

## Do You Have CF? A Colonoscopy Can Save Your Life By Anna Payne

Last year, at the age of 34, I was living in a place of hope. I was thriving on Trikafta, working full time, serving as elected Supervisor for Middletown Township in Bucks County, Pennsylvania, and acting as Vice-Chair of the Pennsylvania Rare Disease Advisory Council. For the first time in a long time, I had hope for a future of a “healthy” life. I had big dreams and a lot of things I wanted to accomplish. But then I found a mass in my groin, and after a long, painful and circuitous diagnostic journey that included numerous invasive tests and long waits between them, I received the news no one wants to hear. “You have Stage 4 colon cancer.”

Known as the “silent cancer,” colorectal cancer remains the third leading cause of cancer-related deaths in the U.S. among the general population. Those with cystic fibrosis have a significantly higher risk of colon cancer than the general population. For those with CF who have not had a transplant, their risk is five to ten times higher, while individuals with CF post-lung transplant have twenty times the risk as the general population.

What makes us especially vulnerable is that colon cancer symptoms can and often do



Anna Payne

mimic issues that we CF survivors experience daily. More research is needed to determine exactly why we’re at such elevated risk for the disease, but it’s believed to be linked to a mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene.

The most effective tool for preventing this silent disease is a colonoscopy. Colon cancer always starts in the form of polyps, which, if found early, can be removed prior to becoming malignant. Colonoscopies are

recommended for the general population at 45, yet despite our highly elevated risk, the current recommendation for a first screening colonoscopy for a person with CF is 40. That’s too late and must change. Screenings can prevent about 60 percent of colorectal cancer deaths.

I was 34 years old when diagnosed; I had few symptoms and no known family history. Colon cancer grows slowly, and it’s possible it’s been in me for years. I initially sensed

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Matthew Porteus, MD, PhD



Sriram Vaidyanathan, PhD

## Identifying Biomaterials that Enable the Transplantation of Gene Corrected Airway Stem Cells to Treat Cystic Fibrosis

Matthew Porteus, MD, PhD and Sriram Vaidyanathan, PhD — Porteus Lab, Stanford Medicine – Division of Stem Cell Transplantation and Regenerative Medicine

Although many cystic fibrosis (CF) patients have benefitted from recently developed drugs (modulators), approximately 10% of patients still need a therapeutic option. The ideal therapy for CF is a gene therapy that corrects CF-causing mutations in their airway stem cells and generates a durable layer of corrected airway

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## Letter from the Executive Director

Dear Friends,

As we enter the third year of the pandemic, CFRI will remain creative, nimble and responsive to our community's needs. The loss of in-person contact has been balanced by increased virtual participation and engagement by people around the nation and globe. This is reflected in our expanded Quality of Life Programs, as in the last few months we have included new CF support groups for adults post-transplant, teenagers, and Spanish-speaking members of our community. We have expanded our research funding, while advocating to raise CF awareness and ensure access to treatments and therapies.

We pursue our mission thanks to our generous and compassionate organizational partners, sponsors, and community members. Our research, advocacy, education, and support and wellness services are dependent upon the generosity of our community.

CF remains a harsh and capricious disease. Over 10% of our community members cannot use CFTR modulators, and people of color are overrepresented in this group. Lung transplant recipients need better therapies. And as those with CF age, a host of new issues emerge. While celebrating expanded longevity, we are focused on new strategies for care and support.

Each one of us plays a part in the search for a cure and I thank you for being a part of this engaged and caring community. Together we accomplish great things.

Warmly,



Siri Vaeth, MSW | CFRI Executive Director and Mother of an Adult Daughter with CF



## News from the Board

Dear CFRI Community,

I hope that you are safe and well. As President of the Cystic Fibrosis Research Institute's Board of Directors, it is an honor to be a member of such a responsive organization and engaged community.

We began 2022 in strong fiscal shape, thanks to the unwavering support of our donors and sponsors, and tremendous efficiency that kept our costs down. As we continue to navigate the pandemic landscape, we are ever vigilant to the evolving needs of our community. We are grateful for your commitment and spirit of partnership that enables us to meet new demands.

The funding of cutting-edge research remains key to our progress, and I am delighted to share that we are expanding our research funding this year. CFRI's Research Advisory Committee and Board of Directors will soon select the 2022 research projects to fund; we look forward to sharing the list of funded researchers. As a member of CFRI's community, you play a role in advancing science.

Thank you for your ongoing support. With your help we will continue to move closer to a cure, while enhancing the lives of those living with cystic fibrosis.

Peace and good health,



Bill Hult | President, CFRI Board of Directors



# Faces of CF Diversity and Inclusion Program Expands Resources and Community Connection

CFRI is committed to inclusion, justice, and equity for all community members, and our mission is grounded in principles of openness and respect so as to address the multifaceted needs of our diverse CF community. Through our Faces of CF Diversity and Inclusion program, we seek to raise awareness of the ethnic and racial diversity of those living with CF, provide resources and services, and pursue strategies to minimize isolation and strengthen connections between community members.

Despite the fact that cystic fibrosis occurs in people of every race and ethnicity, there remains a misperception – among both the general public, and medical care providers – that this disease only impacts people of European descent. As a result, many people of color remain undiagnosed – or misdiagnosed – and are thereby unable to benefit from CF therapies and care, to say nothing of clinical trials. People of color are more likely to have rare mutations that are missed by states' newborn screening panels, exacerbating the likelihood of a late diagnosis. And these rare mutations are far less likely to be responsive to CFTR modulator therapies, thereby leaving fewer therapeutic options.

