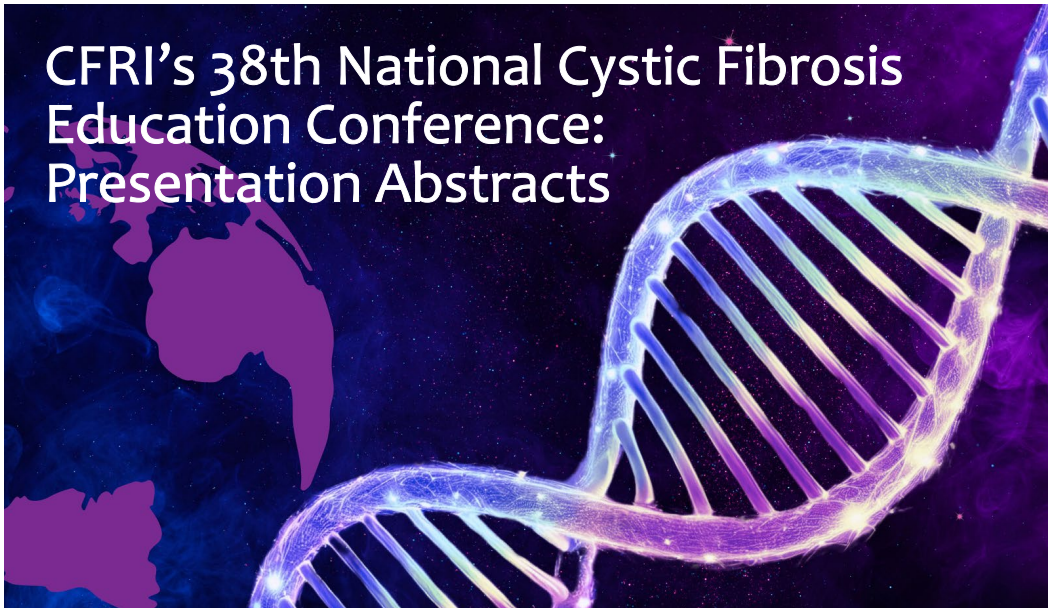
CFRI community
50 Years of Research, Education, Advocacy, & Support
Fall 2025

CFRI's 38th National Cystic Fibrosis Education Conference: Presentation Abstracts



CFRI held its 38th National CF Education Conference, ***A World of Possibility***, as a hybrid event July 25 - 27, 2025. Over three days, attendees from across the country and globe heard from nationally renowned speakers on a wide range of CF-related topics. The abstracts below appear in shortened versions. These presentations are now available for viewing on CFRI's YouTube channel: **https://cfri.tiny.us/2025Conference**

Living Beyond Rare: My Journey with CF, Defying Limits with a Unique Perspective

Jaelyn Cooper, MHA — *Irving, TX*

Jaelyn Cooper, MHA

This presentation shares the experience of a young woman living with cystic fibrosis –- a rare disease made even more isolating by how uncommon it is within her racial community. As an African American, Jaelyn Cooper represents a small and often overlooked group within the CF community. Her journey reflects the added challenges of not only managing a complex chronic illness, but also navigating a healthcare system where racial assumptions, gaps in representation, and limited understanding of diversity in CF care continue to exist.

Beyond the medical demands of CF, Jaelyn's story highlights the emotional and social challenges she faced throughout childhood, adolescence, and adulthood – including hospitalizations, disruptions to daily life, and the emotional weight of feeling different and isolated. She also encountered moments where assumptions about her race created added doubt and misunderstanding about her condition, leading to unnecessary challenges in receiving appropriate care.

Despite these obstacles, Jaelyn's journey reflects strength, perseverance, and growth. Through ongoing care, support, and self-advocacy, she continues to overcome challenges while using her experiences to

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Celeste Riepe and Ron Kopito at Stanford University

Pharmacogenomic Analyses of Corrector-Resistant Cystic Fibrosis

Celeste Riepe, PhD and Ron Kopito, PhD — *Stanford University*

The advent of CFTR modulators – small molecule drugs that correct underlying structural defects in disease-causing CFTR variants - has revolutionized CF therapeutics since FDA approval of ivacaftor in 2012. Despite the remarkable success of CF modulators, ~15-20% of people with CF (pwCF) are unable to be helped because they experience intolerable side effects or because they have CFTR variants that do not respond to the drugs. Consequently, there is a pressing unmet medical need to develop new therapeutic strategies for pwCF. Towards this end, Professor Ron Kopito and Postdoctoral Fellow Celeste Riepe at Stanford University are using genome-wide CRISPR analysis to identify novel drug targets that work through different mechanisms than the current FDA-approved drug therapies.

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CFRI Community
Fall 2025

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Letter from the Executive Director and President of the Board

Dear Friends,

As we approach the final months of 2025, we reflect on CFRI's **fifty years** of research funding and service that has been made possible through generations of CFRI community members. CFRI's founding families were fully committed to advancing cystic fibrosis research, and set the path for our organizational community-based soul. CFRI has always been - and forever will be - by and for the CF community.

As we witness exciting advances in therapeutics and care, we recognize the work that remains ahead. CF remains a harsh and capricious disease, and many members of our community are still waiting for transformative therapies. CFRI is proud to fund innovative research to move us closer to a cure, and this year, CFRI's Board of Directors voted to expand funding to support ten exciting research projects at institutions around the country. The funding provided by CFRI is often the spark that lights a larger funding flame. We have an excellent track record of supporting projects that provide proof of concept for far larger grants from other funding sources, including the NIH. In this issue, you can see the incredible work taking place in labs across the country.

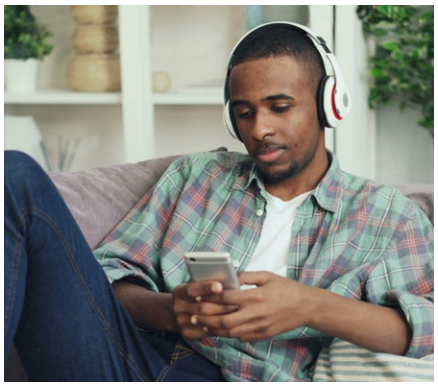
In addition to research, we stand firm in our commitment to programs that enrich the lives of all impacted by CF. This requires creativity in securing new sources of revenue so as to maintain our quality services. As you will see in the enclosed Annual Report, our recent audit once again confirms that we are a financially stable organization with excellent scale management.

