

## Love, Courage, and Miracles – A mother’s journey and her daughter’s story

An Interview with Robin Modlin by Siri Vaeth

Longtime CFRI community member Robin Modlin has released a moving memoir, **Love, Courage and Miracles**, in which she shares the fear, pain, empowerment, and joy of raising her daughter, Anna, who lives with cystic fibrosis. The following is a brief excerpt; to read the full interview, go to <http://tinyurl.com/bp6rwh95>

**You have shared so openly about your life and your family members’ lives. How did this feel for everyone?**

I sought permission from everyone before I began. We all agreed that Anna’s story and our life with CF and transplant needed to be told. When I wrote about them, I let them read the writings to be sure they agreed and were ok. We all believe and hope that this story can help others who go through similar situations.

**How did you juggle your fears for Anna with your hopes?**

We almost lost Anna to CF when she was first diagnosed, so we knew the slippery slope and steep precipice that was always there. Doug (my husband) and I were a team and shared our fears and hopes with each

other, balancing out our concerns. Going to CFRI meetings where Dr. Jeff Wine explained CF and the new research findings helped us a lot. We saw the reality that this disease was extremely serious, and yet we believed that science and medical research would increase hope and lengthen survival.

I also had a spiritual belief that helped to sustain me. I knew we would do whatever we could for Anna, and that her life was precious whether it was cut short or she had the good fortune of living longer than we expected. I believed a voice that said to me, “If she lives a short life there will be blessings. If she lives a long life there will be blessings. They are both the same.”



Anna with her mother, Robin Modlin

**What advice would you share with parents who are just beginning their CF journey?**

The CF world is very different now. The modulators are revolutionizing care and survival statistics are phenomenal, yet I know that a diagnosis such as CF can be a terrible

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Paul Bollyky, MD, PhD and Kevin Qingquan Chen, PhD

## Targeting Bacterial Resistance to Phage Therapy in Cystic Fibrosis

Paul Bollyky, MD, PhD

Despite recent progress, lung infections remain a critical problem for people with cystic fibrosis and their families. Antimicrobial resistant (AMR) bacterial pathogens, including those caused by *Pseudomonas aeruginosa*, continue to cause chronic airway infections in CF. Oftentimes these are polymicrobial (caused by more than one bug), magnifying the challenge. We need new therapies and approaches for tackling these challenging infections.

“Phage therapy,” the use of viral pathogens of bacteria to kill bacteria, is a promising therapeutic strategy to treat multi-drug-resistant bacterial infections. Moreover, phages are highly selective and only kill their particular bacterial host, making phages safe and less

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## Greetings from the President of the Board and the Executive Director

Dear CFRI Community,

We hope that you are safe and well. CFRI is an organization by and for the cystic fibrosis community. Our mission-driven Board, staff and volunteers keep us laser-focused on addressing the ongoing and emerging needs of our community. We pursue our mission thanks to our generous and compassionate community members, organizational partners, and sponsors. Thanks to this support, CFRI's research, advocacy, education, and support services continue to expand their reach, with program participants from around the globe.

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, CFRI is focused on new strategies for care and support; we will share more about these efforts in the very near future.

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

Peace and good health,



Bill Hult | President, CFRI Board of Directors



Siri Vaeth, MSW | Executive Director



## Informative, Inspirational, Insightful: 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 mental health and CF, early screening for colorectal cancer, and the mental health benefits of pets. 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](http://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 2024 CF Community Voices is made possible to date with support from Viatrix, Gilead Sciences and Vertex Pharmaceuticals

# The Many Faces of Cystic Fibrosis By Hannah Dolhai

Cystic fibrosis does not discriminate. While it is hoped that our CF community recognizes that this rare disease is found across every demographic, sadly, misdiagnosis and adverse treatment for people of color remains not only a poor historical legacy, but a present refrain.

