CFRI community
46 Years of
Research, Education,
Advocacy, & Support
Spring 2021

Many Faces of CF: Diversity and Inclusion are CFRI Values

By Siri Vaeth, MSW

Terry Wright was diagnosed with cystic fibrosis (CF) at the age of 54. While in his late thirties, after a lifetime of lung exacerbations, hospitalizations and surgeries, a physician told him, "If you weren't Black, I'd swear you have CF!" Despite these words, his doctor did not test him, and Terry remained undiagnosed for 17 more years. With greater awareness that CF impacts people of all races and ethnicities, Terry would likely have been diagnosed far earlier, saving him from decades of pain and suffering.

Cystic fibrosis impacts people of every race and ethnicity. According to the most recent published CF Foundation Patient Registry, 9.4% of individuals with CF identify as Hispanic (of any race); 4.7% are African American; 3.8% are clustered as "other race." Because those of European descent have the highest incidence rate, those who do not fit this profile may face delays in diagnosis and treatment. There are nearly 2,000 CFTR mutations, hundreds of which are associated with disease expression. Unfortunately, most state newborn screening tests will not detect cystic fibrosis in babies with rare mutations, which are more common in non-Caucasian CF patients.

Faces of CF
Diversity and Inclusion
Advisory Committee

Researchers at Stanford found that 40-50% of alleles present in South Asian and East Asian CF patients are not part of commonly used screening panels, and that 20-30% of patients had mutations in both alleles that are not part of these panels. Failure to detect CF through newborn screening usually leads to a delayed or incorrect diagnosis with negative impacts on health and longevity.

As was the case with Terry Wright, who founded the National Organization for African Americans with Cystic Fibrosis with his wife Michele, care providers may miss the signs of CF in individuals from underrepresented racial/ethnic groups and fail to order testing. CF is an isolating disease regardless of race; this is intensified for those from communities where CF is less common and therefore less understood.

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The Cystic Fibrosis Rapid Response to Phage Therapy

By Forest Rohwer, PhD

Near real-time microbiology approaches are enabling doctors to make better decisions about patient treatments. The San Diego research community has established a collaborative effort to generate and interpret metagenomics, metatranscriptomics, and metabolomics (i.e., -omics) data from cystic fibrosis (CF) sputum samples in approximately 1-2 days. This work is part of a greater background of a long-term sampling effort, where each patient serves as their own benchmarks for different disease states.

This approach allows us to more rapidly determine what has changed at any particular time in the patient's history. Using these "-omics" data we are identifying the underlying viral and microbial mechanisms that drive the cyclical nature – stable, exacerbation and recovery – of CF. This back-

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CFRI Community
Spring 2021

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Letter from the Executive Director

Dear Friends,

I hope that this finds you and yours well. What an extraordinarily tragic and challenging year we have navigated due to COVID-19. I hope that as the number of those vaccinated increases, our sense of hope and optimism will rise as well.

On behalf of CFRI's Board of Directors, I am proud to announce our subtle but meaningful name change. CFRI now stands for Cystic Fibrosis Research Institute. "Institute" is defined as "a society or organization having a particular object or common factor, especially a scientific, educational, or social one." In light of our 46 years of CF research funding and educational and support services, this name well represents our mission and vision.

We pursue our mission thanks to our generous and compassionate organizational partners, sponsors, and community members. Our research, advocacy, education, and support services are dependent upon the generosity of our community. COVID-19 will continue to have a negative impact upon CFRI's revenues this year, and I thank you in advance for your support.

CF remains a harsh and capricious disease. For those in underrepresented groups, a CF diagnosis often arrives too late to prevent permanent lung damage. Many members of our community are still waiting for transformative therapies. Those post-lung transplant need better therapies. 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 has been an honor to be a part of CFRI's nimble response to the prolonged COVID-19 crisis. This past year we have adapted and expanded programs to ensure our community's needs are met.

We began 2021 in strong fiscal shape, thanks to a combination of 2020 cost-cutting measures and the unwavering support of our CF community. As we continue to navigate the pandemic – with a renewed sense of hope thanks to a growing vaccination supply – we hope that your commitment and spirit of partnership will continue.

The funding of cutting-edge research remains key to our progress. CFRI's Research Advisory Committee and Board of Directors will soon select the 2021 research projects to fund. For an example of the high quality work we support, please read Forest Rohwer's cover article on his inspired research. As a member of CFRI's community, you play a role in advancing science.