Thank you for your consistent generosity and support. We ask you to join us in reaffirming our collective commitment to the work ahead to find definitive cures for all.

Warm regards,

Siri Vaeth, MSW | *Executive Director*
Bill Hult | *President, CFRI Board of Directors*

Knowledge and Inspiration: *CF Community Voices* Has Something for Everyone



By the community and for the community, CFRI's video podcast program CF Community Voices was created to share information and insights about a wide variety of topics as well as inspirational stories from within the CF community. Recent episodes address issues including CF and incontinence, the CF gut microbiome, CF and hearing loss, and personal post-transplant journeys. 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 2025 CF Community Voices is made possible with support from Viatris and Vertex Pharmaceuticals.

Moving Us Closer to a Cure: CFRI-Funded Cutting-Edge Research

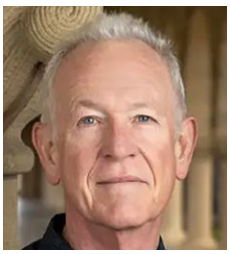
Through its research awards programs, CFRI advances our understanding of cystic fibrosis and the search for new therapies and a cure. With the support of our community, we are currently providing grants to the following researchers. Much of this research will benefit all those living with CF, regardless of their CFTR mutation. CFRI has an excellent track record of selecting innovative projects that then achieve the proof of concept necessary to attract larger funding. CFRI's research awards are provided through contributions from individuals, family foundations and bequests.


Paul Bollyky


Saumel Rodriguez Perez


Steven Jonas


Ruby Sims

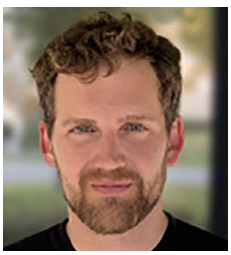

Ron Kopito


Celeste Riepe


Sriram Vaidyanathan


Brodie Ranzau


Katrine Whiteson


Sage Dunham


Ashley Cooney


Daria Van Tyne

Elizabeth Nash Memorial Fellowship Program (For Post-Doctoral Fellows):

- **Paul Bollyky, MD, PhD, *Principal Investigator***
  Saumel Rodriguez Perez, PhD, MS, *Postdoctoral Fellow* / Stanford University
  Development of a Phage-Based Gene Delivery Platform for Restoring Wild-Type CFTR Expression in the Human Lung Epithelia
- **Steven Jonas, MD, PhD, *Principal Investigator***
  Ruby Sims, PhD, *Postdoctoral Fellow* / University of California Los Angeles
  Designing A Cystic Fibrosis Gene Therapy Nanocarrier Platform to Target and Modify Airway Stem Cell-Derived Ionocytes
- **Ron Kopito, PhD, *Principal Investigator***
  Celeste Riepe, PhD, *Postdoctoral Fellow* / Stanford University
  Pharmacogenomic Discovery Of Therapeutic Targets for Corrector- Resistant Cystic Fibrosis
- **Sriram Vaidyanathan, PhD, *Principal Investigator***
  Brodie Ranzau, PhD, *Postdoctoral Fellow* / The Research Institute at Nationwide Children's Hospital
  Gene Insertion of a Gain of Function CFTR Variant to Improve CFTR-Mediated Ion Transport
- **Katrine Whiteson, PhD, *Principal Investigator***
  Sage Dunham, PhD, *Postdoctoral Fellow* / University of California Irvine
  Overcoming Evolved Bacteriophage Resistance Via Next-Generation Directed Evolution

New Horizons Award Program:

- **Ashley Cooney, PhD** / University of Iowa
  Permanent Gene Repair by AAV-mediated Base Editing in CF Pigs
- **Daria Van Tyne, PhD** / University of Pittsburgh
  Optimization Of Activity and Improved Delivery of Bacteriophages Targeting Burkholderia spp
- **Ruobing Wang, MD** / Boston Children's Hospital
  Pulmonary Ionocyte Differentiation and Function Using Stem Cell Derived Airways
- **Daniel Wolter, PhD** / University of Washington
  Role of Bacterial Metabolism in Promoting Antibiotic-Tolerant Staphylococcus Aureus CF Infections
- **Feng Yuan, PhD** / University of Alabama Birmingham
  Dissecting Pulmonary Ionocyte Subtypes and Their Functional Roles In Cystic Fibrosis


Ruobing Wang


Daniel Wolter


Feng Yuan

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

Due to its unpredictability, daily treatment burden, and diverse symptoms, cystic fibrosis remains a challenging disease for those diagnosed, as well as for those who love them. Those with CF and their family members have elevated rates of depression and anxiety, and studies show that depression can negatively impact adherence to one's medical regimen. To provide support, CFRI offers a range of programs to address the psychosocial 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), their parents, partners, spouses, and siblings with the licensed provider of their choice. Participants must live in the U.S.

- **Support Groups — *Facilitated Peer Support, Free and Open to the National and International CF Community via Zoom:***

  — **Caregivers Support Groups:** Two groups are offered – one for parents of children with CF, and another for parents/spouses/partners of adults with CF. The groups are held on the third Tuesday of every month.

  — **CF Adult Support Groups:** Adults with CF are invited to this group, held the third Monday of every month.

  — **Transplant Support Group:** This group is open to CF adults post-transplant. Meetings are held on the fourth Wednesday of every month.

  — **Late Diagnosis Support Group:** This group is offered to adults with a late CF diagnosis. Meetings are held on the first Wednesday of every month.

  — **Conocimiento y Conexion:** This group welcomes Spanish-speaking adults with CF as well as family members of adults and children with CF. Facilitated in Spanish, the group meets the second Wednesday of every month.

  — **Teen Support Group:** Teenagers with CF meet the third Wednesday of every month. Parents must give consent teens' participation.

  — **CF Bereavement Group:** For those who have lost a loved one to CF, this group includes sharing and discussion, goal setting, grief education, and self-care strategies. The group meets the second Tuesday of each month.

