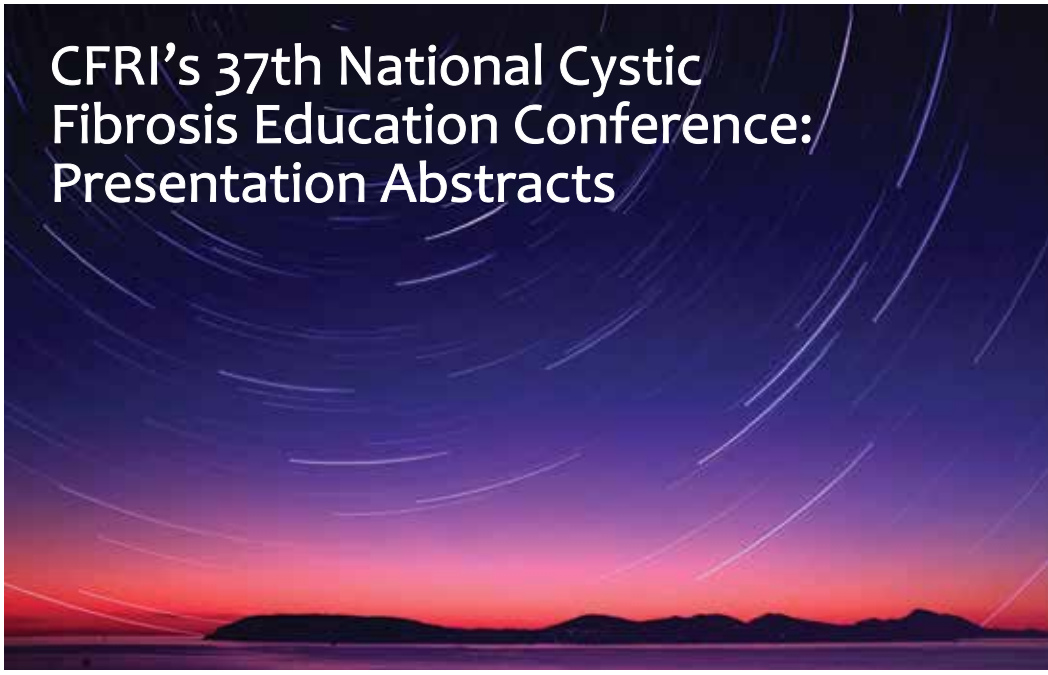
CFRI community
49 Years of Research, Education, Advocacy, & Support
Fall 2024

CFRI's 37th National Cystic Fibrosis Education Conference: Presentation Abstracts



CFRI held its 37th National CF Education Conference, *Transforming CF Together*, as a hybrid event July 26 - 28, 2024. Over three days, attendees from across the country and globe heard from nationally-renowned speakers on a wide range of CF-related topics. These presentations are now available for viewing on CFRI's YouTube channel: **https://tinyurl.com/ycf55jvb**. The abstracts of the presentations appear below.

The Power of Passion

Nicholas Kelly, MS, RD, LD — *Cleveland, OH*

Nicholas Kelly

Do you know what it's like to be told you have a chronic disease, what it takes to fight despite obstacles, and thrive in the face of adversity? That is Nick's life.

Nick's story starts at three months old, when he was diagnosed with cystic fibrosis. Although interesting, this is not what made his story unique. Nick was diagnosed by his mother, a fact further explored later. Despite his diagnosis Nick went on to thrive, becoming a dietitian, speaker, author, artist, advocate and much more.

Nick's advocacy is something he holds dear, as he loves to share knowledge and passion. He believes in the importance of being informed. As his favorite quote says, "A candle doesn't lose anything lighting another candle." Nick hopes to be the light that dispels some of the darkness surrounding CF. He is dedicated to shining a light on research, addressing inadequacies, advocating for the community, and driving the mission to make CF stand for "Cure Found."