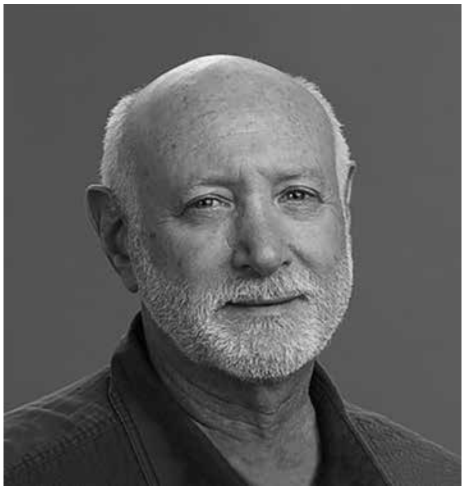
Thank you for your ongoing support. With your help we will continue to move closer to a cure, while enhancing the lives of those living with cystic fibrosis.

Peace and good health,

Bill Hult | *President, CFRI Board of Directors*

Cystic Fibrosis and COVID-19: An Update

By Richard Moss, MD



COVID in People with CF

According to data from the Cystic Fibrosis Foundation (CFF), as of March 25, 2021 there have been 1,328 confirmed cases of COVID-19 among those with CF, with 215 (16.2%) hospitalizations. Of these cases, 386 were children, 39 of whom were hospitalized. Fourteen patients, all adults, have died (1.1%); 8 had received lung transplants and 3 non-transplant patients had advanced lung disease. Quite similar data have been obtained from a consortium of European CF Centers organized by the European CF Society. There were 1,126 reported cases as of March 8, 2021, with 206 (18.3%) hospitalizations and 13 deaths (1.1%).

These data suggest COVID-19 continues to affect people with CF no worse and perhaps less than the general population, likely because of high adherence to public health measures in reducing exposure to respiratory pathogens. Basic infection control measures were accepted and ingrained in our CF community long before SARS-CoV-2. A serendipitous "side effect" of the pandemic for CF patients documented in the 2020 CFF Patient Registry has been a reduction in respiratory illnesses as reflected in reduced numbers of pulmonary exacerbations. (This drop in exacerbations is additional to a large, beneficial Trikafta effect seen since its approval in 2019.)

Research has begun into possible protective effects against COVID-19 in people with CF. Besides social distancing and infection control public health measures, potential factors include a younger age distribution, less frequent high-risk comorbidities (e.g., obesity, hypertension), certain chronic medications (e.g., azithromycin, dornase alpha), and a variety of potential biological mechanisms such as airway fluid pH or content of molecules affecting SARS-CoV-2 entry into cells (the ACE2 receptor for the virus, certain enzymes called proteases that can affect viral entry).

Vaccines

The success of COVID-19 vaccine development has been a singular triumph of human ingenuity, focus and cooperation. Since December, the FDA has approved three vaccines for use under its Emergency Use Authorization power. Currently 78 different vaccines are being tested in clinical trials around the world, with 22 in pivotal late-stage trials, and another 75+ vaccines in preclinical development. While vaccines are currently approved for ages 16 (Pfizer) or 18 (Moderna, J&J) and up, pediatric studies are underway. Over 3.2 million children in America have been diagnosed with COVID-19 and at least 266 children have died. Perhaps the most important fact to keep in mind about the available vaccines is their ability to almost completely prevent serious illness and death from COVID-19.

Variants

Natural selection ensures that some mutations that arise from viral replication errors may increase survival fitness of the virus, and indeed that is the case with SARS-CoV-2, as many identified mutations, labeled "variants of concern," may affect COVID transmission, infection or illness severity. As variants of concern have tended to rapidly dominate their identified regions of origin and quickly spread globally, red flags are being raised for new transmission surges, and the urgency to increase vaccinations.

Worries have focused on how some of these variants may decrease vaccine efficacy. However, data so far are reassuring that the levels of antibody after vaccination seem adequate to afford protection against variants. Importantly, preliminary evidence indicates that the T-cell response, the other big gun of the immune system, is robust even against the variants in vaccinated people. The most important point is to get fully vaccinated as soon as possible with whatever vaccine is available in order to personally protect yourself and help your

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Coping with COVID-Related Stress and Anxiety

By Siri Vaeth, MSW

The pandemic has unleashed a broad spectrum of pain and suffering around the globe. Each lost life is mourned by a larger circle of loved ones; those who survive COVID face ongoing physical and emotional sequelae. For many, depression and anxiety have been triggered by fear, financial challenges, isolation, and the loss of life rituals that bring meaning and joy. Even as the number of vaccinated Americans grows and communities re-open, mental health specialists are calling for attention to both the short and long-term effects of the pandemic upon individual and collective community mental health.