  — **Support Group for Those Who Cannot Use CFTR Modulators:** This group meets on the fourth Thursday of every month.

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

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

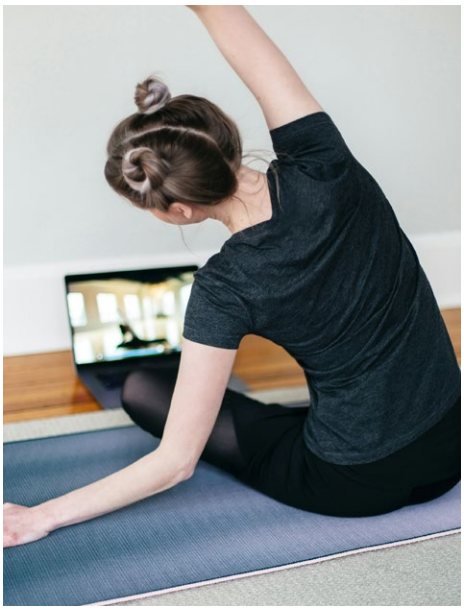
CFRI's Cystic Fibrosis Wellness Classes: Virtual Programs to Improve Physical and Mental Health

CFRI's CF Wellness Program was developed in recognition of the positive impact of movement and exercise upon one's physical and mental health. These online classes are free, fun and interactive, and are open to those with CF, as well as their parents, spouses, partners and siblings nationwide. Participants are able to improve their physical and emotional health while working out in a supportive online environment.

Classes are held on alternating Thursdays (4:00 pm PT / 7:00 pm ET) and Saturdays (9:00 am PT / 12:00 pm ET), and offer a range of classes, from Yoga and Groov3 to strength training and mobility. You can register for both the Thursday and/or Saturday track, and attend as many classes as you would like. No experience is required for any classes, and all abilities and mobilities are welcome. For the complete schedule and to register, go to **cfri.org/wellness-classes/**.

For next year, we're planning some exciting changes to this program. Rather than weekly classes, we will offer interactive educational workshops with participatory activities, to support our community's physical, mental, and emotional health. Stay tuned for details!

CFRI's 2025 CF Wellness Classes are sponsored by Vertex Pharmaceuticals and Viatris, with additional support from individual donors through our Dance Like a Fool event.



The Many Faces of CF

While major changes to U.S. policy and legislation have reshaped access to healthcare and social services nationwide, CFRI remains steadfast in its commitment to advance diversity, equity, inclusion, and belonging across the organization's four foundational pillars of research, education, advocacy, and support. CFRI's Faces of CF Diversity and Inclusion Program is led by an active and engaged Advisory Committee, composed of individuals with CF, family members, and healthcare professionals who translate their lived experiences into expertise that drives impact-focused programming.

CFRI creates video and print media that directly addresses CF diagnosis, treatment, and care across the African American, Hispanic/Latinx, East Asian, and South Asian communities. To improve global health literacy and empowerment, CFRI has translated many of its most popular resources into Spanish, and multilingual captioning is available on many of CFRI's audio-video podcasts, accessible through its YouTube and Podbean channels.

In addition to its longstanding efforts in developing educational materials and podcasts, CFRI launched a new initiative in 2025

to offer quarterly workshops for the CF community, focused on the promotion of inclusive, collaborative, and diverse CF care. These virtual workshops—open to individuals with CF, family members, and CF care team personnel—have covered topics such as mindfulness practices to facilitate diversity-centered conversations, the use of inclusive language, affirming patient rights, and enhancing research recruitment to mirror culturally responsive CF care. To make the content shared in these workshops accessible, presentation materials and video recordings are available at no cost to all registrants.

CFRI also offers many support groups to directly address the multifaceted needs faced by all people with CF, and specifically those of diverse racial and ethnic backgrounds. Support groups include, but are not limited to, adults who received a late diagnosis, have undergone a transplant, cannot access modulator therapies, or feel most comfortable communicating in Spanish. These groups are facilitated by professionals who skillfully create spaces of knowledge, safety and connection for all attendees. To further support mental health, CFRI also offers up to six sessions of counseling with a licensed therapist in any language.

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 CF Diversity and Inclusion Program, please visit **www.cfri.org/diversity-and-inclusion** or contact **cfri@cfri.org**.

CFRI's Faces of Diversity and Inclusion Program is supported through grants from Viatris, AbbVie, ReCode Therapeutics, Genentech, and Gilead Sciences.

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

Studies show that mothers of children with cystic fibrosis have elevated rates of anxiety and depression, which can directly impact their children's outlook and adherence to their medical regimen. Since 2015, CFRI has hosted its Embrace Retreat for mothers to provide women with connection and support. The in-person weekend retreat, held in May 2025 at Vallombrosa Retreat Center, was filled with presentations, journaling, yoga, and an overview of CFRI resources to provide lasting support. For the first time, the Retreat also offered a Broken Bowl® workshop, based on the ancient Japanese art of kintsugi, during which participants broke, decorated, and restored ceramic bowls, mending the cracked seams with gold, creating a powerful symbol of their CF journey. A virtual retreat was also held in September, which brought together women from across the country to connect, while offering an impactful workshop on medical trauma and caregivers, presented by CF social worker, Kate Yablonsky, LCSW. The role of a mother with a chronically ill child is unique. The bonds created during the Embrace Mothers' Retreats sustain participating women beyond the event. Evaluations of Embrace attendees show that Embrace is extremely effective in lowering symptoms of depression and anxiety. Participating in workshops and activities while connecting with others who share the CF path helps mothers to build resilience for the ongoing challenges presented by this disease.

We are very grateful to our sponsors: Vertex Pharmaceuticals and AbbVie.

CFRI's A Breath of Fresh Air Gala ~ Celebrating 50 Years of CF Research Progress!

CFRI's gala to celebrate our 50th anniversary was held on October 11, 2025, at the beautiful Hillsborough Racquet Club. In-person guests enjoyed the festive atmosphere, delicious food and fine wines. The gala program launched with an inspiring video message from CF community members, while our emcee, Chris Chmura of NBC Bay Area, guided us through a fast-paced but moving program which highlighted CF community members and CFRI-funded researchers. Edesa Bitbadal, mother of a teenage son with CF who is part of the 10% unable to benefit from current CF modulator therapies, stressed the importance of continued investment in CF research. We honored John Mark, MD, of Stanford Children's Health, as our 2025 Cystic Fibrosis Champion. An exciting auction led to spirited bidding. The program ended with a moving musical performance by Tess Dunn, who lives with CF. In addition to the live event, community members across the country were able to bid in our virtual auction.