Through the Faces of CF Diversity & Inclusion Program, CFRI aims to dispel the myth that CF is a disease impacting only White people of European descent. CFRI acknowledges that people of every race and ethnicity are impacted by CF, and is committed to elevating the needs of all people through advocacy, research, education, and support. This commitment is led by members of CFRI's dynamic Diversity & Inclusion Advisory Committee, who—in tandem with patients, family networks, care teams and educators—create resources that speak directly to the diversity of the CF community.

Since the top of the year, CFRI has expanded the number of Spanish and Hindi videos and podcasts available online by adding transcriptions to multiple English-language recordings. Additionally, new video and audio content in Spanish has been created to highlight what patient assistance resources CFRI has to offer. To further advance CFRI's commitment to web-based accessibility, the Spanish resources page on CFRI's website has been updated. It is CFRI's hope to continue expanding ways to disseminate the robust offerings of the organization to



members of the CF community in linguistically inclusive ways.

Tapped into the needs of the CF community, CFRI knows that patients and caregivers experience greater levels of anxiety and depression than the general population. For those with multiply-marginalized identities, compounding stressors related to racial discrimination, isolation, and poor accessibility for non-English speakers are present. CFRI's monthly virtual community meeting for the Spanish-speaking CF community aims to mitigate these stressors by offering a supportive space for Hispanic and Latinx individuals to find community through connection.

It is CFRI's hope to be a resource to not only those within the United States, but across international borders. To achieve this, CFRI continues to expand its outreach to patient-led organizations worldwide, most recently to 14 Latin American CF organizations. With these projects and commitments, CFRI continues to make diversity, equity, and inclusion pillars of the organization's values so that all people are supported throughout their CF journey.

For more information go to <https://tinyurl.com/2wecpat7>.

*This program is made possible through grants from Viatris, Vertex Pharmaceuticals and Gilead Sciences.*

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

CFRI's wellness program was developed in recognition of the positive impact of movement and exercise upon one's physical and mental health. 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 have the opportunity 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 movement, from Yoga and Mat

Pilates to U-Jam, strength building, and mobility. You can register for the Thursday and/or Saturday track, and attend as many classes as you would like. You will receive a reminder with a link either the night before or the day of each class.

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/](https://cfri.org/wellness-classes/).

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



## Love, Courage, and Miracles

[Continued from Cover](#)

shock. I would say, first feel the loss of safety that the diagnosis can cause and allow the grief that will come up. Next, know that our fears are just that, our fears. They do not determine the eventual outcome. Begin to look for how CF is providing an opportunity to be a part of a committed community, and a life challenge that will help you grow as a person. It is up to us to accept and use this experience in a way that is beneficial for the community, our family and ourselves personally.

### **Share with me the importance of humor in coping with chronic progressive disease? It sounds like it is Anna's superpower!**

Humor is one of Anna's superpowers for sure. Humor helps you to stop fixating on the causes of your suffering. It is not funny to feel the grief and pain that can be caused by a chronic progressive disease but making light of some of its effects or situations it puts you in can elevate the moment.

### **I appreciated hearing about Anna's sister, Sara, and her hidden grief, chronic sorrow, and "proactive survivor's guilt." What would Sara say to siblings of people with CF?**

Sara always wanted to connect with other siblings who could understand her experience. She wanted to know if what she felt was common and for her experience to be acknowledged. I believe she would encourage other CF siblings to open to their feelings of fear and loss and share them with whomever they trust. She would want to tell them that this is a very difficult role to play in a family. To be the one who is considered to be the survivor and to watch the challenges of their sibling is fraught with complicated emotions. If it feels overwhelming it is good to seek counselling.

### **Tell us about your entrance to the transplant community, where hope, joy and grief coexist.**

When a CF patient receives a lung transplant, they and their family enter a new door. CF takes a back seat as surviving the surgery and immunosuppressants becomes primary. If it is a successful transplant, what is witnessed is nothing less than a miracle. The world of transplant introduces you to people who have survived their impending death and are reborn with another chance



Robin Modlin with her two daughters Sara (l) and Anna (r).

where there are no guarantees but each day feels more than ever as though it is a gift and a miracle. Some donor families also become active in the community. The organ recipients offer them meaning and support by showing their gratitude for life itself. It is truly a remarkable world to be a part of.

