf toward cost-sharing requirements. Studies have shown that when out-of-pocket costs reach $75 to $125, more than 40% of patients leave their prescriptions at the counter. By helping minimize the risk of patients making such a decision, HR 6423 ensures that payments, whether they come directly out of a patient's pocket or with help from non-profit organizations and prescription drug manufacturers, contribute toward an individual's annual deductible and out-of-pocket maximum.

In addition to the role they play in copay accumulator policies, PBM reform more broadly is a significant area of focus of CFRI's advocacy efforts. As the powerful intermediaries between insurers and drug manufacturers, PBMs have direct influence over the accessibility and pricing of prescriptions. The Pharmacy Benefit Manager Transparency Act of 2025 (S. 526) intends to stop the unfair and deceptive practices—such as steering patients to higher-cost drugs and preferred pharmacies. The bill would require PBMs to report pricing and formulary practices, pass 100% of rebates and discounts to health plans, and protect whistleblowers who report violations. In addition to advocating for progress of this bill at the federal level, CFRI is also actively engaged in monitoring PBM reform in states nationwide.

Coverage for Medicare beneficiaries to the least restrictive types of oxygen—such as portable concentrators and liquid oxygen—also remains an important policy issue for CFRI. Despite treatment advancements, many people with cystic fibrosis still require supplemental oxygen. A bipartisan bill, the Supplemental Oxygen Access Reform (SOAR) Act (S. 1409/HR 2902) would allow Medicare beneficiaries to choose oxygen suppliers and to receive transparent communication about services. In addition to those with CF aged 65 and above, 41.2% of people with CF under age 65 rely on Medicare through their Social Security Disability Insurance status. Everyone, regardless of insurance, has the right to breathe freely and fully. As an organization committed to improving quality of life for people with CF, CFRI continues to advocate for the passage of this bill.

Learn more, get involved, and begin advocating with CFRI today. For more information visit, **https://curecf.cfri.org/42h5wzvh**.

Supported to date through grants from Genentech and Vertex.

2026 Mothers' Day Fundraiser Brings Awareness and Hope! CFRI and the CF Community Need Your Support!

CFRI's annual Mothers' Day Celebration fundraiser is an annual tradition that involves hundreds of people, promotes awareness of cystic fibrosis (CF) among our friends and family around the globe, and ultimately raises over $165,000 to support CFRI's vital services to the CF community.

Your participation will have a meaningful impact!

While we celebrate therapeutic advancements that provide better health to many living with CF, thousands of people with CF are unable to benefit from the new CFTR modulators. We still have no cure for CF and the median age of death remains far too low.

This card's artwork, "Chrysler Imperial #28 of 65 Roses," was painted by Wanda Olson, who lost her 33-year-old daughter Michele to CF in 1999. Inspired by the story of a child who misheard his diagnosis of cystic fibrosis as "sixty-five roses," the rose symbolizes hope for a cure for CF. Wanda is creating 65 rose paintings in Michele's memory.

There are several ways to send your Mothers' Day invitations: in the mail, online, or through Facebook. If you have questions or need assistance, please contact Mary at 650.665.7559 or **cfri@cfri.org**; or go to **http://cfri.org/mothers-day-celebration/**. Thank you for supporting CFRI and those living with cystic fibrosis!

Jessica Fredrick Memorial CF Research Challenge Circle and Fund: Advancing CF Research

Members of CFRI's Jessica Fredrick Memorial CF Research Challenge Circle give generously to inspire others to join the search for new CF therapies and a cure. Last year, members of our circle contributed over $110,000 to match – dollar for dollar – donations from individuals designated to CF research. Together, these donations supported our New Horizons and Elizabeth Nash Memorial Fellowship CF research awards.

Please join this inspiring group! Become a member of the Jessica Fredrick Memorial CF Research Challenge Circle by making a minimum gift of $2,500. You will help inspire others to make the dream of a CF cure a reality. Challenge Circle Members receive updates on our research awards and the satisfaction of knowing their gift will attract additional donors.

Our Circle was initiated by Suzanne Freiley, whose beloved niece, Jessica Fredrick, lost her battle with CF at the age of 21. Despite tremendous progress in CF therapies, we continue to lose treasured members of our community to this cruel disease, and there is still no cure.

If you are unable to join the Circle, please consider making a gift to the Research Challenge Fund, which will be designated for CF research awards. In doing so, you help advance the search for new therapies and ultimately, a CF cure.