Over $137,000 was raised to support CFRI's research, education and support programs. $40,000 of this total is being matched dollar-for-dollar by members of CFRI's Jessica Fredrick Memorial CF Research Challenge Circle and designated for our CF research awards.

Warm thanks to all who played a part in the production of our gala. We are grateful for our generous sponsors, in-kind donors, attendees and hardworking Gala Committee members. Everyone played a role in our gala's success – it was truly *A Breath of Fresh Air!*

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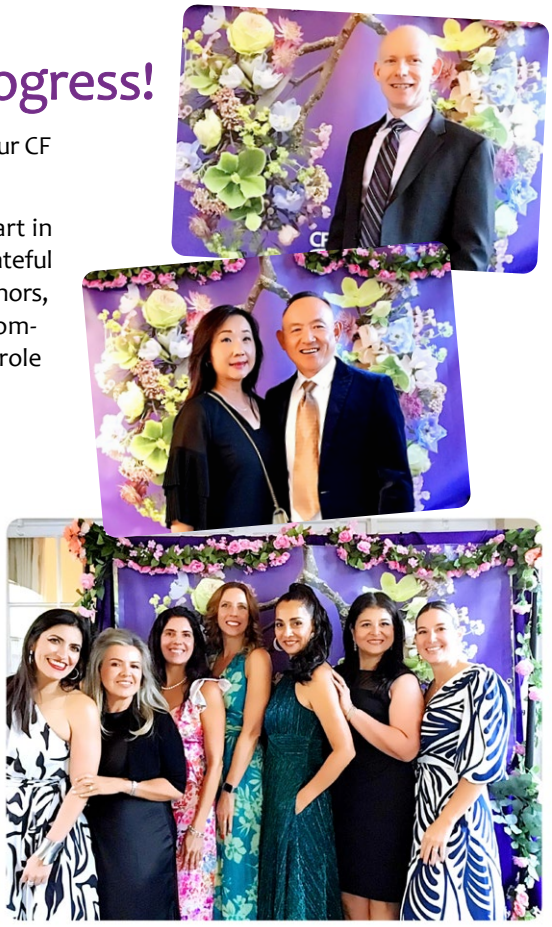

A BREATH OF FRESH AIR GALA
at the Hillsborough Racquet Club
Celebrating 50 Years
CFRI Cystic Fibrosis Research Institute
1975 - 2025

CFRI's Retreats for Adults with CF: Keeping the Community Connected

The CF Summer 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 in August, 2025. Those attending in person enjoyed the tranquil beauty of the El Retiro Retreat Center in Los Altos, California.

The retreat provided a wide array of health-related and psychosocial support programs and activities. In addition to exercise activities tailored to individuals' unique capacities, participants heard from experts in the field on topics including phage therapy for CF lung infections, CF and the gut microbiome, and vaccines for people with CF. Art projects, yoga, qigong, support groups, a talent show and improv workshop made this a full experience for all involved. Participants ranged in age from 18 to 70. New connections were forged, while old friends reunited in person and online.

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. Retreat provides a welcoming community for adults with CF looking for connection, information, and camaraderie. The 2026 Spring Retreat will be held as a hybrid event April 6 - 10 at El Retiro in Los Altos, CA. More details coming soon.

CF Summer Retreat was generously sponsored by Vertex Pharmaceuticals, AbbVie, Devin Wakefield, and generous bequests.

CFRI Is Your Partner in Living!

- **HOLD YOUR OWN VIRTUAL 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.
- **PARTICIPATE IN A CFRI EVENT:** Dance Like a Fool, Purple Power, Year-End Research Challenge, or the Gala – we have something for everyone!
- **FACEBOOK:** Every penny raised through Facebook goes to CFRI with no fees. Many community members create fundraisers for CFRI by donating their birthdays or other special events on Facebook. Go to **https://www.facebook.com/cfri.curecf**, scroll down to Fundraisers, and click on Create!
- **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. To participate, go to our website or contact Stacie Reveles (see below).
- **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 will 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 Mary Convento at ***cfri@cfri.org****.*

Be the Change – CFRI Advocacy Efforts Address Issues Impacting the CF and Rare Disease Communities

Through its Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program, CFRI seeks to engage the CF community to raise awareness among the general public and legislative sectors about the burdens and complications of the disease, lack of cure, impact of its rare disease status, and the need for further support for CF research.

CFRI advocates seek to address issues that are detrimental to those impacted by the disease. In recent months, CFRI advocates have participated in virtual and in-person meetings with elected representatives and their aides at both the state and federal level.

Currently we are monitoring the impacts of the Medicaid cuts upon patients and providers and invite members of our community to share their experiences with us. Personal stories will have great power as we advocate for our community.

At the federal level we encourage increased financial support for the Food and Drug Administration (FDA) and National Institutes of Health (NIH). We support the SOAR Act (Supplemental Oxygen Access Reform), which would access to portable oxygen by members of our community. Currently, due to low reimbursement rates, many people are tethered to oxygen tanks or concentrators at home.

We also highlight the bipartisan Nancy Gardner Sewell Medicare Multi-Cancer Early Detection Screening Coverage Act (MCED) (H.R. 842 / S. 339) that would ensure coverage for innovative FDA-approved early cancer detection tests for those on Medicare. As life expectancy for people with CF increases, the prevalence of cancer diagnoses follows suit. A growing number of individuals with CF under age 65 rely on Medicare through their Social Security Disability Insurance status (16.8% among those ages 30-35; 26.8% among those ages 40-64). This bill has the potential to save and extend the quality of life for those with CF as well as millions of Americans through advanced and more comprehensive multi-cancer early detection (MCED) screening. This bill is currently the most broadly co-sponsored bill in Congress.