Language barriers create further challenges for many, and worsen isolation for those impacted by CF. In response, CFRI has

launched a monthly support group for Spanish-speaking members of our community. The group is facilitated by a licensed clinical social worker and is open to both adults with CF and parents/spouses/partners of those with CF for whom Spanish is their first language.

CFRI's Diversity and Inclusion Advisory Committee is comprised of a committed group of people who represent the racial and ethnic diversity of our CF community. Thanks to their efforts, CFRI has released a series of informational sheets to raise awareness of CF among the South Asian, East Asian, Black, and Hispanic/Latinx communities. They have been translated to Hindi and Spanish and are available for download on our website ([www.cfri.org/advocacy/diversity-and-inclusion/](http://www.cfri.org/advocacy/diversity-and-inclusion/)); complimentary printed copies may also be requested.

In addition, we have released a series of video podcasts that explore the personal impact of CF upon people of color in our community. These are available to view



on our YouTube Channel (<https://tinyurl.com/4bnte3nc>).

CFRI is committed to expanding critical awareness, while providing resources and support to all members of our community.

*Vertex Pharmaceuticals, Gilead Sciences, Genentech, Chiesi USA, and Viatris provided educational grants to advance this work.*



## Do you have CF? A Colonoscopy Can Save Your Life *Continued from Cover*

that something was wrong when I had minor digestive issues. They persisted, but I second-guessed myself. Then I found a mass in my groin about the size of a dime.

After an inconclusive ultrasound, and while waiting for an appointment with a general surgeon, the lump grew to the size of a walnut. I went to my CF team for help. They found a bowel blockage, a common condition for those with cystic fibrosis known as Distal Intestinal Obstruction Syndrome, or DIOS. We hoped a colon cleanse would clear the blockage, but deep down I knew it was something more serious.

After a CT scan and a biopsy of the groin mass came the bad news. Cancer. I burst into tears. A PET scan then revealed the

cancer had spread to other organs, including my ovaries, liver – which had 14 lesions – and lymph nodes.

After thriving on modulators, I have been transformed by cancer back into that sick, little vulnerable girl with CF who spent many nights curled up in a hospital bed, unsure of her future. I am now undergoing aggressive chemotherapy, requiring me to be outfitted with a take-home pump. Five times a week, I'm hooked up to an IV pole at home, on fluids to help me re-hydrate. Chemotherapy leaves me fatigued and immunocompromised, susceptible to infections and viruses that can be deadly.

Naturally, that's required me to adjust my social life, relying on a network of friends. Work has taken a back seat to the battle at hand, but my supportive employer allows

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## Do you have CF? A Colonoscopy Can Save Your Life *Continued from Page 3*



me to work remotely — as much as I'm able. My wonderful colleagues have carried the load in my absence. I miss them. I've even come to miss the 45-minute commute to my office with a stop to get a hot tea at Dunkin'.

Simple joys like eating — which most of us take for granted — are now a chore. I eat for calories, not pleasure. My diet changed drastically, and I no longer enjoy foods I'd grown up eating, such as macaroni and

cheese and steak. If you looked in my cabinets now, you'd mainly find massive amounts of Fruit Loops and Apple Jacks.

I was shocked when my platinum blonde hair — with blue streaks — fell out in clumps. Losing hair is traumatic — it's about body image, one's sense of self, and feeling normal. Many have told me not to worry, that it will grow back, but I have no idea how long I will be on chemo, and whether that is true. While I have multiple wigs that allow me to feel like a different superstar each day, and a wide array of knitted hats, I often scrap these so I can emulate my idol, the Rock.

As a little girl, I spent a lot of time inpatient at St. Christopher's Hospital for Children in Philadelphia. Watching the Rock on the weekly Smackdown was a great escape. Amazingly, the Rock learned about my diagnosis and sent me a heartfelt video wishing me luck in my fight. It's been viewed millions of times on his Instagram page, and has allowed me to feel less isolated, with a virtual connection to countless people who channel their positivity toward me.

Prior to my diagnosis with colon cancer, I planned to travel across the globe. I wanted to hold a koala bear in Australia and visit Costa Rica. I planned to run for higher elected office. I had hopes and dreams that have been put on pause. I live in a world of uncertainty. Once again, I am learning to be comfortable living in the uncomfortable.

As science improves and evolves, so should our thinking. Cancer screenings must become a normal routine for cystic fibrosis adults, and the sooner the better. My hope is that the recommended age for a first colonoscopy will be lowered to 25 years for those with CF.

But you don't have to wait for that to happen. If you have symptoms, don't write them off as the usual CF GI issues. Go and get screened. You may end up saving your own life.

### Symptoms of Colon Cancer Mimic CF-Related GI Issues

- A change in bowel habits (diarrhea, constipation) lasting for more than a few days;
- Cramping or abdominal (belly) pain;
- Bloating or full feeling;
- The feeling that you need to have a bowel movement that is not relieved by having one;
- Rectal bleeding with bright red blood;
- Blood in the stool;
- Weakness and fatigue

## Identifying Biomaterials to Treat Cystic Fibrosis *Continued from Cover*

cells. Past gene therapy trials that attempted to deliver the CF gene into the lungs failed due to several technical challenges related to gene delivery. Hence, we are working to develop methods to correct airway stem cells outside the body followed by their transplantation into the sinuses and the bronchi of CF patients.