### **You write, "I was learning we were on a remarkable adventure that was unique and good despite the difficulty, Anna's suffering, and our fear of loss." How did your perspective shift?**

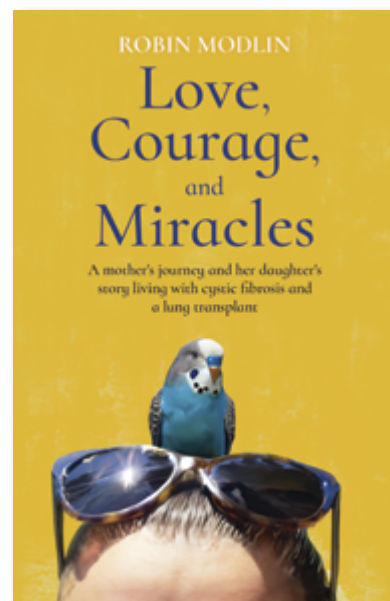
During the time when Anna was just a toddler, on life support and first diagnosed, I clung to the medical interventions that were saving her life. I did not feel at the time that we were on any great adventure. It was after, when her life was saved, and I could feel what a miracle it was to have a second chance to be able to be her mother. Gratitude and a new perspective filled my experience. I saw that I could take this opportunity to be Anna's mother, as fragile as her life was, and use that experience to grow as a person and be engaged to help others too. It became a grand adventure with learning about acceptance, life and death, miracles and hope.

Being Anna's mom is still a source for learning more about me, how I can live, be

better as a human and open to new experiences. And the greatest miracle of all is our granddaughter, Zoe. Who would have ever, ever thought that would be possible?

**Love, Courage, and Miracles** is available for preorder.

To learn about meeting the Dalai Lama; hunting for Chinese herbs in San Francisco; waiting for Anna's new lungs; and the surprising life turn when Anna married, moved to Australia, and became a mother, go to [www.robinmodlin.com](http://www.robinmodlin.com).



# 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 Horizons and Elizabeth Nash Memorial Fellowship CF research awards.

Please join this inspiring group! Become a member of the 2024 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 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.

To become a member of the Circle, please contact Stacie Reveles at [sreveles@cfri.org](mailto:sreveles@cfri.org).



## CFRI Funds Innovative CF Research

At the core of CFRI's mission is to pursue a cure for cystic fibrosis through supporting innovative research. CFRI is committed to ensuring that research will continue toward a cure. 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 2024 research grant awards, with awardees to be shared with our CF community in early May.

### Current CFRI-funded researchers include:

#### Elizabeth Nash Memorial Fellowship Award:

- *Targeting Bacterial Resistance to Phage Therapy in Cystic Fibrosis*. Paul Bollyky, MD, PhD, Principal Investigator; Kevin Chen, PhD, Postdoctoral Fellow; Stanford University
- *A Hybrid Gene Correction Strategy for Cystic Fibrosis*. Matthew Porteus, MD, PhD, Principal Investigator; Anais Amaya Colina, PhD, Postdoctoral Fellow; Stanford University

#### New Horizons Award

- *Elucidating the ion transport functions of CFTR High Expresser Cells (CHEs) and its relevance to intestinal disease in Cystic Fibrosis*. Nadia Ameen, MD, Principal Investigator; Yale University School of Medicine
- *Optimization of Phage Therapy to Reduce Pseudomonas-Induced Inflammation in Cystic Fibrosis*. Benjamin Chan, PhD, Principal Investigator; Yale University School of Medicine
- *Improving CF Airway Mucociliary Clearance: Toward Transition from Animals to Humans*. Carlos Milla, MD, Principal Investigator; Stanford University