Yelizaveta Sher, MD, Clinical Associate Professor of Psychiatry at Stanford and an embedded psychiatrist at the Stanford CF Center, has worked directly with many individuals experiencing depression and anxiety triggered and exacerbated by COVID-19. In addition to her work with patients at Stanford, Dr. Sher volunteers her time facilitating CFRI's online

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Many Faces of CF: Diversity and Inclusion are CFRI Values *Continued from Cover*

Marianela Fajardo remembers when her daughter Maria was first diagnosed with CF after months of inconclusive tests. "I was so distraught. I didn't know what cystic fibrosis was, and I didn't know anyone who had it." Soon after, Marianela stepped in to help families whose struggles were exacerbated by language barriers. "Imagine how hard this is," she says, "to learn about the disease when you don't speak English." These barriers exacerbate health disparities and worsen health outcomes.

CFRI recently launched its Faces of CF Diversity and Inclusion Program with the formation of a dynamic CF Diversity and Inclusion Advisory Committee to amplify the voices of all impacted groups and enhance CFRI's outreach, resources, and programs for our diverse community. The Diversity and Inclusion Advisory Committee, comprised of adults with CF and parents of children/adults with CF, provides vital leadership in ensuring CFRI's culture of inclusion is further enhanced to offer meaningful support to the community.

With advisory committee input and guidance, CFRI will expand its educational resources to increase accessibility and representation through enhanced content offerings in multiple languages. A series of webinars are in the works to address health disparities for those with CF from the African American, Latino, South Asian and East Asian communities. To achieve these goals, CFRI is working with our current organizational advocacy partners while developing new and impactful alliances with existing groups supporting diverse populations.

There is a vital need for focus and attention on the unique needs of all members of our cystic fibrosis community, as well as the development of resources and strategies to address them. CFRI is fully committed to reaching those in need of support and connection while expanding awareness of cystic fibrosis among members of all communities.

CFRI is grateful to the members of our Diversity and Inclusion Advisory Committee for sharing their time, perspectives and expertise:

Isa Stenzel Byrnes, LCSW, MPH
Marianela Fajardo
Jean Hanley, MD
Alicia Maciel, MBA
Haimlata Patel
Harini Seshadri
Michele Wright, PhD
Terry Wright

Funding for CFRI's Faces of CF Diversity and Inclusion Program was provided by Vertex Pharmaceuticals, Gilead Sciences, Genentech, Chiesi USA, and private donors.

The Cystic Fibrosis Rapid Response to Phage Therapy *Continued from Cover*

background data is extremely useful for diagnosing what is unique about fatal and near-fatal exacerbations and points to possible treatment options. We are now using the DNA sequence data to build phage, which are viruses that kill bacteria, with the goal of performing phage therapy to stop severe exacerbations.

With the support of CFRI, we are developing phage and tailocins as a personalized treatment to kill multi-drug resistant pathogens affecting cystic fibrosis (CF) patients. Both the phage and tailocins are designed to kill *Stenotrophomonas* and *Achromobacter*. A tailocin identified in *Stenotrophomonas maltophilia* is used as a backbone to which tail fibers would be swapped to confer specific antibiotic activity against other *Stenotrophomonas* or *Achromobacter* strains.

We have aimed to clone the tail structural genes individually, and using this strategy, we successfully cloned 11 out of the 12 structural genes of *S. maltophilia* tailocin P28 into individual plasmids. To screen for additional tailocins, two *Achromobacter* spp. and two *Stenotrophomonas* spp. isolates from CF patients were sequenced, as well as 3 metagenomes from CF exacerbations. Expression of these tailocin proteins was accomplished.

Nineteen additional *Achromobacter* phages were included in our collection, and five new *Achromobacter* phages were isolated by our group and are referred to as the "San Diego collection." Fourteen *Achromobacter* phages were obtained from Dr. Christine Pourcel's group in France, this collection is referred as the "Côte d'Ivoire collection." 98% of the *Achromobacter* strains isolated at the San Diego CF clinic are susceptible to at least one those 30 phages. During this year, two patients in the San Diego CF clinic suffered multi-drug resistant *Achromobacter* infections. We screened our *Achromobacter* phages collection against their *Achromobacter* isolates and identified phages capable of killing these isolates.

Two *Achromophages* were identified and prepared for phage therapy for one patient and the FDA paperwork has been submitted. The second *Achromobacter*-infected patient has stabilized; we have isolated and prepped phages for this patient, but are holding off on treatment. Phages have also been isolated for a patient with a severe, acute exacerbation caused by an *E. coli* infection (the strain's genome has been sequenced). These phages are being prepped for phage therapy and the FDA paperwork was submitted in early 2021.