In working towards this aim, we first optimized gene editing using Cas9 to achieve 30-60% correction of the F508del in CF patient samples and restore 30-60% CFTR function. We have further improved on this system to insert the full coding sequence of CFTR in airway stem cells and restore CFTR function to levels seen in non-CF patients. Further clinical translation of this approach requires the transplantation of gene corrected airway stem cells. Cell transplantation into the

lower airways has never been done in humans, and can be potentially life-threatening. Recognizing this, our aim is to first validate the use of this gene corrected airway stem cell therapy for treating CF sinus disease.

Transplantation of airway cells requires an injury to make space for the transplanted cells and a biomaterial to hold the cells in place after delivery into the sinus. In this project, we first screened several biomaterials for their ability to support the proliferation of airway basal stem cells. Among the materials tested, fibrinogen (a human protein involved in blood clot formation) best supported the growth of airway basal cells. Significantly, fibrinogen is already used in the clinic as a surgical glue, further facilitating clinical translation. Ongoing studies are testing the ability of fibrinogen scaffolds to facilitate airway basal stem cell transplantation into the sinuses.

Collaborative studies with Dr. Jayakar Nayak's lab helped us identify multiple injuries including clinically applicable mechanical injuries that facilitate the transplantation of airway basal stem cells into the sinuses of immunocompromised mouse models. Preliminary results indicate that both mouse and human basal stem cells can survive in the sinuses of mice for >4 months when transplanted using fibrinogen.

Ongoing studies are evaluating the ability of the transplanted cells to form a functional sinus epithelium. Upon the successful completion of these studies, we will approach the FDA to discuss our plans for the further clinical translation of this approach to treat CF sinus disease. The results from this clinical trial will inform future efforts to treat CF lung disease using gene corrected airway stem cells.

*We are grateful to the Cystic Fibrosis Research Institute for its support of this research.*

# CFRI Advocacy and Awareness on the State and Federal Level: Many Issues to Address

By Siri Vaeth, MSW

Through its Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program, CFRI engages our CF community to raise awareness among the general public and legislative sectors about the burdens of the disease, impact of its rare disease status, the diversity of our CF community members, and the critical need for CF research funding.

With only 31,000 people diagnosed with CF in the United States, CF is a rare disease, meaning one that impacts less than 200,000 people in the country. Many of our needs and issues are mirrored by other rare disease communities. As such, CFRI works closely with groups and coalitions to strengthen our voice and impact on both the state and federal level.

CFRI responds to a broad range of issues related to access. Currently our efforts are focused on several key issues. Among them is the proliferation of co-pay accumulator programs embedded in private insurance plans which do not apply payments from drug manufacturer discount cards toward a person's deductible and out-of-pocket

expenses. In essence, the deductible is paid twice, once by the manufacturer, and once by the patient.

Those who rely on specialty medications are most impacted by these policies, and CFRI works with other organizations to support legislation to ban this practice at the state and federal level. To date, 13 states and Puerto Rico have passed laws to make all co-pays count.

CFRI continues to support the creation of Rare Disease Advisory Councils (RDACs) in states across the country. RDACs provide the rare disease community with an official voice at the state level. Currently, less than half the states in the US have an RDAC, and CFRI is a member of several coalitions working to advance these efforts.

CFRI remains firmly opposed to methodology using Quality Adjusted Life Year (QALY) measures to assess drug value and price. The use of QALY is inherently discriminatory toward people with chronic disease and disabilities and its use to assess drug pricing is likely a violation of the Americans with

Disabilities Act. CFRI is concerned that several states have begun to explore the use of QALYs to save on medication costs, which could block access to needed therapies.

We are also supporting efforts to address onerous 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, forcing them to first try and fail using less expensive medications. This interference with physician-prescribed treatment creates delays in necessary care that can have catastrophic consequences.

There are many ways to get involved with CFRI's advocacy and awareness efforts. We seek your engagement! Please email Stacie Reveles at [sreveles@cfri.org](mailto:sreveles@cfri.org) for more information.

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

## CFRI Funds Innovative CF Research

The core of CFRI's mission is the pursuit of a cure for cystic fibrosis through innovative research. We invest in the highest quality and most innovative scientific research that will increase understanding of the disease, broaden treatment options, improve quality of life, and expand the search for a cure. We seek to attract the next generation of researchers and foster a long-term thriving national CF research community, with an emphasis on outreach to ensure gender, race and ethnic diversity. We also seek to encourage research that will contribute toward therapies for those ineligible for CFTR modulators.

Members of CFRI's Research Advisory Committee (RAC) are currently in the process of reviewing and vetting a diverse range of high-quality research proposals. The RAC recommendations will guide CFRI's Board of Directors, which will vote on 2022 research grant awards, with the list of awardees to be shared with our CF community in early May.