On the state and federal level, CFRI is concerned by the growing power of pharmacy benefit managers (PBMs) in impacting medication costs. These powerful intermediaries between insurers and drug manufacturers often put profits ahead of patients and local pharmacies. Today, just three PBMs—Express Scripts, CVS Caremark, and Optum Rx—control approximately 80% of the prescription drug marketplace, impacting nearly every insured person in the US. PBMs have been known to steer patients toward higher-cost drugs and preferred pharmacies, charge excessive administrative fees, and reimburse pharmacies for less than what patients pay. These practices have led to higher costs for patients, while forcing many smaller pharmacies – particularly in rural areas – to close. There is both federal and state level legislation to better regulate this industry (including in California, where SB41 was just signed into law to mandate greater PBM transparency).

On the state level, we continue to focus on the creation of Rare Disease Advisory Councils (RDACs), which provide the rare disease community with a formal platform and official voice at the state level to help advise state officials on policies and services that impact us. CFRI is a member of several coalitions working to advance these efforts.

CFRI also participates with several coalitions to address the proliferation of co-pay accumulator policies within private insurance plans which create significant financial hardship for many members of our community. Co-pay accumulator programs do not allow payments from drug manufacturer discount cards to be applied toward a person's deductible and total out-of-pocket expenses. As a result, many individuals with CF and their families are shocked to find that they still have a large deductible to meet months into the calendar year. It has been found that one in four people with CF have delayed seeking care or skipped treatments because of costs related to insurance premium rates, deductibles, out-of-pocket expenses, and co-payments. CFRI is working with others to support legislation that will mandate that all

Continued on page 15

In Honor of

April 1, 2025 – October 15, 2025

The Adelman Family
Kyle Baker
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Lucy Larkin Barnes
Maggie-Faye Bendz
Andrew Carl
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Siri Vaeth
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Matthew Weiner
Ricky Whicker
Jonathan Witczak

In Memory of

April 1, 2025 – October 15, 2025

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Lisa Steiding
Anabel Stenzel
Robin Stephenson
David Stuckert
Laurie Stuckert
Norma Stuckert
Erin Phillips Taylor
Tara Telford
Roxanna Thomas
June Thompson
John Trask
Louis Anthony Trigueiro
Todd Trisch
Mark and Doris Ures
Tom Walton
Sean Waltrip
Debbie Ware
Gerry Weatherly
Tara Weir
Kelly Wilson

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.

Honoring Our Community Heroes

At the 38th National CF Education Conference in July, CFRI proudly honored four remarkable people for their outstanding contributions to the CF community. We are grateful for their time and commitment to those living with cystic fibrosis.

Christine Nash, MBA

David Stuckert Memorial Volunteer of the Year Award

Christine Nash, MBA

Christine Nash is recognized for her exceptional dedication and contributions to the CFRI community and unwavering commitment to advancing research and care for people with CF. Christine is the sister of the late Patrick Nash and the late Elizabeth Nash, both of whom lived with cystic fibrosis. Christine has worked in partnership with CFRI for many years through the Elizabeth Nash Foundation, which provides support for CFRI's research awards. In recent years, Christine has demonstrated exemplary service to the inaugural CFRI Patrick Nash Fellows Training Program, where she has played a vital role in shaping the program's vision and objectives to create a new model of multi-disciplinary care for adults with CF. Christine's passion, empathy, and dedication uplift the CFRI community.

Raksha Jain, MD

CFRI CF Professional of the Year Award

Raksha Jain, MD

Dr. Jain is Medical Director of the Adult Cystic Fibrosis Program at UT Southwestern Medical Center, a Professor in the Department of Internal Medicine and member of its Division of Pulmonary and Critical Care Medicine. She is a leader in the field of pulmonology, participating in research on an international scale that has translated to new therapies for those living with CF. Dr. Jain brings hope to those living with this devastating disease due to her patient-focused clinical care, impactful research, and volunteer service. She has over 100 published research articles focusing on diverse CF-related topics. Dr. Jain has been involved with CFRI for many years, presenting at CFRI conferences, participating in podcasts, and serving as a resource for CFRI's team members. She is committed to health equity and has advocated for a new roadmap for clinical trial recruitment on a global level. We celebrate Dr. Jain.

Anna Payne

CFRI Partners in Living Award in Memory of Anabel and Isabel Stenzel

Anna Payne (Posthumous)

Anna Payne's involvement with CFRI began in 2018, through CFRI's Externally-Led Patient Focused Drug Development meeting with the FDA. She then joined the CF Adult Advisory Committee. Anna was a Pennsylvania Rare Disease Advisory Council appointee, and served as an elected Township Supervisor. In 2021, at the age of 34, Anna was diagnosed with stage-4 colon cancer. She faced this battle with bravery and pragmatism, and an unwavering commitment to help others avoid her fate. She pursued every means to raise awareness of the high incidence of colorectal cancer among those with CF, and the need for earlier screening. She became an ambassador with Fight Colorectal Cancer, formed the Bucks County CF Alliance, and raised funds to support CFRI's advocacy efforts. Anna died from complications of colon cancer in February 2025. Her quick wit, passion, and commitment are greatly missed, but her legacy will continue.

Carol Conrad, MD

Paul M. Quinton Cystic Fibrosis Research Legacy Award

Carol Conrad, MD (Posthumous)

Dr. Conrad, pediatric pulmonologist at the CF Center at Lucile Packard Children's Hospital at Stanford, was the former director of the Pulmonary Function Lab and of the Lung and Heart-Lung Transplant Program at Stanford Medicine Children's Health. During her fellowship training at Johns Hopkins University, Dr. Conrad played a central role in demonstrating proof-of-concept for gene therapy in cystic fibrosis. Dr. Conrad joined Stanford Medicine in 1995. She received CFRI funding for a research project, "Efficacy of AAV-CFTR Vectors." Dr. Conrad was a beloved CF clinician who treated hundreds of pediatric CF patients during her 26+ years in clinic. She served as medical director of Stanford Children's Pediatric Lung and Heart-lung Transplant Program for nearly 20 years. A brilliant researcher, Dr. Conrad studied lung inflammation that results from transplantation. Dr. Conrad died unexpectedly in November 2024. She is remembered and missed by her family, colleagues and the countless patients and families who benefited from her exceptional care.