Most phage therapy is only performed under emergency conditions. Since CF exacerbations are usually not fatal, the emergency criteria do not apply, even though these disease flares substantially impact the patient's short- and long-term well-being. Therefore, these CFRI-sponsored studies are helping the FDA, doctors, and scientists understand how to navigate the complicated regulatory and scientific hurdles surrounding phage therapy in CF. The goal is to provide another tool to fight the chronic lung infections in a personalized fashion.

Many Voices ~ One Voice: Advocating for Our Community

By Siri Vaeth, MSW

Throughout the pandemic, CFRI's efforts to raise awareness and advocate for those living with cystic fibrosis have never faltered. While in-person events remain on hold, CFRI has continued its work through virtual meetings with elected representatives, the creation of action alerts on pressing issues, and engagement with other rare disease groups to address discriminatory policies and advance access to care and therapies.

One issue that impacts all who need specialized – and often expensive – medication is that of co-pay accumulator programs, which are increasingly added to health insurance plans unbeknownst to subscribers. These programs no longer allow payments from drug manufacturer co-pay cards to apply towards annual deductibles and out-of-pocket limits. Once patients exhaust their co-pay cards, they discover that they still have thousands of dollars due in out-of-pocket payments before their insurance coverage applies. Many people with CF have been forced to make difficult decisions at the pharmacy counter when they learn that the cost of their prescriptions exceeds their financial resources, and that the clock to pay down their deductible has just begun.

As such, insurers and/or pharmacy benefit managers are being paid twice: once by the drug manufacturer and then by the patient. Four states have outlawed these programs and federal legislation has been introduced to allow co-pay accumulator programs only when a generic drug equivalent is available. CFRI believes that all co-pays should count, and we are working with a broad-based nationwide coalition of patient advocacy organizations to address this issue.

CFRI remains firmly opposed to the use of the Quality Adjusted Life Year (QALY) to measure drug value and price. The use of QALY originated as a means to ration care, and it is inherently discriminatory toward people with chronic disease and disabilities. The use of QALY to assess medication pricing for the CF and rare community is unethical, subjective, and likely a violation of the Americans with Disabilities Act. CFRI is concerned that several states have begun to explore the use of these measures to save on medication costs, which could ultimately block access to needed therapies.

Our many voices create one strong voice. CFRI will continue to keep our community informed, supported and engaged.

2021 Virtual CF Summer Retreat: Dawning of a New Day

August 19 - 22, 2021

Are you an adult with CF? Are you looking for connection and camaraderie with your CF peers? CFRI's CF Summer Retreat provides a welcoming community for adults with cystic fibrosis. It was created to enhance education, positive coping skills, and social support for people who share common experiences with CF who may be increasingly isolated due to cross-infection protocols.