### Current CFRI-funded researchers include:

#### Elizabeth Nash Memorial Fellowship Award:

- *Characterizing the intracellular diversification of Pseudomonas aeruginosa in chronic lung infections.* Suzanne Fleiszig, PhD, Principal Investigator; Naren Kumar, PhD, Post-Doctoral Fellow; UC Berkeley
- *Targeting V-type ATPase in Human Small Airways for CF Lung Disease Treatment.* Xiaopeng Li, PhD; Michigan State University

#### New Horizons Award

- *Role of CFTR Arginine-933 in Folding, Gating and Potentiator Drug Binding.* Steven Aller, PhD, The University of Alabama at Birmingham
- *Developing Nanotechnology-Enabled Gene Therapy Solutions to Correct CFTR Mutations in Airway Stem Cells: Toward a One-Time Cure for Cystic Fibrosis.* Steven Jonas, MD, PhD; The Regents of the University of California, Los Angeles
- *Identifying Biomaterials that Enable the Transplantation of Gene Corrected Airway Stem Cells to Treat Cystic Fibrosis.* Matthew Porteus, MD, PhD; Sriram Vaidyanathan, PhD; Stanford University School of Medicine
- *Development of Tailocins Against Microbial Infections in Cystic Fibrosis Lungs.* Forest Rohwer, PhD; San Diego State University

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

These researchers will present their work at CFRI's 35th National CF Education Conference, July 30 and July 31, 2022. Note: Dr. Rohwer's project will be discussed by Gregory Burkeen, PhD Candidate, in his presentation, *Novel Models of CF Mucus Plugs for Testing Phage and Tailocin Therapy.*

# May is Cystic Fibrosis Awareness Month

During Cystic Fibrosis Awareness Month, we honor our community while educating others about CF and our ongoing need to find a cure.

## CF Purple Hair Challenge:

Purple is the color of CF awareness! If you were ever tempted to dye your hair and you want to raise CF awareness, now is the time to go purple! Join us, and challenge your circle of friends and family to support our CF community. It's simple, and follows the idea of the ALS ice bucket challenge.

**Step 1** — Accept the Challenge! Color your hair purple (all or a portion) with permanent or temporary dye, or use a phone app to do this digitally!

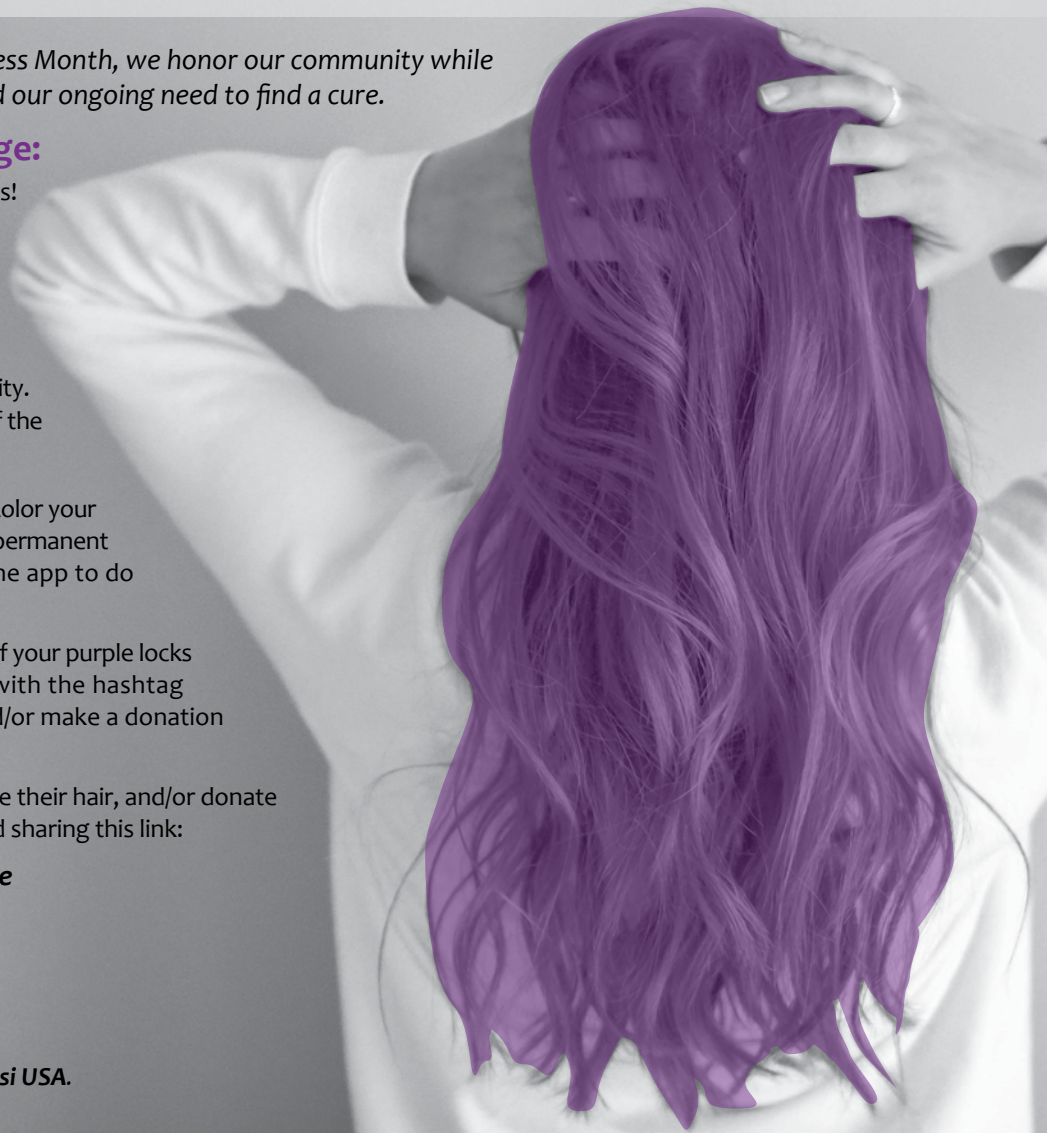
**Step 2** — Post a photo or video of your purple locks on your social media network with the hashtag #purplehairchallenge; tag us and/or make a donation to CFRI.