- *Pathways Maintaining Basal Mucin and CFTR-mediated Fluid Secretion in the Human Distal Airway*. Kenichi Okuda, MD, PhD, Principal Investigator; University of North Carolina at Chapel Hill
- *Targeting IRBIT to Correct Bicarbonate Secretory Defects in Cystic Fibrosis*. Zachary Sellers, MD, PhD, Principal Investigator; Stanford University
- *Targeting recalcitrant CF pathogens with phages, antibiotics, and small molecule adjuvants*. Katrine Whiteson, PhD, Principal Investigator; University of California Irvine

#### Special Circumstances Grant

- *CFTR mRNA Delivery to CF Airways*. Beate Illek, PhD, Principal Investigator; University of California San Diego

The researchers above will present their work at CFRI's 37th annual National Cystic Fibrosis Education Conference, which will be held July 26 to 28, 2024. All Research Track presentations will take place on Friday, July 26, at the Grand Bay Hotel San Francisco in Redwood City, CA. (Note: Dr. Benjamin Chan will present on Saturday, July 27.) Conference registration is open at: <https://tinyurl.com/mwupxnn2>.

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

# May is 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:

<https://tinyurl.com/37sthuah>

All donations will be matched by Jessica Fredrick Memorial CF Research Challenge Funds and designated to CFRI's Patrick Nash Fellow Training Program on Aging in the New Era of CF.

## Go purple!

Sponsored by **Vertex Pharmaceuticals**



## 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, 2023 — February 29, 2024

Alexander Adams	Joan and Bart Favero	Niall Hibbard	Nancy Melvin	Noah Singer
Sandra Aguirre	Darren, Tina, Caoimhe, and Oonagh Fitzgerald	Susan Hoffman	Jonathan Miller	Wende Sinnaeve
Peter Backus	Victoria and Oscar Flamenco	Courtney Hollis	Matthew Mitchell	Matthew Spadia
Kyle Baker	Ann Du Frane	Vincent Holmquist	Alex Mooney	Ethan Spain
Lucy Barnes	Isabella Frisbee	Anna Holyoak	Harper Murphy	Linda Stanford
Jennifer Belken	Taylor Frisbee	Clark Huddleston	Juliet Murphy	The Stenzel Family
Maggie-Faye Bendz	Sean Gallagher	Bill and Vicci Hult	Austin Murray	Mckaylin and Alayna Stoddard
Robert E. Boswell	Cheri Geoghegan	Eric Hyman	Jessica Nett	Shealyn Stone
Lucas Buchanan	Mark Gerow	Alexander Jenkins	Tristan O'Neill	Paige Stout
Brian Burks	Todd Giebenhain	Michelle Jones	Aly, Maddie and Killian O'Reilly	Melissa Compton Sullivan
Gabriela Castillo	Larissa Giuliano	Beckett Kelly	Scott Parks	Brian Tacke
Tiffany Christensen	Mark Glisson	Cary and Ralph Kelly	Kent Peterson	David Tacke
Casey Collins	Elyse Elconin Goldberg	Jeremy Kharrazi	Damian Peterson	The Tacke Family
Shaun Collins	Antonio Gonzalez	Franny Kiles	Natalie Puzia	Adam Thompson
Michael and Allison Conway	Andy Gordon	Kristin Favero Konvolinka	Michael Reuscher	Katherine Thompson
Lauren Colonna Cooper	Gianna Gutierrez-Serrato	Daniel Lagasse	Megan Reveles	Todd Trisch
Cameron Cornell	Rev. Bill Gutknecht	Douglas Lagasse	The Reynolds Family	Robert Turk-Bly
Jordan Cote	Sonya Haggett	Alyssa Lenart	Rebecca Roanhaus	Miguel Vilas
Jean Cross	Treyvon Hall	Adam Levy	Carl Robinson	Devin Wakefield
Barbara and Jim Curry	Alex Hampton	Michael Livingston	Elizabeth Rogers	Aaron Waldrum
Mackenzie Dondanville	Liz Hampton	Josh Loux	Alanah Rosenbloom	Matthew Weiner
Dylan Dunn	Brendan Harrigan	Emily Lucas	Ryan Sanderson	Melissa Weiner
Tess Dunn	Christian Heavner	Eric Marten	Collin Santos	Nina Wine
Daniel Ellett	Mary Helmers	David Martin	Corey Sarkis	Jonathan Witczak
Janelle and Andre Estournes	Joanna Henry	Jean Mathews	Mike and Carol Shroul	Brandon and John Wright
Thomas Evans	Melanie Henshaw	Rachael and Rebecca McMullen	Rachel Silver	Laura Zellmer