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

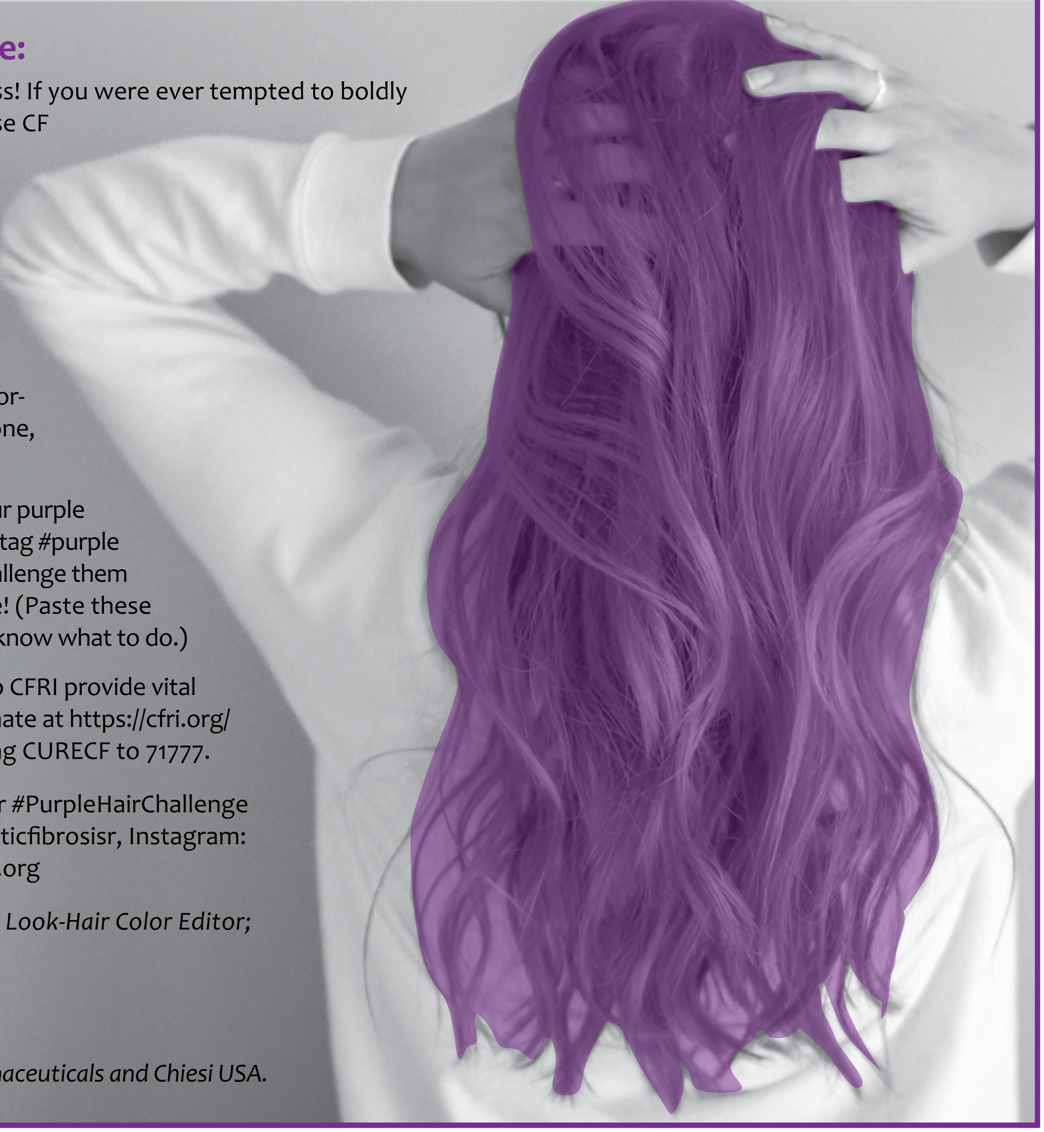
- Exercise activities tailored to individuals' unique capacities;
- Educational workshops with guest speakers from CF centers across the country, addressing transplant, GI challenges, hemoptysis, nutrition, and sinus disease;
- Rap sessions (support groups) to support positive mental health;
- Dedicated 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, their adult family members and supportive peers are welcome if their family member/friend with CF is registered and attending as well. **Join us!**

For more information, go to www.cfri.org or call Mary Convento at 650.665.7559.

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

May is Cystic Fibrosis Awareness Month



CF Purple Hair Challenge:

Purple is the color of CF awareness! If you were ever tempted to boldly dye your hair and you want to raise CF awareness, now is the time! Join us, and challenge your circle of friends, co-workers and family members to support our CF community. Just follow these three easy steps:

Step 1 — Dye some or all of your hair purple with permanent, temporary, or digital* dye (using your phone, tablet or computer).

Step 2 — Post a pic or video of your purple locks on social media with the hashtag #purplehairchallenge. Tag 3 friends and challenge them to dye and/or donate to the cause! (Paste these instructions into your post so they know what to do.)

Step 3 — Make a donation to help CFRI provide vital support to the CF community. Donate at https://cfri.org/purple-hair-challenge/ or by texting CURECF to 71777.

Don't forget to tag CFRI in all your #PurpleHairChallenge posts! Follow us on Twitter: @cysticfibrosisr, Instagram: @cfri.cure.cf, and Facebook: /cfri.org

**Phone app for purple hair: Fabby Look-Hair Color Editor; also look for filters on Instagram.*

Go purple!

Sponsored to date 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 to make a donation online.

DONATE LIFE

www.donatelife.net

In Honor of

September 15, 2020 — March 31, 2021

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Claire Alexander
Sadie Anderson
Kyle Baker
Lucy L. Barnes
Joseph Batchelder
Makinnon and Marin Baugh
Jamie Beasley-Killinger
Jim Bella
Michael Benedetto
Frank Berry
Alison Best
Francine Bion
Molly and Emily Bonnell
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Ashley Wilson
Nina Wine
Jonathan Witczak
Amanda Wood
Kathryn Wright
Laura Zellmer

In Memory of

September 15, 2020 — March 31, 2021

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Joe Anderson
Jodi, David, Bob and Janette Armknecht
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Rose Weatherly
Jeff Weaver
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Doris Weghorn
Tara Weir
Josiah Woodhouse

2021 Mothers' Day Fundraiser Brings Awareness and Hope!

Now More Than Ever, CFRI Needs 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 $100,000 to support CFRI's vital services to the CF community.