**Step 3** — Challenge others to dye their hair, and/or donate to the cause by tagging them and sharing this link:

[cfri.org/purple-hair-challenge](http://cfri.org/purple-hair-challenge)

## Go purple!

Sponsored by  
Vertex Pharmaceuticals and Chiesi USA.



## 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](http://www.cfri.org) to make a donation online.



# In Honor of

October 1, 2021 — March 30, 2022

Alexander Adams  
Sandra Aguirre  
Claire Alexander  
Alison Allen  
Sadie Anderson  
Lisa Avery  
Kyle Baker  
Lucy Larkin Barnes  
Joseph Batchelder  
Marin and Makinnon Baugh  
Jamie C. Beasley-Killinger  
Jim Bella  
Michael Benedetto  
Allison Best Bertagnoli  
Abigail Biow  
Rebecca Boyer  
Brian Burks  
Isabel Stenzel Byrnes  
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Mackenzie Dondanville  
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Jarrod Fischer  
Victoria Flamenco  
Taylor and Isabella Frisbee  
Sean and Jill Gallagher  
Mark E. Gerow  
Todd Giebenhain  
Larissa Giuliano  
Mark Glisson  
Elyse Elconin Goldberg  
Ray Goldstein  
Antonio Gonzalez  
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Emily Gorsky-Bonanno  
Tim and Marion Goudeau  
Bonnie Grossman  
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Sonya Haggett  
Julianna Harding  
Hardy Family  
Kenneth and Maria Heinz  
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Courtney Hollis  
Vincent Holmquist

Scott Hoyt  
Clark Huddleston  
Vicci and Bill Hult  
Eric Hyman  
Michelle Jones  
Cary and Ralph Kelly  
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Kia and Karlie  
Franny Kiles  
Shae Kish-Walters  
Eleanor Kolchin  
Kristin Favero Konvolinka  
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Susan Lane  
Vivian Lee Foundation  
Dylan Lennard  
Maureen Lenssen  
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Steve and Shelli Lindley  
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Joseph Arthur Lopez  
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Kassi Watkins  
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Laura Cryan Zellmer  
Estelle Zuckerman

# In Memory of

October 1, 2021 — March 30, 2022

Chelsa About  
Gianna Rose Altano  
Carl Anderson  
Rodney F. Ayers  
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Reed Baird  
James R. Barton  
Anne C. Beltrame  
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Sonya Chartrand  
Cynthia Ann Clark  
Cassandra Cochran  
Kalynn Cole  
Deborah A. Cox  
Christina Williamson Crow  
Diane and Lorne Dauer  
Neva L. DeVore  
Anthony Di Profio  
Dietrick Family  
Jason Dolan  
Maxine Eggerth

Jennifer Eisner  
Susie Ellerson  
Ted "Tater" Ferguson  
Joseph Fink  
Jessica A. Fredrick  
Ken Friedenbach  
Laura Gale  
Erby George III  
Larry Gherlone  
Jenise Giuliano  
Ray Goldstein  
Carol Gualco  
Susan Guenza  
Mary Beth Hardy  
Patti and Robert Henderson  
TJ Hidalgo  
Robert and James Houston  
Robert Hunziker  
Brian Jensen  
Edward J. Jensen  
John Cronkrite  
Karen Johnson  
Mary Kay Jones  
Matthew Jones  
Kathy and Peter Judge  
Edward Kinney  
Kathleen Kious  
Lori Kipp  
Bridget and John Klein

Robert and Alyce Konen  
Jason Konkel  
David Kroepfl  
Jane Ellen Kulik  
H. Lane  
Amber Leab  
Barbara Longero  
Dawn Longero  
Alyson Lowery  
Nadine Mackey  
Robert Mackey  
Taylor Malone  
Richard Marias  
Lucy Marsh  
Nahara Mau  
David McAfee  
Leslie McDonald  
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Dorothy Mize  
Bud Modlin  
Donald B. Modlin  
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Kimberly Myers  
Elizabeth Nash  
Kim and Scott Nelson  
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Michele D. Olson  
Ronald Orthwien

Jennifer Ortman  
Lisa Pearne  
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Sean Peterson  
Tim and Jon Prater  
Marvin H. Primack  
Catherine Rawlings  
Katie Robinson  
Pamela K. Rockhold  
Thomas Rockhold  
Mary Roy  
Anne Rudin  
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Randy Rupracht  
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Ann Schroeder  
John Sentman  
Steven L. Shepherd  
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Mallory Smith  
T.J. Smith  
Jamie Smolin  
Lisa Steiding  
Anabel Stenzel  
Kimball Stewart  
Robert Stewart Jr.  
Cammi Stohl

David and Laurie Stuckert  
Erin Phillips Taylor  
Loretta Taylor  
Frank Thibault  
Patricia Thibault  
Thibault Family  
Roxanna Thomas  
Glenn Thompson  
June Thompson  
Larry A. Thompson  
Louis Anthony Trigueiro  
Roy and Mary Tripp  
Rory and Jerry Vaeth  
Cindy Vidak-Haley  
Joy Villasenor  
Erynn Vondell  
Ron Walton  
Clare J. Webster  
Tara Weir  
Josiah Woodhouse  
All those we have lost

## Pet Memorials

Bella (cat)  
Lilo (dog)  
Mutley Mackie (dog)

# 2022 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 \$110,000 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 only 34.