Community Abounds at the 41st Annual Golf Tournament for CFRI

On a sunny August day, dedicated golfers gathered for the 41st annual Cystic Fibrosis Benefit Golf Tournament at the beautiful Cinnabar Hills Golf Club in San Jose, California. Participants enjoyed a day of golf, camaraderie, good food, and a boisterous auction in support of the search for a cystic fibrosis (CF) cure. By the end of the day, over $70,000 was raised to support CFRI's research and programs for the CF community. Of this total, $15,000 is being matched by CFRI's Jessica Fredrick Memorial CF Research Challenge Circle and designated for CFRI's research grant awards. In 41 years, this event has raised over $3.5 million for CFRI! The event is deeply personal for the event co-chairs, Scott Hoyt and Mike Roanhaus – both have daughters living with cystic fibrosis. CFRI is extremely grateful to the dedicated members of the event committee – Scott, Mike, Tina Capwell, and Ralph Swanson - and the many participants whose support advances cutting-edge research and much needed support programs for those living with CF. We also thank the long-time major sponsors of the event – Star One Credit Union, the Kirkorian Family Foundation, as well as the Roanhaus family. Dates for 2026 will be announced soon!

Jessica Fredrick Memorial CF Research Challenge Circle and Fund

Real generosity toward the future lies in giving all to the present.

— Albert Camus

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. This year, Circle members will contribute nearly $100,000 so as to match – dollar for dollar – donations from individuals committed to CF research. Together, these donations are used for our CF research awards.

Our Circle is named in memory of Jessica Fredrick, who lost her battle with CF at the age of 21. There is still no cure for CF. We need your help to improve and save the lives of our loved ones. 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 inspire others to make the dream of a CF cure a reality.

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. By giving all to the present, you are generously supporting the future hopes of those with CF.

SAVE THE DATES!

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

CF Virtual Support Groups
See dates on page 4

Dance Like a Fool
Six-hour dance-a-thon to support CFRI's Wellness Programs
February 20, 2026

CF Spring Retreat
A hybrid retreat for adults with CF, their friends and family
April 6-10, 2026
El Retiro Retreat Center
Los Altos, CA, and virtual

Purple Power Challenge
Share your purple pride and challenge your friends to raise CF awareness!
May 2026

Embrace Mothers' Retreat
An in-person retreat for mothers of children and adults with CF
May 1 – 3, 2026
Vallombrosa Retreat Center
Menlo Park, CA

CFRI 39th National CF Education Conference
A Wave of Progress
July 24 – 26, 2026
A hybrid event: Ameswell Hotel, Mountain View, CA, and virtual

CF Virtual Retreat for Adults with CF
Summer, 2026
More details coming soon!

For information or to register for these events, please visit our website ***www.cfri.org,*** *email* ***cfri@cfri.org*** *or call* **650.665.7559.**

bring attention to the importance of equity, inclusion, and culturally responsive care in the management of CF.

Addressing Pain in Cystic Fibrosis: Causes, Strategies, and Self-Advocacy

Nicole Tovar, PT, DPT —
Endurance PT, San Diego, CA

Nicole Tovar, PT, DPT

Pain and musculoskeletal problems are common but under-addressed challenges for people with cystic fibrosis. This presentation highlights key causes of these CF-related issues, including chronic coughing, poor posture, and pelvic floor dysfunction, such as urinary incontinence. Physical therapy can offer effective strategies for managing these symptoms through tailored movement, breathing techniques, and pelvic floor rehabilitation.

However, many individuals face barriers to accessing physical therapy, especially when their CF care center does not include a dedicated physical therapist. This session also provides practical tools for self-advocacy, how to request referrals, communicate specific needs, and explore community-based or telehealth PT options.

Getting Older, Growing Bolder: Navigating Aging with CF

Ahmet Uluer, DO, MPH —
Boston Children's Hospital/ Brigham & Women's Hospital, Boston, MA

Ahmet Uluer, DO, MPH

With advances in CFTR modulator therapies, people with cystic fibrosis (pwCF) are living longer than ever - including those with rare variants or intolerant to modulators. As the adult CF population grows, a new challenge emerges: aging with a lifelong, multisystem disease marked by inflammation and chronic complications. This presentation explores the evolving needs of aging adults with CF, emphasizing not just longevity, but wellness, autonomy, and quality of life.

Age-related comorbidities such as CF-related diabetes, osteoporosis, GI and liver disease, cardiovascular disease, and cancer now impact many pwCF. Other aging-related concerns – menopause, hearing loss, vestibular dysfunction, chronic pain, cognitive changes, and mental health – require integration into long-term care models. Lung transplant recipients face additional challenges due to immunosuppression and complex CF-related issues.

Beyond clinical care, aging pwCF must navigate careers, insurance, and long-term planning after years of uncertain prognosis. This presentation calls for a comprehensive, multidisciplinary approach, including early screening, individualized care, and specialized training, to support healthy aging. Initiatives like the CFRI-sponsored Pat Nash Fellows Program are vital to preparing providers and systems for this future, ensuring that pwCF not only live longer, but also live better.

Reproductive Health in People with CF

Raksha Jain, MD, MSc —
University of Texas Southwestern, Dallas, TX

Raksha Jain, MD, MSc

As people with CF are leading longer and healthier lives, sexual and reproductive health has become an increasingly important topic with a number of unique questions. It is critical that we provide high quality evidenced-based data to men and women with CF on topics including contraception, fertility, pregnancy and lactation, and assisted reproductive technology options. More females are experiencing pregnancy, and more males are seeking assisted reproductive technology options with a large population of people with CF wanting to become parents overall. This session will highlight what is known and unknown about male and female infertility in CF, contraception and its impact on health in CF, and pregnancy, lactation in the era of widespread use of CFTR modulators.

Increased Risk of GI and Other Cancers in People with CF

Steven Freedman, MD, PhD —
Beth Israel Deaconess Medical Center / Harvard Medical School, Cambridge, MA

Steven Freedman, MD, PhD

As people with cystic fibrosis (CF) live longer due to improved care, cancer has emerged as a growing concern – particularly in the gastrointestinal (GI) tract, but also in the breast, lungs, and cervix. The exact cause of increased cancer risk in CF is unknown, but several contributing factors are recognized. CFTR itself acts as a tumor suppressor, and its loss disrupts pathways involving PTEN, leading to a pro-oncogenic, hyperinflammatory state and impaired defense against infections like *Pseudomonas*.