# In Memory of

October 1, 2023 — February 29, 2024

Marcus Adelman	Kalynn Cole	Jenny	Danielle Mandella	Dhea Schalles
Kimberley Adelman	Jean Cross	Karen Johnson	Lucy Marsh	John Sentman
Gianna Rose Altano	Caroline Daly	Melody Johnson	Catharine Martinet	Steven Shepherd
Joe Anderson	Neva DeVore	Mary K. Jones	David McAfee	Joseph Marden Sinnaeve
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Gerald Aspinall	Brenda DiGiovanni	Leona F. Kaplan	Stacy Ann Melle	Anabel Stenzel
Ronald Baldwin	Jason Dolan	Peggy and Janet Kessell	Rochelle Merrit	Kim Stewart
Cara Baysinger	Joseph and Selma Fink	Fred and Anna Killion	Kristy Monroe	Robert Stewart Jr.
David Beebee	Veronica Fleming	Edward Kinney	Jennifer Montgomery	Erin Phillips Taylor
Anne Beltrame	Patricia Flynn	Lori Kipp	Ross Moran	The Thibault Family
Irvin Beltrame	Jessie M. Franks	Bridget Klein	Lynette Moulton	Glenn Thompson
Kitsy Bennett	Jessica Fredrick	John Klein	Lynn Moyse	June Thompson
Brett Bennett	Roy Fronk	Kurt Koenig	Tom Murphy	Louis Anthony Trigueiro
Larry Bergeson	Jenise Giuliano	Eleanor Kolchin	Michele Denise Olson	Todd Trisch
James W. Bertolini	Royce Goertzen	Robert and Alyce Konen	Jennifer Ortman	Gus Uccello
Rebecca Boyer	Emily Gorsky-Bonanno	Jason Konkell	Lisa Pearne	Rory and Jerry Vaeth
Greg Brazil	Barbara Greenberg	David Kroepfl	Scott "eDog" Peterson	Cindy Vidak-Haley
Alicia Brogle	Janice Gwin	H. Lane	Kevin Pira	Joy Villasenor
Christopher Broom	Erika Schlotterbeck Harrington	Maeve Leonard	Chrystal Reusch	Gail Wakelee
Cheri Brower	Nicholas Hollis	Jimmy Lewis	Ann and Rob Robinson	Tom Walton
Jarod Bulthuis	John Holmes	Dawn Longero	Pamela Rockhold	Debbie Ware
Kyle Butler	Robert Houston	Jennifer Longoria	Mary Roy	DeAnne Wolthoff
Isabel Stenzel Byrnes	Clark Hummel	Alyson Lowery	John Runge	
Traci Carwana	Ed and Orzella Jemas	Robert Mackey	Randy Ruprecht	
Cassandra Cochran		Taylor Malone	Michelle Sanderson	

# 2024 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 \$125,000 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 too low.

The artwork on this year's card was painted by Wanda Olson, mother to Michele Denise Olson, who passed away in 1999 at the age of 33 from CF complications. Inspired by the story of a child who misheard his diagnosis of cystic fibrosis as "sixty-five roses," the rose symbolizes hope for a cure for CF. To honor her daughter's memory, Wanda is creating 65 unique rose paintings. This is the 20th painting in the series. To honor the late Stenzel sisters who enriched the lives of so many people, Wanda has retitled this piece, "Sisters, in Memory of Isabel and Anabel," #20 of 65 Roses.