In light of the long-term financial impacts of COVID-19, this will be another challenging year for CFRI. 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.

The artwork on this year's card was painted by Wanda Olson, mother to Michele, who passed away from CF complications at the age of 33. Wanda is creating 65 rose paintings in Michele's memory; this features her daughter's favorite – a Sterling Silver rose.

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 to assist you; or go to: http://cfri.org/mothers-day-celebration/.

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

Prior to the stress of COVID-19, those impacted by cystic fibrosis (CF) already demonstrated higher rates of depression and anxiety than found in 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. Making the issue more complicated, 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), their parents, partners, spouses and siblings 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. The groups are held via Zoom, and caregivers participate from across the country.

— **CF Adult Support Groups:** Adults with CF are invited to this support group, held the third Monday of every month and facilitated by CF social workers Meg Dvorak, LCSW, and Kate Yablonsky, LCSW. The groups are held via Zoom, and participants log in from across the country.

— **COVID-19 and CF Support Group:** Open to adults with CF and CF family members, this group is facilitated by Liza Sher, MD, psychiatrist at the Stanford CF Center. Launched in March 2020, this regular group offers a supportive place to discuss the stress of COVID-19.

— **"Mindfulness 2.0" Online Classes:** The course is based on Unified Mindfulness and has been adapted for the CF community, including those who have taken mindfulness classes before and those completely new to meditation. It 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.

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

Cystic Fibrosis and COVID-19: An Update

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community stave off a potential variant-related surge.

Long Haul COVID

COVID-19 survivors across the globe have reported long-term sequelae and complications that have been merged under the general name of long haul COVID. The most frequent symptoms include ongoing fatigue, cognitive changes ("brain fog") and shortness of breath, but many more varied problems have been noted such as ongoing loss of smell/taste, headache, tachycardia, sleep disturbance, anxiety and depression. Objective tests such as lung, heart and brain imaging techniques have uncovered evidence of unhealed and often otherwise undetected damage. Some studies that have separately localized virus- and immune response-related pathology suggest the reason some people have long-lasting damage may have to do with their body's inflammatory response rather than direct viral tissue damage. While men are at higher risk for more severe acute COVID, some evidence suggests women are at higher risk for long haul COVID. The implications of this emerging vast cohort of chronically ill people post-COVID are enormous. They add one more utterly compelling reason to do what you can to avoid exposure to the virus, encourage fact-based behavior by your fellow citizens--and get your vaccine as soon as possible!

Coping with COVID-Related Stress and Anxiety

Continued from Page 3

CF and COVID-19 Support Group, which has had steady nationwide participation for over a year. Dr. Sher, along with Jay Fishman, MD and Theodore Stern, MD, recently released "Facing COVID-19: A Guide for Patients and Their Families," which addresses the diverse and significant physical, psychosocial, and mental health issues wrought by the pandemic, offering expert advice on how to cope now, and how to move forward. In the book, Dr. Sher writes, "We are living through unprecedented times with real risks and worries, significant losses and grief, and a lot of uncertainty. Many people experience sadness, anger, worry, concern, fear, loss, and feel overwhelmed or numb."

The severity and frequency of anxiety and depressive disorders has increased during the pandemic, with roughly one-third of the general population affected by higher levels of these symptoms. Dr. Sher notes that stress triggers a fight, flight or freeze response, but that when the stress is sustained and chronic, as with the pandemic, this response becomes maladaptive, which "adds to your suffering and promotes worsened general health."

What are strategies to cope? For some with significant symptoms, psychotherapy may be optimal, possibly combined with medication. Cognitive-behavioral therapy (CBT), in which one learns to recognize and reframe maladaptive thought processes can be helpful, as can acceptance and commitment therapy (ACT). It is helpful that therapy is more widely available now thanks to virtual visits. Other strategies include yoga, mindfulness, meditation, progressive muscle relax-ation and guided imagery. There are also many phone apps available for a range of relaxation practices and strategies to cope with depression and anxiety.

Social connection is vital for maintaining one's mental health. Whether through phone calls, Zoom chats, or socially distanced outdoor activities, strive to reach out to alleviate loneliness and isolation. While working from home has its benefits, it can disrupt sleep schedules, physical activity and diet, all of which impact one's mental health. Setting routines, getting outside when possible and focusing on healthful eating will improve both physical and emotional wellbeing.