Book Reading: *Love, Courage and Miracles*

Robin Modlin, MA — *Livermore, CA*

Embark on a heart-warming journey through a tale of love, courage, and miracles. Robin shares excerpts from her book, as she confronts her daughter Anna's life-limiting prognosis, navigates the challenges of cystic fibrosis, and witnesses Anna's

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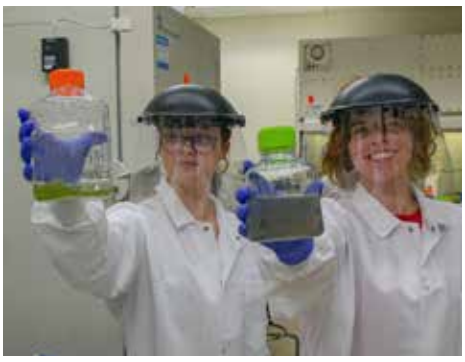

CFRI-supported PhD student Kayla Raygoza and UCI undergrad researcher Faith Cribbs holding phage-rich sewage samples from the Hyperion Treatment Plant.

How Everyday Molecules and Bacteriophages Can Help Eradicate Tough CF Infections

Katrine Whiteson, PhD and Sage Dunham, PhD — *UC Irvine*

The increase in antibiotic-resistant bacteria and the lack of new antibiotics has created an urgent need for new treatments. One promising approach is to use bacteriophages, or phages — viruses that target specific bacteria — to treat infections that don't respond to regular antibiotics. Phages are the natural predator of bacteria in every imaginable environment on Earth, and although they have been studied for medical use for more than 100 years, antibiotics were the preferred treatment throughout most of the 20th century. The rise of antibiotic resistance has renewed interest in phage therapy.

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CFRI Community
Fall 2024

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Letter from the Executive Director and President of the Board

Dear Friends,

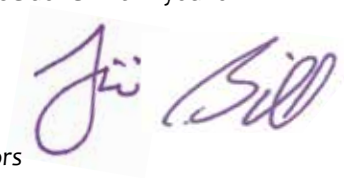
As a community we celebrate recent advances in cystic fibrosis therapeutics and care, while recognizing the work still ahead of us. CF remains a harsh and capricious disease, and many members of our community – particularly people of color – are still waiting for transformative therapies. CFRI is proud to fund innovative research to move us closer to a cure.

As you read this, members of CFRI's Research Advisory Committee are evaluating Letters of Intent for our next round of research awards. In 1977 CFRI provided our first grant to Dr. Paul Quinton, a legend in the field of CF whose work transformed our understanding of the disease. Thanks to the support of our community, we are currently supporting 8 exciting research projects. The funding provided by CFRI is often the spark that lights a larger funding flame. In this issue you will see what incredible work is taking place in labs across the country.

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

As we approach the end of 2024, let us reaffirm our collective commitment to the work that remains to be done. Thank you for your consistent generosity and support.

Warm regards,



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

Information, Inspiration, Inclusion: *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 parenting with CF, colon cancer screening and colonoscopies, and tips for living on a limited budget. In addition, there are videos from our Diversity and Inclusion Initiative. Many of the episodes are available with Spanish and Hindi subtitles, as well as captioning in English for the hearing impaired. New episodes are released monthly and can be downloaded on CFRI's podhosting site: **cfri.podbean.com**. You can also watch on CFRI's YouTube channel: **https://tinyurl.com/39kfd3ws** We look forward to sharing our community's diverse voices.

CFRI's 2024 CF Community Voices is made possible with support from Viatris, Gilead Sciences and Vertex Pharmaceuticals

Nadia Ameen, MD

Benjamin Chan, PhD

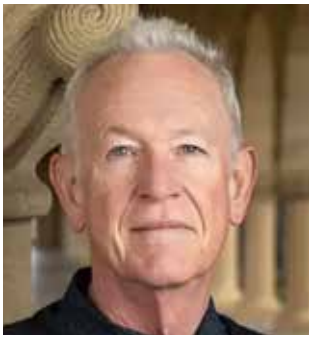
Daria Van Tyne, PhD

Katrine Whiteson, PhD

Feng Yuan, PhD

Steven Jonas, MD, PhD

Ruby Sims, PhD



Ron Kopito, PhD

Celeste Riepe, PhD

Matthew Porteus, MD, PhD

Anais Amaya Colina, PhD

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

With the support of our community, we are providing grants to support the work of the following researchers. Much of this research will benefit all those with CF, regardless of their CFTR mutation.