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/>.

Thank you for supporting CFRI and those living with cystic fibrosis!

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

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

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

**Support Groups:** CFRI offers monthly online support groups for our diverse CF community members. Participants register once and then are able drop in monthly to connect with their peers. All groups are facilitated by trained professionals who either work in CF centers or who have CF themselves. Monthly groups are offered for:

- Caregivers/Parents of Children with CF;
- Caregivers/Partners/Spouses of adults with CF;
- Adults with CF;
- Adults with CF Post-Transplant;
- Adults with a Late CF Diagnosis;
- Teens with CF;
- Spanish-Speaking CF Community Members;
- Those Who have Lost a Loved One to CF;
- Adults with CF Who Are Ineligible/Cannot Use Modulators (launching this summer)



**Mindfulness:** CFRI will offer two six-week sessions in 2024. The classes combine mindfulness practices with meditation, which has been shown to reduce anxiety and depression. Open to those with CF and their family members, 16 years and up. Taught by Julie Desch, MD, who herself lives with CF.

All 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 at [www.cfri.org](http://www.cfri.org) for meeting dates.

These programs are offered at no charge to our community members, thanks to our supportive sponsors. For more information, go to <https://tinyurl.com/4dzj7a6p>, or email Sabine Brants at [sbrants@cfri.org](mailto:sbrants@cfri.org).

*Partners in Living Initiative – CF Quality of Life Programs are generously supported by Viatris, Amgen, Gilead Sciences, Vertex Pharmaceuticals, and private donors, as well as contributions through CFRI's CF Quality of Life Program, a Living Legacy of Peter and Kathy Judge.*



# Many Voices ~ One Voice: CFRI's Advocacy & Awareness Efforts on Behalf of the CF community

Through its Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program, CFRI engages our CF community to raise awareness about the burdens and complications of the disease, including the lack of a cure, impact of its rare disease status, the need for CF research funding, and barriers faced by our community in accessing care.

Along with numerous patient advocacy groups, CFRI is involved in the movement to create Rare Disease Advisory Councils. There are 10,000 identified rare diseases (defined as one that impacts less than 200,000 Americans) including cystic fibrosis, and it is estimated that 1 in 10 Americans has a rare disease. State Rare Disease Advisory Councils (RDACs), provide the community with a formal platform and official voice to help advise state officials on policies and services that impact us. Currently, nearly 30 states in the U.S. have RDACs, and CFRI is a member of several coalitions working to advance these efforts. This includes in Calif-

ornia, where AB 2613 has been introduced to create an RDAC.

CFRI also participates with several coalitions to advance legislative bans on co-pay accumulator policies, which do not allow payments from drug manufacturer assistance programs to be applied toward a person's deductible and total out-of-pocket expenses. These policies are embedded in 64% of private insurance plans and create significant financial hardship for many members of our community. CFRI is working with others to support legislation mandating that all payments for prescriptions be applied toward one's deductible and annual out-of-pocket total. In California, CFRI is a cosponsor of AB 8130 which would ban these policies.

This type of legislation has already passed in a twenty states, Washington DC and Puerto Rico, with broad bipartisan support. On the federal level, bipartisan legislation has been introduced in the House and Senate



(H.R.830 and S.B.1375, the Help Ensure Lower Patient (HELP) Copays Act. If you would like to get involved, or need more information, please contact us at CFRI.

*Supported through grants from Vertex, Genentech, Viatrix, AbbVie, Gilead Sciences, and Amgen.*

## 2024 CF Summer Retreat: Created By and For Adults with CF July 28 – August 1, 2024

CFRI's Retreats for Adults with CF bring together community members from across the nation and globe. Our recent virtual Spring Retreat in March was attended by over 50 adults with CF as well as family members and friends. We are now gearing up for our annual CF Summer Retreat, which offers adults with CF a welcoming place to engage with their peers. The retreat will be held as a hybrid event. For those attending in person at Vallombrosa Retreat Center in Menlo Park, California, we will have our usual stringent cross-infection and COVID-19 protocols in place. For those unable to travel to California, many of the sessions will also be offered online.