Additional cancer risks in CF stem from high saturated fat diets, gut dysbiosis, slow GI transit, and chronic intestinal inflammation – factors linked to colorectal cancer. Diabetes, common in CF, further increases pancreatic cancer risk. Together, these create a "perfect storm" for malignancy.

Important unanswered questions remain: Can CFTR modulators reduce cancer risk? Would dietary changes help? Are CF-related tumors biologically more aggressive? What are the best ways to screen and treat cancers in pwCF? This evolving landscape highlights the need for more research into cancer prevention, early detection, and treatment strategies tailored to the unique physiology of CF patients.

Emerging Cardiovascular and Metabolic Risk Factors in the Era of Highly Effective CFTR Modulators

Gregory Ratti, MD —
University of Texas Southwestern, Dallas, TX

With the advent of highly effective CFTR modulators, people with CF have experienced remarkable improvements in their health: improved pulmonary function, reduced exacerbations, and weight gain. This weight gain has resulted in a dramatic increase in the number of people meeting BMI criteria for overweight and obesity. In the 2023 CF Foundation Patient Registry Report, 28% of people were classified as

overweight and 13% as obese, compared to 17% meeting these combined criteria in 2003. This has resulted in a more individually-tailored approach to dietary counselling for individuals with CF, based on the person's BMI.


Gregory Ratti, MD

In addition, modulators have been associated with increases in blood pressure and changes in lipid profiles. The emergence of obesity, dyslipidemia and hypertension may contribute to the development of metabolic syndrome which is associated with increased cardiovascular risks in the general population. As people with CF live longer and healthier lives, it will be important to recognize these emerging cardiovascular and metabolic risk factors and address them early. This presentation will review available literature examining the metabolic and cardiovascular changes in individuals treated with CFTR modulators and discuss interventions to improve the overall health of people with CF.

Living to Dream or Fighting to Breathe? Why Cystic Fibrosis Isn't Equal for All

Meghan McGarry, MD, MAS — *University of Washington, Seattle, WA*


Meghan McGarry, MD, MAS

Treatments for cystic fibrosis have transformed the disease, leading to significantly improved outcomes for people with CF. However, not all people with CF have benefited equally from these advances in CF care and treatments. Certain groups of people with CF face worse outcomes, including severe lung disease, increased risk of pulmonary infections, increased risk of CF-related diabetes, and higher mortality. These health disparities are not explained by CFTR genetic severity, age of diagnosis, or socioeconomic status. Most CF clinical trials included very few people who were of a race or ethnicity other than non-Hispanic white. Genetic testing and newborn screening often did not screen for CFTR variants that occur in all groups, leading to some groups having delayed diagnoses. Unequal access to novel therapeutics such as CFTR modulators has widened existing health disparities. Even lung transplantation is not equally available to all people with CF. The drivers of health disparities in CF are likely multifactorial and involve biases in care, the environment a person lives in, community differences, education, language barriers, and economic stability. This presentation explores what further research and actions are needed to advance care and improve outcomes for all people with CF.

Nucleic Acid-Based Therapies for Cystic Fibrosis: Progress and Challenges

Joseph Pilewski, MD — *University of Pittsburgh, Pittsburgh, PA*


Joseph Pilewski, MD

Effective CFTR modulators have had a dramatic impact on lung disease in CF. However, not all people with CF are eligible, some are intolerant, and some have less benefit than others. The need for new therapies and ultimately a cure for CF in the lung and other organs remains significant and is a high priority for the CF community. Nucleic acid-based therapies (NABTs) are designed to restore or correct the CF gene defect and are a form of gene therapy. Current approaches include recombinant viruses (AAV, HSV, lentivirus) to deliver a normal copy of the CF gene to airway cells, lipid nanoparticles (like those used for COVID-19 vaccines) to deliver a normal CFTR messenger RNA, and antisense oligonucleotides to overcome defects in specific CF genes. Research with these approaches has progressed from laboratory studies to early phase clinical trials focused on specific populations to assess safety and efficacy. This presentation will review the basic biology and approaches to NABTs for CF, discuss the challenges with designing and executing clinical studies of NABTs, and consider the future of these therapies and gene editing approaches that are under development.

Panel: Mental Health Impacts of CF Upon the Family

Deborah Menet, LCSW – Moderator — *Stanford CF Center, Palo Alto, CA*

Jacob Fraker, MSW — *Sacramento, CA*
Sara Modlin-Tucker, DO — *Novato, CA*
Hema Patel — *Mission Viejo, CA*
Gail Wright, RN — *Pleasant Hill, CA*


Deborah Menet, LCSW – Moderator

Cystic fibrosis (CF) affects not only the individual diagnosed with the disease, but the entire family system—parents, siblings, partners, spouses, and children. The TIDES study (Quittner) revealed high rates of depression and anxiety among both people with CF and their caregivers, with mothers often reporting more anxiety than their children. The emotional toll of CF can strain family dynamics, leading to altered communication, differing parenting styles, and tension between partners over treatment decisions and infection control practices.


Jacob Fraker, MSW


Sara Modlin-Tucker, DO


Hema Patel


Gail Wright, RN

Siblings may feel neglected or suppress their own needs, believing they shouldn't distract attention from their sibling with CF. Daily medical regimens and hospitalizations

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CFRI's 38th National Cystic Fibrosis Education Conference *Continued from page 13*

further disrupt routines and increase stress across the household. Despite these challenges, CF can also foster resilience, deepen relationships, and shift family priorities. This panel discussion, led by a CF social worker, features perspectives from a person with CF, a sibling, a mother, and a spouse, offering insight into the wide-ranging emotional and relational impacts of CF on the family.