New Horizons Award Program:

- **Nadia Ameen, MD**
  Yale University School of Medicine
  Elucidating the Ion Transport Functions of CFTR High Expresser Cells (CHEs) *and its Relevance to Intestinal Disease in Cystic Fibrosis (CF)*
- **Benjamin Chan, PhD**
  Yale University School of Medicine
  Optimization of Phage Therapy to Reduce Pseudomonas-Induced Inflammation in Cystic Fibrosis
- **Daria Van Tyne, PhD**
  University of Pittsburgh
  Optimization of Activity and Improved Delivery of Bacteriophages Targeting Burkholderia spp
- **Katrine Whiteson, PhD**
  University of California Irvine
  Targeting Recalcitrant CF Pathogens with Phages, Antibiotics, and Small Molecule Adjuvants
- **Feng Yuan, PhD**
  University of Iowa
  Dissecting Pulmonary Ionocyte Subtypes and their Functional Roles in Cystic Fibrosis

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

- **Steven Jonas, MD, PhD, *Principal Investigator***
  Ruby Sims, PhD, *Postdoctoral Fellow*
  University of California Los Angeles
  Designing a Cystic Fibrosis Gene Therapy Nanocarrier Platform to Target and Modify Airway Stem Cell-Derived Ionocytes
- **Ron Kopito, PhD, *Principal Investigator***
  Celeste Riepe, PhD, *Postdoctoral Fellow*
  Stanford University
  Pharmacogenomic Discovery of Therapeutic Targets for Corrector-Resistant Cystic Fibrosis
- **Matthew Porteus, MD, PhD, *Principal Investigator***
  Anais Amaya Colina, PhD, *Postdoctoral Fellow*
  Stanford University
  A Hybrid Gene Correction Strategy for Cystic Fibrosis

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

Due to its unpredictability, daily treatment burden, and diverse symptoms, cystic fibrosis remains a challenging disease for those diagnosed, as well as for those who love them. Those with CF and their family members have elevated rates of depression and anxiety, and studies show that depression can negatively impact adherence to one's medical regimen. To provide support, CFRI offers a range of programs to address the psychosocial needs of our community.

- **Counseling Support:** CFRI provides up to $125 per session for six sessions of counseling to individuals with CF (children and adults), their parents, partners, spouses, and siblings with the licensed provider of their choice. Participants must live in the U.S.
- **Support Groups — *Held Via Zoom, Facilitated Peer Support, Free and Open to the National and International CF Community:***
  - **Caregivers Support Groups:** Two groups are offered – one for parents of children with CF, and another for parents / spouses / partners of adults with CF. The groups are held on the third Tuesday of every month.
  - **CF Adults Support Group:** Adults with CF are invited to this group, held the third Monday of every month.
  - **Transplant Support Group:** This group is open to CF adults post-transplant. Meetings are held on the fourth Wednesday of every month.
  - **Late Diagnosis Support Group:** This group is offered to adults who had a late CF diagnosis. Meetings are held on the first Wednesday of every month.
  - **Spanish-Language Support Group:** This group welcomes Spanish-speaking adults with CF as well as family members of adults and children with CF. Facilitated in Spanish, the group meets the second Wednesday of every month.
  - **Teen Support Group:** Teenagers with CF meet the third Wednesday of every month. Parents must give consent for their teens to attend.
  - **CF Bereavement Group:** For those who have lost a loved one to CF, this group includes sharing and discussion, goal-setting, grief education, and self-care strategies. The group meets the second Tuesday of each month.
  - **New! Support Group For Those Who Cannot Use CFTR Modulators:** This group meets on the fourth Thursday of every month.
- **Practical Mindfulness:** CFRI offers this six-week course in mindfulness for the CF community with Dr. Julie Desch. Mindfulness practices and meditation have been shown to reduce anxiety and depression. Open to those with CF and their family members, 16 years and older. Offered twice a year.

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

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

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

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

Classes are held on alternating Thursdays (4:00 pm PT / 7:00 pm ET) and Saturdays (9:00 am PT / 12:00 pm ET), and offer a range of classes, from Yoga and Groov3 to strength training and mobility. You can register for both the Thursday and/or Saturday track, and attend as many classes as you would like. 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**/.

CFRI's CF Wellness Classes are sponsored by Vertex Pharmaceuticals and Viatris, with additional support from individual donors.