**The retreat 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 kidney disease;
- Rap sessions (support groups) to support positive mental health;
- Dedicated time to connect, network, and socialize with others.

Attendees consistently 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.

*The CF Retreat is generously sponsored by Vertex Pharmaceuticals, AbbVie, and private donors, with special thanks to Devin Wakefield.*

## 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 take place on Sunday, October 6, 2024, at the breathtaking Nestldown estate in the Santa Cruz Mountains (Los Gatos, California). Join us for this afternoon Gala event to celebrate our strong community and exciting research progress! Attendees will be free to explore the unparalleled beauty of Nestldown, with its ponds, waterfalls, and a myriad of whimsical spaces. Sip extraordinary Northern California wines while enjoying delicious food, music, inspiring stories of hope, and an exciting live auction. Help us to honor the 2024 CF Champion, an individual who tirelessly works to improve the lives of those with CF. While this magical Gala experience is only available to in person attendees, there will be an online auction with a wide array of get aways, art, wine, and exciting experiences.

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, GRAIL, Viatrix, and Heritage Bank.*

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

From May 3 – 5, 2024, CFRI will host its 10th annual Embrace Mothers Retreat at the beautiful 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.



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

For more information go to [www.cfri.org](http://www.cfri.org).

*Embrace Mothers Retreat is generously sponsored by Vertex Pharmaceuticals and AbbVie.*

## Targeting Bacterial Resistance to Phage Therapy

*Continued from Cover*

toxic than conventional antibiotics. Indeed, personalized phage therapy can successfully treat individual cases of AMR infections. However, bacterial immunity against phage predation potentially confounds development of this life-saving therapy and it has been challenging to scale up this approach to make it more readily available to more patients.

While phage therapy is saving individual lives in the setting of compassionate use cases, and is generally safe and well-tolerated, broadly effective phage therapy and successful clinical trials have been elusive. Moreover, individual phages are of limited utility for treating polymicrobial infections such as those in people with CF, who can be colonized by many phenotypically distinct strains of *Pseudomonas aeruginosa* or other pathogens. Combining multiple phages and delivering them together with antibiotics (phage cocktails) is attractive, but the fundamental principles governing phage-phage interactions are unclear.

Many strains of *Pseudomonas aeruginosa* use CRISPR-based gene editing to defend themselves against bacteriophages. Worse, *Pseudomonas* has the ability to acquire phage resistance from other bacteria, though the underlying mechanisms are unclear. Understanding these mechanisms of resistance to phages is critical to the success of phage therapy.

Dr. Kevin Chen, a scientist supported by the CFRI, together with Dr. Paul Bollyky and Dr. Carlos Milla at Stanford University, are working to develop effective phage therapy cocktails to treat antimicrobial resistant lung infections in CF. They have pioneered a novel approach for selecting synergistic combinations of bacteriophages.

Using this strategy, Dr. Chen and his collaborators were able to develop phage/antibiotic cocktails effective against 95% of 174 *Pseudomonas aeruginosa* clinical isolates collected from people with CF, including biofilm cultures. They are currently working to develop analogous cocktails for *Staphylococcus aureus* and for mixed, polymicrobial cultures. This approach provides a blueprint for generating effective phage/antibiotic cocktails. Their hope is that this work will revolutionize the treatment of multidrug-resistant bacterial infections in cystic fibrosis.



## 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, a benefit yoga session, Pictionary challenge – no idea is too big or too small. Create an event, and we'll help you make it happen.
- **FACEBOOK:** 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 would come to CFRI – tax-free to your heirs and CFRI.
- **VEHICLE DONATIONS:** CFRI is partnering with CARS (Charitable Adult Rides & Services) to accept donations of used vehicles. CARS takes care of everything from the pick-up and sale to sending you the donation receipt and tax documents. You can donate a car, motorcycle or boat.