A Breath of Fresh Air ~ Celebrating 51 Years of Service to the CF Community *A Gala to Support CF Research, Education, Support & Advocacy Programs*

Save the date! CFRI's Breath of Fresh Air Gala will take place on **Saturday, October 17, 2026**, at the elegant Hillsborough Racquet Club (Hillsborough, California). Join us for this exciting evening event to celebrate our strong community and exciting research progress! Help us honor our 2026 CF Champion, Jacqueline Zirbes, DNP, RN.

Take a deep breath and be inspired to support the search for a CF cure! All proceeds will benefit CFRI's research, education, advocacy, and support programs to improve the lives of those with CF.

Sponsorship opportunities are available. For more information, go to **www.cfri.org**, or call **650.665.7586**.

Our thanks to our Hillsborough Racquet Club hosts, Jim & Barbara Curry. Generously sponsored to date by Vertex Pharmaceuticals and Viatris.

Advancing Delivery of Cystic Fibrosis Gene Therapies *Continued from Cover*

team to test the efficacy of these treatment strategies.

Researchers in the Kohn lab then explored using the CRISPR/Cas9 gene editing system to make cells permanently express functional CFTR. Three gene editing components are required for successful editing: messenger RNA (mRNA) encoding for DNA cutting enzymes, guide RNAs that target a specific location in the genome, and DNA templates encoding for CFTR. Upon successful delivery inside the cell, mRNA is translated into the Cas9 enzyme, which then complexes with the guide RNA to cut the cell's DNA at a precise location. When DNA inside the cell is cut or damaged, it races to fix the defect. At this point, there is an opportunity for additional DNA templates to be integrated into the cut site during repair. The UCLA research team takes advantage of this process to insert DNA that codes for a functional CFTR gene. As there are over 2,000 known CFTR gene mutations that lead to CF, the Kohn lab designed these reagents to cut and insert a correct full-length copy of CFTR upstream of any CF mutations. This work was recently reported as a preprint in bioRxiv (Sinha, V. et al. bioRxiv, 2025.2009.2021.677613 (2025). **https://doi.org:10.1101/2025.09.21.677613)**.[1] This strategy ensures that CFTR can be corrected irrespective of the type of mutation present, with the aim of creating a universal CF gene therapy.

To ensure that the gene editing tools are delivered to the most appropriate stem/progenitor cells in the airway, the Jonas Lab has been exploring the design of lipid nanoparticles (LNPs) optimized for packaging and transporting the gene editing constructs designed by the Kohn Lab. In a bronchial epithelial cell model (16HBEgeG542X), this approach achieved complete restoration of CFTR protein expression and function with only 3.5% genomic integration, underscoring the efficiency of this strategy. The team recently published these results in the journal Advanced Functional Materials where their article was featured as the front cover of the issue (Foley, R. A. et al. Lipid Nanoparticles for the Delivery of CRISPR/Cas9 Machinery to Enable Site-Specific Integration of CFTR and Mutation-Agnostic Disease Rescue. Advanced Functional Materials, e02540 **https://doi.org: https://doi.org/10.1002/adfm.202502540)**.[2]

Collectively, the UCLA team's uniquely integrated and multidisciplinary approach—combining gene editing, mRNA delivery, targeted nanoparticle engineering, and physiologically relevant in vitro models—establishes a comprehensive framework for the development of clinically translatable CF gene therapies. These advances represent a step toward achieving the complete and lifelong restoration of CFTR function required to achieve truly curative treatments for CF.

CFRI Is Your Partner in Living! Thank You for Your Support!

- **PURPLE POWER CF AWARENESS CHALLENGE:**
  Challenge friends and family to help us turn social media purple to raise CF awareness and support CFRI. Post your pics of purple outfits, purple makeup, purple food, etc. and tag us!
- **HOLD YOUR OWN EVENT:**
  Cocktails for a cure, a benefit yoga session, Pictionary challenge – no idea is too big or too small. Create an event, and we'll help you make it happen.
- **FACEBOOK/INSTAGRAM:**
  Many community members create fundraisers for CFRI by donating their birthdays or other special events on Facebook and Instagram.
- **MONTHLY GIVING:**
  Champions of Hope! Donations to *Champions of Hope* provide a consistent revenue stream to support research to find a cure for CF and enhance CFRI's programs in CF education, support and advocacy.
- **TRIBUTES:**
  "In Honor Of" and *"In Memory Of"* – Recognize a loved one with your choice of gift. CFRI will promptly send an acknowledgement letter to your designee.
- **STOCK DONATIONS TO CFRI:**
  Donating appreciated stock avoids capital gains taxes incurred had the stock been sold. You're also entitled to an income tax charitable deduction for the stock gift date's fair market value.
- **PLANNED GIVING:**
  Benefits provided through planned giving may include increased income, substantial tax savings, opportunity to meet your philanthropic goals, and the satisfaction of making a very significant gift to CFRI during your lifetime.
- **BEQUESTS:**
  Include CFRI as a beneficiary in your Will or Living Trust. At the time of your passing, your designated amount would come to CFRI – tax-free to your heirs and CFRI.
- **VEHICLE DONATIONS:**
  CFRI is partnering with CARS (Charitable Adult Rides & Services) to accept donations of used vehicles. CARS takes care of everything from the pick-up and sale to sending you the donation receipt and tax documents. You can donate a car, motorcycle or boat.