The Many Faces of CF

Among the approximately 40,000 individuals diagnosed with cystic fibrosis (CF) in the United States are those who often feel isolated due to a lack of awareness by medical care providers and the public of the diversity of those living with CF. This can be alienating, limit access to resources, exacerbate health disparities, and worsen mental health.

While cystic fibrosis (CF) occurs more frequently in those of European descent, it impacts people of every racial and ethnic group. CFRI's Faces of CF Diversity and Inclusion Program advances the organization's goals to expand awareness of CF diversity among the CF community and medical care providers, while raising awareness of the disease and its symptoms among communities of color. This work is guided by an engaged Cystic Fibrosis Diversity and Inclusion Advisory Committee whose members provide vital input and guidance to create and provide enhanced outreach, resources, and support.

There are nearly 2,000 CFTR mutations, and over 700 are known to be disease causing.

Many state newborn screening programs test for only a small number of the most common mutations. Because people of color are more likely to have rare mutations, babies from underrepresented groups are less likely to be diagnosed through newborn screening, leading to delayed or incorrect diagnoses.

Due to the persistent misperception of CF as a disease among people of European descent, many physicians will miss the signs of CF in underrepresented groups and fail to order testing. A delayed CF diagnosis has been documented to lead to worse outcomes for patients, as they may go years without benefit of therapies that will open the airways, treat opportunistic infections and allow the absorption of needed nutrients. Early intervention is key.

There is much work to be done. Minorities are underrepresented in clinical trials of pharmaceutical agents for cystic fibrosis. Outcomes remain worse among non-White CF community members. A disproportionate percentage of those ineligible for modulators are people of color. Multiple studies demonstrate implicit biases negatively impact the level of care provided to racial and ethnic minorities. CFRI is committed to increasing awareness, providing resources, and advancing positive change.

As an organization, the Cystic Fibrosis Research Institute embraces diversity, inclusion, justice, and equity for all community members. We are grounded in principles of openness and respect so as to address the multi-faceted needs of our diverse CF community.

CFRI's Faces of Cystic Fibrosis Diversity and Inclusion Program is supported through grants from Viatris, Vertex, and Gilead Sciences.

Innovative CFRI-Funded Researchers at 37th Conference Inspire Hope for the Future

At CFRI's 37th National CF Education Conference, held July 26 – 28, 2024 at the Grand Bay Hotel San Francisco, nine (9) CFRI-funded researchers presented work from their ongoing CF research projects, covering topics like phage therapy, mucociliary clearance, gene editing and much more.

The abstracts of their presentations can be found at https://tinyurl.com/39atcmrw
You can watch recordings from their presentations at https://tinyurl.com/ycf55jvb

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

Studies show that mothers of children with cystic fibrosis have elevated rates of anxiety and depression, which can directly impact their children's outlook and adherence to their medical regimen. Since 2015, CFRI has hosted its Embrace Retreat for mothers. The in-person retreat, held in May 2024, was offered at Vallombrosa Retreat Center. Over the weekend, women participated in presentations, therapeutic art and writing workshops, yoga, and an overview of additional resources offered by CFRI to provide lasting support. Most importantly, women were able to connect and provide peer support. A virtual retreat was also held on September 21th. The role of a mother with a chronically ill child is unique. The bonds created during the Embrace Mothers' Retreats sustain participating women beyond the events. Evaluations of retreat attendees show that Embrace is extremely effective in lowering symptoms of depression and anxiety. Participating in workshops and activities while connecting with others who share the CF path helps mothers to build resilience for the ongoing challenges presented by this disease.

Generously sponsored by Vertex Pharmaceuticals and AbbVie.

CFRI's Retreats for Adults with CF Keep the Community Connected

The CF Summer Retreat provided five days of connection adults with cystic fibrosis (CF), along with family and friends. The event was held in a hybrid fashion from July 28 to August 1, 2024. Those attending in person enjoyed the tranquil beauty of the Vallombrosa Retreat Center in Menlo Park, California.

The retreat provided a wide array of health-related and psychosocial support programs and activities. In addition to exercise activities tailored to individuals' unique capacities, participants heard from experts in the field on topics including CF and kidney disease, cardiovascular complications associated with aging and CF, mental health issues, and CF related diabetes. There was a fun kayaking/paddle boat excursion, arts and crafts, and a very hilarious night of improv. In addition, there were daily rap sessions (support groups) to support positive mental health, and dedicated time to connect, network, and socialize with others.