The artwork on this year's card was created by Ria Louise McKee, a sweet six-year-old living with cystic fibrosis. Ria dreams of becoming a construction worker when she grows up. Her mother, Rohini, believes this dream was born from Ria's many weeks in the hospital, where, confined to

her room, she spent hours at the window, watching the construction of a new medical wing at Stanford.

No matter how you would like to send your Mothers' Day invitations – in the mail, online or through Facebook - you can contact Mary at **650.665.7559** or [cfri@cfri.org](mailto:cfri@cfri.org) to assist you; or go to <http://cfri.org/mothers-day-celebration/>.



## 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, cystic fibrosis is a challenging disease for those diagnosed, as well as for those who love them. Studies show that depression can negatively impact adherence to one's medical regimen. In response, CFRI offers a range of programs to address the psychosocial needs of our community.

- **Counseling Support:** CFRI provides up to \$120 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. Participants must live in the U.S.
- **Caregivers Support Groups:** Two groups are offered – one for parents of children with CF, and another for parents/spouses /partners of adults with CF – and facilitated by CF social workers Meg Dvorak, LCSW, and Kate Yablonsky, LCSW.
- **CF Adult Support Groups:** Adults with CF are invited to this support group, facilitated by CF social workers Meg Dvorak, LCSW, and Kate Yablonsky, LCSW.
- **Transplant Support Groups:** The group addresses the unique issues faced by those with CF who have received a double lung transplant. Facilitated by Sonya Haggett, LCSW, a social worker with CF who received a lung transplant.

- **Teen Support Group:** Led by CF social workers Teresa Priestley, MSW, and Deborah Menet, LCSW, this group addresses the unique issues faced by teenagers (ages 13 – 18) growing up with CF. Parents must provide consent for their teenagers to attend.
- **Support Group for the Spanish-Speaking CF Community:** The group addresses the unique issues faced by Hispanic/Latinx individuals and families affected by CF. Facilitated in Spanish by Marilyn Calderon, LICSW.
- **Bereavement Support Group:** Led by Isabel Stenzel Byrnes, LCSW, MPH, and Alanah Rosenbloom, LCSW, this group offers support for those who have lost a loved one to CF.

**All support groups are held via Zoom, and participants log in from across the country and world. Please refer to the "Save the Dates" on page 11 or our website for meeting dates.**

- **"Mindfulness 2.0" Online Class:** Based on Unified Mindfulness and adapted for the CF community, the class aims to reduce anxiety and depression, and is offered to individuals with CF and their family members. Taught by Julie Desch, MD, who herself lives with CF.

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 Brants at [sbrants@cfri.org](mailto:sbrants@cfri.org).

*Partners in Living Initiative – CF Quality of Life Programs are supported through grants from Gilead Sciences, Genentech, Chiesi USA, Viatris, Vertex Pharmaceuticals, individual donors, and contributions through CFRI's CF Quality of Life Program, a Living Legacy of Peter and Kathy Judge.*



# 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 \$100,000 to match – dollar for dollar – donations from individuals designated to CF research. Together, these donations supported our New Horizon and Elizabeth Nash Memorial Fellowship CF research awards.

Please join this inspiring group! Become a member of the 2022 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 a certificate, CFRI swag, and updates on our research awards.

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 a CF cure.

## 2021/2022 CF Research Challenge Members

(as of 3/31/2022)

John and Sallie Best  
Francine and Joel Bion  
Sanjeev and Saritha Bode  
Rhonda and Bernie Fredrick  
Adam and Giselle Galper  
Mike and Kathy Konkel  
Fred A. Miller III  
Elizabeth Nash Foundation  
Doug and Robin Modlin  
Wanda Olson  
Phyllis and David Pann  
Santa Barbara Foundation  
Terri and Roland Sturm Family Foundation  
Devin Wakefield  
And donors who wish to remain anonymous.



## 2022 Virtual CF Summer Retreat: Created By and For Adults with CF August 11 – 14, 2022

CFRI's virtual Retreats for Adults with CF bring together community members from across the nation and globe. Our recent Spring Retreat was attended by 50 adults with CF as well as family members and friends. Now we are gearing up for our CF Summer Retreat, which provides a welcoming community for adults with CF looking for connection and camaraderie with their peers.

**This year the retreat will be fully virtual again, and will provide health-related and psychosocial support programs and activities including:**

- Exercise activities tailored to individuals' unique capacities;
- Educational workshops with guest speakers from CF centers across the country, addressing such issues as transplant, GI challenges, hemoptysis, nutrition, and sinus disease;
- Rap sessions (support groups) to support positive mental health;
- Dedicated time to connect, network, and socialize with others.

Attendees report that the retreat offers new information about CF therapies and treatments, dramatically improves psychosocial health, and provides resources and strategies for coping with the



daily challenges of CF. While the retreat is geared toward adults with CF, attendees are able to invite adult family members and supportive peers.