Most importantly, you are not alone. Beyond the support of family and friends, do not hesitate to seek professional help. Symptoms can be addressed and alleviated. Says Dr. Sher, "There is always something that we (mental health professionals) can find for you, be it an individualized therapy plan, a medication, a combination of both, or just a safe place – physically or virtually – where we can be there for you and acknowledge together all the losses and challenges of the past year and now."

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. Last year, members of our circle contributed over $90,000 so as to match – dollar for dollar – donations from individuals designated for CF research. Together, these donations support our New Horizons and Elizabeth Nash Memorial Fellowship CF research awards.

Please join this inspiring group! Become a member of the 2021 Jessica Fredrick Memorial CF Research Challenge Circle by making a minimum gift of $2,500. Challenge Circle Members receive a certificate, CFRI swag, and updates on our research awards. You will help inspire others to make the dream of a CF cure a reality.

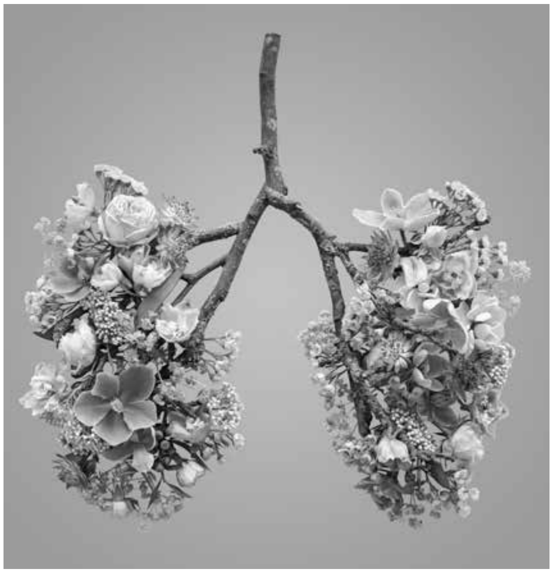
Our Circle is named in memory of Jessica Fredrick, pictured right, who lost her battle with CF at the age of 21. Despite tremendous progress in CF therapies, we continue to lose treasured members of our community to this cruel disease. There is still no cure.

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

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* podcast series was created to share information and insights on diverse topics. Recent releases include an update on COVID-19 and vaccinations with Dr. Rick Moss, episodes on ototoxicity and individualized nutrition therapy, as well as a four-part series on financial planning. 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. We look forward to sharing our community's diverse voices.

Generously sponsored by Vertex Pharmaceuticals, Chiesi USA, Gilead Sciences, Viatris, 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 16, 2021 from 6:00 pm to 7:00 pm. Help us celebrate exciting research progress! Enjoy music, compelling stories of hope, celebrity appearances, and an exciting silent auction, all while we honor our 2021 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 are directed to CFRI's research, education, advocacy, and support programs to improve the lives of those with CF.

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

Generously sponsored to date by Vertex Pharmaceuticals, AbbVie, Genentech, Chiesi USA, Heritage Bank, and NBC Bay Area.

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

Due to the ongoing COVID-19 pandemic, our Embrace Retreat will once again be held virtually. While there is no substitute for in-person interaction, the virtual version reduced barriers so that 35 women from 15 states could participate. In advance of the full-day retreat on May 1, online writing and art workshops were offered, allowing participating mothers to reconnect and get acquainted. On the day of the main event, attendees participate in presentations, therapeutic art and writing workshops, yoga, and an overview of additional resources offered by CFRI throughout the year to provide lasting support.

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, and their family's wellbeing. Evaluations of Embrace participants show that the retreat is extremely effective in lowering depression and anxiety. Participating in a variety of workshops and activities while connecting with others who share the CF path helps mothers to build upon their inner strength and resilience to be better prepared for the ongoing challenges presented by this disease.

We are very grateful to our sponsors: 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. Working out together, participants have the opportunity to improve their physical and emotional health.

In 2021, CFRI is offering yoga, strength-building and physical therapy classes. Through these wellness sessions, our community builds emotional and physical resilience while forging new connections and friendships.

For the current schedule, go to the events page at cfri.org.

CFRI's CF Wellness Initiative is supported to date by Ionis Pharmaceuticals, Vertex Pharmaceuticals, Translate Bio, Viatris, and individual donors.

CFRI Is Your Partner in Living

- **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.org/, 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 and enhance 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.

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 17 • June 21 • July 19
August 16 • September 20
October 18

Go to www.cfri.org for information.