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

## SAVE THE DATES!

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

### Practical Mindfulness

Led by Dr. Julie Desch — Tuesday Class for Six Weeks  
May 28 – July 2, 2024

### CF Adults Support Group

Third Monday of Every Month  
May 20 • June 17 • July 15 • August 19  
September 16 • October 21

### CF Caregivers Support Groups

Third Tuesday of Every Month  
May 21 • June 18 • July 16 • August 20  
September 17 • October 15

### Spanish-Speaking CF Community Meetings

Second Wednesday of Every Month  
May 8 • June 12 • July 10 • August 14  
September 11 • October 9

### Support Group for Teenagers with CF

Third Wednesday of Every Month  
May 15 • June 19 • July 17 • August 21  
September 18 • October 16

### Support Group for CF Adults Post-Transplant

Fourth Wednesday of Every Month  
May 22 • June 26 • July 24 • August 28  
September 25 • October 23

### Bereavement Support Group

First Tuesday of Every Month  
May 7 • June 4 • July 2 • August 6  
September 3 • October 1

### Late Diagnosis Support Group

First Wednesday of Every Month  
May 1 • June 5 • July 3 • August 7  
September 4 • October 2

### Support Group for Adults with CF NOT on Modulators

Dates to Be Announced

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

### CFRI 37th National CF Education Conference

July 26 – July 28, 2024  
Grand Bay Hotel San Francisco (Redwood City, CA) and Online  
(See back page for speakers, topics, and sponsors)

### CF Summer Retreat – Hybrid

July 28 – August 1, 2024  
Vallombrosa Retreat Center, Menlo Park, CA and Online

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

Sunday, October 6, 2024  
Nestltdown (Los Gatos, CA)

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, Viatris, AbbVie, Sionna Therapeutics, Gilead Sciences, and Nestle Health Science**

Visit our website at:  
**[www.cfri.org](http://www.cfri.org)**

for more information about us and about cystic fibrosis.  
**Call toll free: 855.cfri.now**

# CFRI's 37th National Cystic Fibrosis Education Conference: Transforming CF Together ~ A Hybrid Event

**July 26 – July 28, 2024** – Grand Bay Hotel San Francisco (Redwood City, CA) and Virtual

Join us for a full weekend of information and community! CFRI's Conference will launch on Friday, July 26, with presentations by CFRI-funded researchers, and an inspirational opening reception. Speakers on Saturday and Sunday will present on topics including CF and cancer, reproductive health, mRNA and gene therapy, and coping with medical trauma. Exhibitors, the annual awards dinner and dance party make this a full weekend of community connection.

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

**Register Today:** <https://tinyurl.com/mwupxnn2>

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

**Research Track Registration: \$100 (Friday attendance only)** – includes Friday presentations, Friday lunch and reception.

**Virtual Registration: Free**

**Room rate at the beautiful Grand Bay** – only \$139 per night – must book through CFRI Block.

**Confirmed speakers to date include:** Nadia Ameen, MD • Paul Bollyky, MD, PhD • Kevin Chen, PhD • Benjamin Chan, PhD • Anais Amaya Colina, PhD • Jennifer Taylor-Cousar, MD, MSCS • Luke Hoffman, MD, PhD • Thomas Horal • Beate Illek, PhD • Samantha Johnson, LCSW • Nicholas Kelly, RD • Luanne McKinnon • Carlos Milla, MD • Robin Modlin, MA • Richard Moss, MD • Kenichi Okuda, MD, PhD • Matthew Porteus, MD, PhD • Amy Ryan, PhD • Zachary Sellers, MD, PhD • Natalie West, MD, MHS • Katrine Whiteson, PhD • Kate Yablonsky, LCSW

For more information, go to [www.cfri.org](http://www.cfri.org) or call **855.cfri.now**.

Generously sponsored to date by: **Viatris, Vertex Pharmaceuticals, Gilead Sciences, AbbVie, and the Boomer Esiason Foundation**

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