Guts, Glitter, Glory

Dylan Mortimer, MFA — *Long Beach, CA*

Dylan was diagnosed with cystic fibrosis as a baby and received a life-saving double lung transplant in 2017, and a second transplant in 2019. Dylan is a talented artist whose work has been featured in dozens of public art installations, solo exhibitions, and many group exhibitions across the nation and globe. He graduated with a BFA from the Kansas City Art Institute and an MFA from the School of Visual Arts in New York. Dylan's artwork directly reflects his journey through CF and lung transplant, and the symbols in his work come from this experience and often include IVs, scars, cells, and bronchial trees. Dylan transforms these images using shiny material, most often glitter – his medium of choice. This transformation shifts all these symbols to joyful beacons of hope. The excessive use of glitter symbolizes an aggressive hope and aggressive joy, the kind it takes to survive this kind of difficulty.

Dylan Mortimer, MFA

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Pharmacogenomic Analyses of Corrector-Rresistant CF *Continued from cover*

Given that many pwCF who are not on modulators carry mutations that prevent CFTR from being produced, current CF research largely focuses on gene therapies designed to deliver full-length CFTR into affected organs. However, there are pwCF who cannot take modulators yet still produce full-length CFTR, which could be rescued with the next generation of small molecules. The key advantage of small molecule therapies is that they can reach multiple organs that produce CFTR throughout the body, which is an enormous technical challenge of gene delivery systems.

Because CFTR modulators work by binding directly to CFTR protein to help the mutant protein fold into a more correct shape, their efficacy is strongly influenced by mutations that affect how tightly each variant of the protein binds to corrector drugs, explaining why the drugs are more effective for some variants than for others. The Kopito lab works to discover targets for new types of correctors – those that, instead of relying on direct binding to CFTR, work by tweaking the cellular "quality control" machinery to make the cellular environment less hostile to variant CFTR. Riepe and Kopito have shown that inhibiting the intracellular machinery that degrades CFTR can dramatically enhance the ability of FDA-approved modulators to increase the amount of CFTR that traffics to the cell surface, where it needs to be to do its job as an ion channel.

As with other important discoveries in biomedicine, this new approach is enabled by understanding the basic underlying cell biological mechanisms that target folding-defective CFTR for destruction. The Kopito laboratory is using state-of-the art genetic screening approaches to determine which of the 20,000 genes in the human genome influences the stability and plasma membrane trafficking of CFTR variants. Once drug targets have been identified in the screen and validated using cell models, the Kopito laboratory will collaborate with the Milla and Porteus laboratories at Stanford to validate that their strategy restores CFTR function in airway cells from pwCF. Through these screens, the Kopito laboratory aims to identify novel targets for new small molecule drugs that can synergize with existing and future modulators.

Be the Change – CFRI Advocacy Efforts

Continued from page 8

payments for prescriptions be applied toward one's deductible and annual out-of-pocket total. This type of legislation has already passed in over 20 states and Puerto Rico, with broad bipartisan support.

CFRI has advocated for expanded telehealth services, which continues to be vitally important for access to healthcare and that has proven to increase adherence to clinic visits and alleviate stress for patients.

We are concerned by increasing efforts to expand pre-authorization requirements for prescriptions and treatments, and a growth in step therapy (or "fail first") requirements by insurance companies and pharmacy benefit managers. These programs deny patients access to the specific medications their physicians have prescribed, first forcing them to try and fail using less expensive medications. This interference with physician-prescribed treatment creates delays in necessary care that can have catastrophic consequences.

CFRI also continues to support improvements in state newborn screening programs. Cystic fibrosis impacts people of every race and ethnicity, and individuals from underrepresented groups are more likely to have rare mutations that will not be detected through many states' current screening panel. Awareness must be raised about the diversity of our community so as to address these disparities.

CFRI invites our community to engage with our advocacy efforts. Please visit our advocacy page on our website to learn more about our awareness activities. You can see our current action alerts and download our advocacy toolkits. You can also sign up to participate as an advocate, no matter where you live: **www.cfri.org/cystic-fibrosis-advocacy**.

CFRI's Many Voices ~ One Voice CF Advocacy and Awareness Program is funded through educational grants from Vertex Pharmaceuticals, Viatris, and Genentech.

2025 Patrick Nash Fellows Training Program – Aging in the New Era of CF: Inspiring Multidisciplinary Research and Care

The therapeutic advances that have extended lives for many, have opened a Pandora's box of new health challenges for adults with cystic fibrosis. There is an urgent need for expanded research and improved clinical care strategies to address the multifaceted impacts of CF and aging.

The Patrick Nash Fellows Training Program, *Aging in the New Era of Cystic Fibrosis*, is now in its second year. The program, which honors Patrick Nash, an adult with CF who lost his battle with pancreatic cancer, brings together providers from multiple disciplines to increase understanding of the many non-pulmonary CF-related comorbidities that present or progress in adulthood. Recently, 14 fellows, representing 13 institutions and 7 medical disciplines, attended a symposium in Chicago, where a faculty of highly recognized clinician-researchers presented on the diverse facets of care for adults with CF. Each session began with a presentation by an adult with CF who shared the impact of that specific session's topic on their lives.

Fellows receive ongoing mentorship and opportunities to collaborate. The program identifies, educates, and connects the next generation of multidisciplinary CF care providers and thought leaders, while serving as a catalyst for innovative research activities. The research currently being pursued by the first year cohort is astounding. With each year, the number of Nash Fellows will grow, expanding a vital national network to advance critical research and improve care models for our aging CF community.

CFRI thanks Vertex Pharmaceuticals, and the family of Patrick Nash for the grants and donations that made the 2025 program possible.

CFRI Cystic Fibrosis Research Institute
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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, AbbVie, Viatris, Nestlé Health Sciences, *and* **Arna Pharma**

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

S A V E T H E D A T E !

CFRI's 39th Annual CF Education Conference

A Wave of Progress

Friday July 24 – Sunday July 26, 2026 ***A Hybrid Event!***

In person: At the Ameswell Hotel in Mountain View, CA

Virtually: All sessions streamed, with ability to ask questions in real time.

Topics to be addressed include gene and mRNA therapies in the pipeline; reproductive health; cancer risks for those with CF and CF carriers; mental health issues and strategies; aging and CF, sleep and CF.

Please join us! More information and registration coming soon.

Cystic Fibrosis Research Institute a 501(c)(3) nonprofit organization Federal EIN# 51-0169988