Participate by Zoom or by phone

CF Caregivers Support Groups

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

Go to www.cfri.org for information.

Participate by Zoom or by phone – no in-person meetings until further notice

Support Groups sponsored by Gilead Sciences, Chiesi USA, Genentech, and Ionis Pharmaceuticals

CFRI's 34th National CF Education Conference

July 30 – August 1, 2021

The Conference will be presented as a virtual event.

(See back page for schedule and sponsors)

CF Summer Retreat

August 19 – August 22, 2021

The Retreat will be presented as a virtual event.

Sponsored by AbbVie, Gilead Sciences and Vertex Pharmaceuticals

CFRI's Gala "A Breath of Fresh Air"

October 16, 2021

The Gala will be presented as a virtual event.

Sponsored to date by Vertex Pharmaceuticals, AbbVie, Genentech, Chiesi USA, NBC Bay Area, and Heritage Bank

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

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

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CFRI Mission

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

CFRI Vision

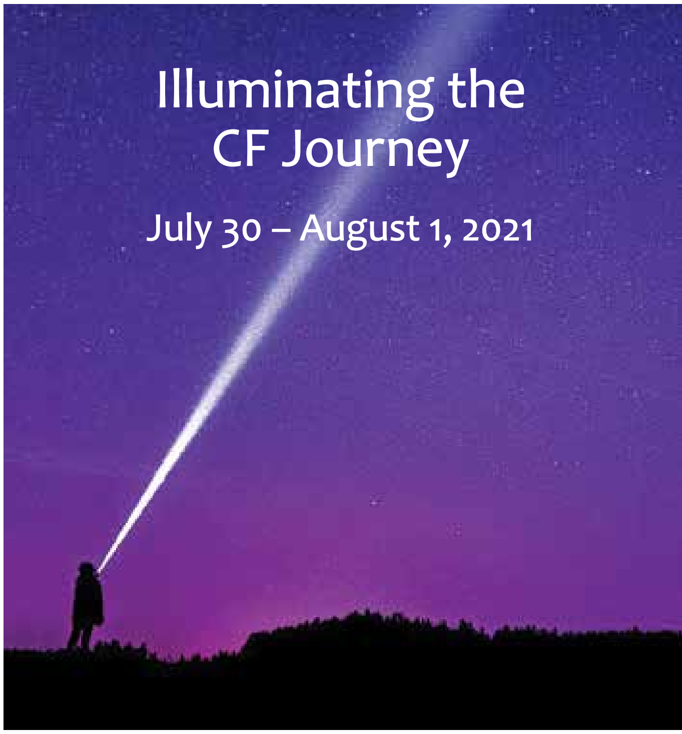
To find a cure for cystic fibrosis while enhancing quality of life for the CF community.

For their generous support of ***CFRI Community,*** special thanks to: **Vertex Pharmaceuticals, Genentech, Gilead Sciences, AbbVie, Chiesi USA, Viatris,** *and* **Translate Bio**

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

CFRI's 34th National Cystic Fibrosis Education Conference: *A Fully Virtual Experience*

Our 34th annual conference will be offered in an engaging virtual format, and offers outstanding speakers, support and discussion groups, an inspiring awards event, wellness activities, and the opportunity to connect with your CF community from across the country and globe. **Join us!**



Speakers Include:

— **John Engelhardt, PhD** – *Advances in Gene Therapy for Cystic Fibrosis*
— **Gunnar Esiason** – *My Life with Cystic Fibrosis, Our Unlocked Futures, and Breaking Down Barriers for the Continued Success of the CF Community*
— **Raksha Jain, MD** – *Reproductive Health in Men & Women with CF*
— **Taylor Lewis, BA, MA** – *Strength-Building with CF*
— **Paul Mohabir, MD** – *Hemoptysis*
— **Rick Moss, MD** – *Getting to the After Times – CF and COVID in Year 2*
— **Deepika Polineni, MD, MPH** – *mRNA Therapy for the Treatment of CF*
— **DB Sanders, MD** – *Pulmonary Exacerbations in the Era of Highly Effective CFTR Modulators*
— **Jennifer Taylor-Cousar, MD, MSCS** – *Until It's Done For Everyone: Diversity, Inclusion and Equity in CF Care and Research*
— **Bijal Trivedi** – *Breath from Salt (book presentation plus panel discussion)*
— **Ahmet Uluer, DO, MPH/Angela Garinis, PhD, CCC-A** – *Ototoxicity Monitoring and Management in Patients with Cystic Fibrosis*

Registration is Free! For more information, visit **www.cfri.org** or call **855.cfri.now**.

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

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