Attendees reported that the retreat offered new information about CF therapies and treatments, dramatically improved psychosocial health, and provided resources and strategies for coping with the daily challenges of CF. Retreat provides a welcoming community for adults with CF looking for connection, information, and camaraderie with their peers. Dates for the 2025 Spring and Summer Retreats will be announced soon!

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

Celebrating 50 Years of Research and Service!

In 2025, CFRI will celebrate five decades of cystic fibrosis research progress and community engagement. CFRI was founded in 1975 by a small group of parents whose children were not expected to survive to adulthood. Over the past 50 years, tremendous advances in CF therapeutics have improved and extended the lives of those with CF. With the support of our community, CFRI has played a pivotal role in these advances.

CFRI is proud to fund innovative research while providing educational and psychosocial support to those impacted by this still challenging disease. CFRI is by and for the CF community!

Stay tuned for special activities to celebrate our golden anniversary!

CFRI's *A Breath of Fresh Air* Gala A Success!

CFRI's annual gala was held on October 6, 2024 at the stunning Nestldown estate in Los Gatos, CA. Guests explored the breath-taking beauty of the venue and its ponds, forests, waterfalls and hidden treasures, while enjoying the festive atmosphere, delicious food and fine wines, and musical entertainment from the Magnolia Jazz Trio. Our emcee, Andrew Byrnes, guided us through a fast-paced but moving program which highlighted CF community members and CFRI-funded researchers. Gina Serrato, mother of a teenage daughter with CF, stressed the importance of continued investment in CF research. We honored Matthew Porteus, MD, PhD, of Stanford as our 2024 Cystic Fibrosis Champion. The program ended with a moving musical performance by Tess Dunn, a singer and writer who lives with CF. In addition to the live event, community members across the country were able to bid in our virtual auction.

By the end of the evening, the live, silent and virtual auctions and Bid for a Cure helped raise over $133,000 to support CFRI's research, education and support programs. $40,000 of this total is being matched dollar-for-dollar by members of CFRI's Jessica Fredrick Memorial CF Research Challenge Circle and designated for our CF research awards.

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

A Breath of Fresh Air Sponsor — *Vertex Pharmaceuticals*

Mistral Sponsors — *AbbVie; GRAIL; ReCode Therapeutics*

Breeze Sponsors — *Heritage Bank of Commerce; InterWest Insurance Services LLC; Longfellow Real Estate Partners; Viatris*

Media Sponsor — *NBC Bay Area*

CFRI Is Your Partner in Living

- **Monthly Giving:** *Champions of Hope!* Donations to Champions of Hope provide a revenue stream to support research to find a cure for CF and enhance CFRI's programs in CF education, support and advocacy.
- **Tributes:** "*In Honor Of*" and "*In Memory Of*" – Recognize a loved one with your choice of gift. CFRI will promptly send an acknowledgement letter to your designee.
- **Hold Your Own Fundraising Event:** Cocktails for a cure, yoga, cornhole, pickleball – 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 on Facebook. Go to https://www.facebook.com/cfri.org/, scroll down to Fundraisers, and click on Create!
- **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.
- **Special Events:** Gala, Golf Tournaments and more – join the community fun.
- **Planned Giving:** Benefits can include increased income, substantial tax savings, the opportunity to meet your philanthropic goals, and the satisfaction of making a very significant gift to CRFI 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****.*

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

Through its Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program, CFRI engages our CF community to raise awareness of the physical, mental and financial burdens of the disease, policies and legislative acts that negatively impact access to therapies and care, and the need to expand funding for CF research.

At the federal level we encourage increased financial support for the Food and Drug Administration (FDA) and National Institutes of Health (NIH). We support passage of the Pasteur Act, to find creative strategies to address antimicrobial resistance. We support the Supplemental Oxygen Reform (SOAR) Act, which will improve access to portable supplemental oxygen by members of our community. Without portable oxygen, many people are trapped at home, unable to exercise, go to the store, or to medical appointments.

On the state level, we have focused on the creation of Rare Disease Advisory Councils (RDACs), which provide the rare disease community with a formal platform and official voice at the state level to help advise state officials on policies and services that impact us. CFRI is a member of several coalitions working to advance these efforts, and we are excited to announce that California's legislation passed, making it the 29th state with an RDAC.