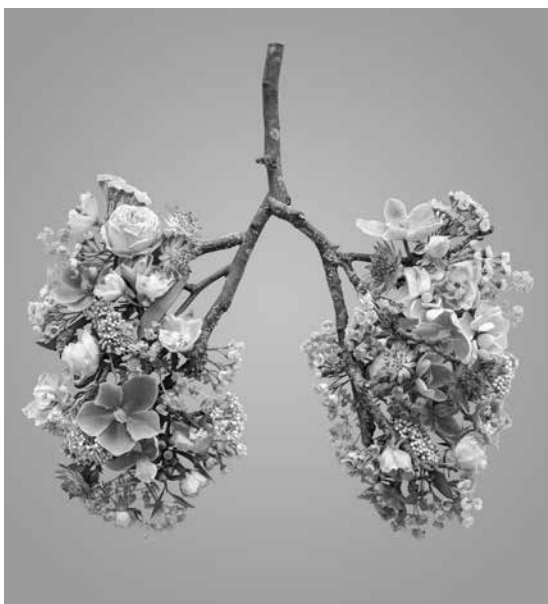
**Join us!** For more information, go to [www.cfri.org](http://www.cfri.org) or call Mary Convento at **650.665.7559**.

CF Summer Retreat is generously sponsored by Gilead Sciences, Vertex Pharmaceuticals and AbbVie.

## From a COVID-19 Playlist to Ototoxicity: CF Community Voices Has Something for Everyone

By the community and for the community, CFRI's *CF Community Voices* was created to share information and insights about a wide variety of topics. Recent releases address CF and colon cancer, advocacy awareness, navigating insurance issues, CF Vests 4 Life, and the personal stories behind CF-related tattoos. New episodes are released monthly, and can be downloaded on CFRI's podhosting site: [cfri.podbean.com](http://cfri.podbean.com). You can also watch on CFRI's YouTube channel. We look forward to sharing our community's diverse voices.

Generously sponsored by Vertex Pharmaceuticals, Chiesi USA, Gilead Sciences, Viatrix, and Genentech.



## A Breath of Fresh Air

### A Gala to Support CF Research, Education, Support & Advocacy Programs

**Save the date!** CFRI's Breath of Fresh Air Gala will be held virtually Saturday, October 15, 2022 from 6:00 pm to 7:00 pm. Join us to celebrate our strong community and exciting research progress! Enjoy music, a virtual cocktail hour, compelling stories of hope, and an exciting online auction, all while we honor our 2022 CF Champion, an individual dedicated to improving the lives of those with cystic fibrosis. There is no charge to attend. 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.

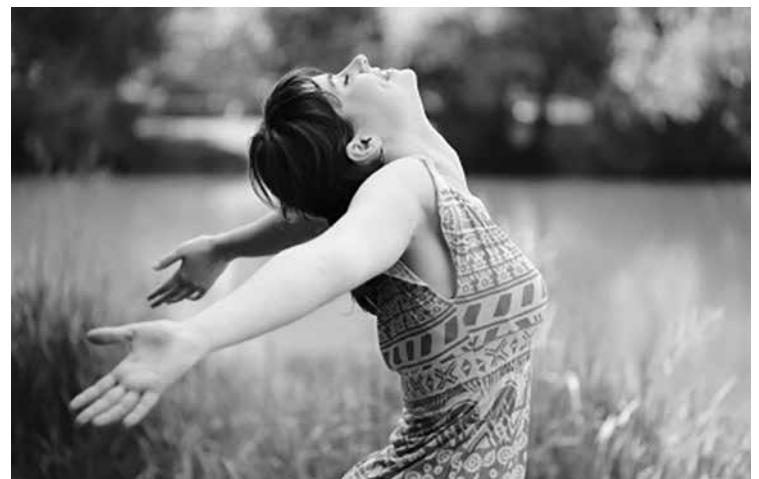
Sponsorship opportunities are available. For more information go to [www.cfri.org](http://www.cfri.org), or call 650.665.7586.

Generously sponsored to date by Vertex Pharmaceuticals, AbbVie, Genentech, Chiesi USA, and Viatrix.

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

In 2022, CFRI's 8th annual Embrace Mothers Retreat will consist of two parts: a virtual Retreat on Saturday, May 7, and - COVID permitting - an in-person Retreat Friday, September 23 to Sunday, September 25, at Vallombrosa Retreat Center in Menlo Park, CA. Through art, yoga, writing and advocacy workshops, the retreat offers an opportunity for women who share the CF path to connect and rejuvenate.

Studies show that mothers of children with cystic fibrosis have extremely high rates of anxiety and depression. This can directly impact their children's outlook and adherence to their medical regimen. Evaluations of Embrace participants show that the retreat 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.

Both Embrace Retreats are generously sponsored by Vertex Pharmaceuticals, AbbVie, and Gilead Sciences.

# CFRI's Cystic Fibrosis Wellness Initiative: Virtual Programs Improve Physical and Mental Health

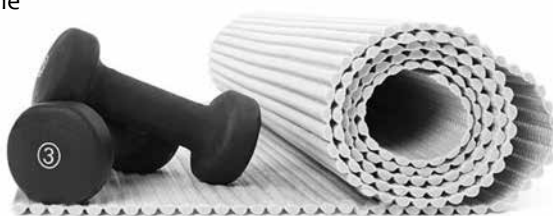
CFRI's wellness programs were developed in recognition of the positive impact of movement and exercise upon one's physical and mental health. These online programs are free, fun and interactive, and are open to those with CF, as well as their parents, spouses, partners and siblings nationwide.