For more information, please contact
***Marina Gonzales**, Programs & Outreach Associate,*
*at **mgonzales@cfri.org***

SAVE THE DATES!

Please sign up to receive our weekly eNewsletter to stay informed of our many programs and events!

CF Virtual Support Groups – Nine Options Held Monthly

See groups and dates on page 8, or go to **www.cfri.org** for information.

All support groups are free and held on Zoom.

Purple Power CF Awareness Campaign

May 1 – May 31, 2026

See details on page 6

Mindfulness Workshops

June 9 / September 8 / December 8, 2026

Topics to be announced

Quarterly online Mindfulness workshops for the CF community with Dr. Julie Desch

CFRI 39th National CF Education Conference

July 24 – July 26, 2026

Ameswell Hotel (Mountain View, CA) and Online

(See back page for speakers, topics, and sponsors)

CF Summer Retreat – Virtual

August 2026

Dates to be accounced soon!

Cinnabar Hills Benefit Golf Tournament for CFRI

August 17, 2026

For information contact Scott Hoyt:
dscott.hoyt@gmail.com

CFRI's Gala "A Breath of Fresh Air"

Saturday, October 17, 2026

Hillsborough Racquet Club (Hillsborough, CA)

For information or to register for these events, please email cfri@cfri.org or call 650.665.7559.

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

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CFRI's mailing list is confidential. We do not sell our list, nor do we give out any names or addresses under any circumstance.

CFRI Mission

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

CFRI Vision

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

For their generous support of ***CFRI Community,*** special thanks to:
Vertex Pharmaceuticals, Viatris, AbbVie, *and* **Sionna Therapeutics**

Visit our website at:
www.cfri.org
for more information about us and about cystic fibrosis.
Call toll free: 855.cfri.now

A Wave of Progress ~ CFRI's 39th National Cystic Fibrosis Education Conference

July 24 – July 26, 2026

A Hybrid Event: In Person (Ameswell Hotel Mountain View, CA) and **Virtual**

A full weekend of information and community!

- Renowned clinicians, speakers and CFRI-funded researchers presenting on diverse topics including : sleep and CF, mRNA and gene therapies, CF gut and lung health connection, reproductive health, phage therapy, CFRD, and the impacts of aging with CF.
- Opportunities to connect with expert clinicians, researchers and exhibitors.
- Lively receptions, including our "Innovations and Libations" reception, annual awards dinner and dance party.

Virtual attendees can view all presentations live on our interactive event platform.

In-Person Registration: $240 – *includes all presentations, conference meals, award banquet, receptions, and support groups.*

Single Day Rates Available: $55 – $150 **Virtual Registration: *Free***

Room rate at the boutique Ameswell Hotel only $149 per night – *must book through CFRI block (use QR code on the right or link on Conference website) by July 3.*

Ameswell Hotel

2026 Speakers include: Sigrid Barrett, PhD, RN • Jake Brockmeyer, PharmD, BCPS, BCPPS • Kimberly Canter, PhD • Ashley Cooney, PhD • Sage Dunham, PhD • Steven Freedman, MD, PhD • Manu Jain, MD • Tré La Rosa • Kimberly Morse, MSW, LCSW • George O'Toole, PhD • Gabriela Oates, PhD • Niraj Patel • Brodie Ranzau, PhD • Celeste Riepe, PhD • Saumel Perez Rodriguez, PhD • Kevin Scully, MB, BCh, BAO • Ruby Sims, PhD • **Panel:** Art Brace, PhD; Julie Desch, MD; Laura Mentch, EdM - Moderated by Ahmet Uluer, DO, MPH • Daria Van Tyne, PhD • Ruobing Wang, MD • Daniel Wolter, PhD • Feng Yuan, PhD

For more information or to register, visit **www.cfri.org** or scan QR code.

Conference Info.

Generously sponsored to date by: **Vertex Pharmaceuticals, Viatris, Sionna Therapeutics,** *and the* **Boomer Esiason Foundation**

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