In 2022, CFRI will be offering yoga, strength-building and physical therapy classes. Our instructors are all part of the cystic fibrosis community. They understand the issues faced by those with CF and every session is either structured for those with CF, or includes modifications to exercises, should they be necessary.

By exercising together, our community builds emotional and physical resilience while forging new connections and friendships in a supportive online environment.

For the current schedule, go to the events page at [www.cfri.org](http://www.cfri.org).

CFRI's CF Wellness Initiative is sponsored to date by Vertex Pharmaceuticals with additional support from the Dance Like A Fool Event donors and sponsors.



## CFRI Is Your Partner in Living

- **MOTHERS' DAY CELEBRATION:** Be a part of this important annual fundraiser! See page 8 for details.
- **PURPLE HAIR CHALLENGE:** Challenge friends and family to color their hair purple to raise CF awareness and support CFRI.
- **HOLD YOUR OWN VIRTUAL EVENT:** Cocktails for a cure, yoga, Pictionary challenge – no idea is too big or too small. Create an event, and we'll help you make it happen.
- **FACEBOOK:** 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 CFRI's programs. 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:** Offers benefits that can 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.

For more information, please contact Stacie Reveles, CFRI's Advocacy and Programs Associate: 650.665.7586 or [sreveles@cfri.org](mailto:sreveles@cfri.org).

## SAVE THE DATES!

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

### CF Adult Support Groups

Third Monday of Every Month  
May 16 • June 20 • July 18 • August 15  
September 19 • October 17

### CF Caregivers Support Groups

Third Tuesday of Every Month  
May 17 • June 21 • July 19 • August 16  
September 20 • October 18

### Support Group for the Spanish-Speaking CF Community

Second Wednesday of Every Month  
May 11 • June 8 • July 13 • August 10  
September 14 • October 12

### Support Group for Teenagers with CF

Third Wednesday of Every Month  
May 18 • June 15 • July 20 • August 17  
September 21 • October 19

### Support Group for CF Adults Post-Transplant

Fourth Wednesday of Every Month  
May 25 • June 22 • July 27 • August 24  
September 28 • October 26

### Bereavement Support Group

First & Third Tuesday of Every Month  
May 3 & 17 • June 7 & 21 • July 5 & 19  
August 2 & 16 • September 6 & 20  
October 4 & 18

Go to [www.cfri.org](http://www.cfri.org) for information. All support groups are held on Zoom.

Support Groups are sponsored by Chiesi USA, Genentech, Viatrix, Gilead Sciences, Vertex Pharmaceuticals, and private donors

### CFRI's Virtual 35th National CF Education Conference

July 29 – July 31, 2022  
(See back page for schedule and sponsors)

### CF Summer Retreat

August 11 – August 14, 2022  
Retreat will be presented as a virtual event.  
Sponsored by AbbVie, Gilead Sciences, and Vertex Pharmaceuticals

### Embrace Mothers Retreat (In-Person)

September 23 – 25, 2022  
Sponsored by Vertex Pharmaceuticals, Gilead Sciences, and AbbVie

### CFRI's Gala "A Breath of Fresh Air"

October 15, 2022  
Sponsored to date by Vertex Pharmaceuticals, AbbVie, Genentech, Chiesi USA, and Viatrix

For information or to register for these events, please email [cfri@cfri.org](mailto:cfri@cfri.org) or call 650.665.7559.



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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, Genentech, Gilead Sciences, AbbVie, Chiesi USA, and Viatrix

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

# CFRI's 35th National Cystic Fibrosis Education Conference: A Fully Virtual Experience

Our 35th annual conference will be presented in an engaging virtual format, and offers outstanding speakers, support and discussion groups, an inspiring awards event, wellness breaks, and the opportunity to connect with your CF community from across the country and globe. **Join us!**

## Speakers to date Include:

- **Ella Balasa, BS** – Phage Therapy Panelist
- **Donald Chi, DDS, PhD** – Oral Health Considerations for Individuals with CF
- **Jacob Fraker, MSW** – Advocating for the CF Community
- **Christine Hachem, MD** – Cystic Fibrosis – Navigating GI Cancers and What Can Be Done?
- **Manu Jain, MD, MSCI** – Something for Everyone: The Possibilities and Challenges of mRNA Therapy on the Horizon for People with CF
- **Emily Kramer-Golinkoff, MBE** – Inspirational Presentation by the Co-Founder of Emily's Entourage
- **Paul McCray, MD** – Gene Therapy for CF
- **Dao Nguyen, MD, MSc, FRCPC** – Emerging Pathogens in CF
- **Hanna Phan, PharmD, FCCP, FPPA** – Partnership in CF Care: Communication and Collaboration When Considering Complementary Therapies
- **Richard Simon, MD** – The Challenges of Aging for People with CF
- **Steffanie Strathdee, PhD** – Author of *The Perfect Predator* – A Scientist's Race to Save her Husband from a Deadly Superbug
- **Panel:** Impact of CF on the Siblings – Marina Gonzales, Suraj Patel, and Damian Rice

In addition, CFRI-funded researchers will be presenting their work. See page 5 for topics.

**Registration is Free!** For more information, visit [www.cfri.org](http://www.cfri.org) or call 855.cfri.now.

Generously sponsored by: **Vertex Pharmaceuticals, Genentech, Gilead Sciences, Chiesi USA, AbbVie, and Ionis Pharmaceuticals**

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



## Focus on the Future

July 29 – July 31, 2022