CFRI also seeks to address the proliferation of co-pay accumulator programs that are increasingly embedded in private insurance plans and create significant financial hardship. Those who rely on specialty medications are most impacted. It has been found that one in four people with CF has delayed care or skipped treatments because of costs related to insurance premiums, deductibles, and co-payments. CFRI is working with others to support bipartisan legislation that will mandate that all payments for prescriptions be applied toward one's deductible and annual out-of-pocket total.

CFRI has advocated for expanded telehealth services, which were vitally important through the pandemic, and which have proven in many instances to increase adherence to clinic visits and alleviate stress for patients. CFRI also continues to support improvements in state newborn screening programs. Cystic fibrosis impacts people of every race and ethnicity, and individuals from underrepresented groups are more likely to have rare mutations

that will not be detected through many states' current screening panel. Awareness must be raised about the diversity of our community so as to address these disparities.

CFRI invites our community to engage with our advocacy efforts. Please email Stacie Reveles at **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, AbbVie, Viatris, and Amgen.

In Honor of

March 1, 2024 — September 15, 2024

Ashley Aboud
All People living with CF
Susie Baldwin, MD
Lucy Barnes
Francine Bion
Naomi Burks
Joy Butler
The Capriotti Children
Lauren Catron
Susan Charpie
Shaun Collins
Mary Convento
Cameron Cornell
Dr. Carol Curnadi
Barbara and Jim Curry
Julie Desch
Kat DeVoe
Gordon DeVore
Sharon Dunn
Tess Dunn
Debbie Duplessis
Daniel Ellett
Thomas Evans
The Flynn Family
Tricia Fickel
Jarrod Fischer
Kathleen Flynn
Jessica Fredrick
Zaylee Fults
Cheri Geoghegan
Mark E Gerow
Gaynell Gleason
Elyse Elconin Goldberg
Alec and Lizzy Hampton
Mary Helmers
Anna Modlin Holyoak
Kristen Hoyt
Erinn Hoyt
William Hult
Eric Hyman
Alexander Jenkins
Darren Johst
Michelle Jones
Harper Jorgenson
Kristin Favero Konvolinka
Steven Kusalo
Daniel Lagasse
Douglas Lagasse
Dr. Elizabeth Lewis
Emily Fredrick Lucas
David Martin
Rose Logue Martini
Rachael and Rebecca McMullen
Carly McReynolds
Matthew Mitchell
Jessica Nett
Lucille and Dick Otto
Scott Parks
Anna Payne
Briauna Red Peters
Missy Peterson
Natalie Puzia
Serenity Raffetto
Mario Reveles
Megan Reveles
Rebecca Roanhaus
Carl Robinson
Clare Robinson
The Robinson Family
Taylor Rolefson
Alanah Fink Rosenbloom
Janice Shaul
Matthew Spadia
Ethan Spain
The Stenzel Family
Brian Tacke
Christine Tacke
Adam Thompson
Robert Turk-Bly
Siri Vaeth
Devin Wakefield
Matthew and Melissa Weiner
Chris Wernli
Maggie Williamson
Jonathan Witczak

In Memory of

March 1, 2024 — September 15, 2024

Chelsa Aboud
Gordon Adelman
Marcus, Kimberley, and Carol Adelman
Doris Alexis
Gianna Altano
Gary Anderson
David Beebee
Anne Beltrame
Brett Bennett
Kitsy Bennett
Jamie Bertolini
Debbie Boswell
Robert Boswell
Rebecca Boyer
Greg Brazil
Christopher Broom
Victoria Buehl
Wava Hebbron Burby
Kyle Butler
Peter Byram
Isabel Stenzel Byrnes
Camille
Traci Carwana
Cassandra Cochran
Ryan Coelho
Kalynn Cole
Kelly Colgan
Martha Colla
Michelle Compton
Parker G Cronin
Christina Crow
Carol Curnadi's mother
Caroline Daly
Neva DeVore
Jason Dolan
Ann Nee Donnelly
John M Duffy
Kerri Efird
Susie Ellerson
Jessica Fredrick
Laura Gale
Erby George, III
Royce Goertzen
Ray Goldstein
Diana Goodman
Rob Greene
Willie Harbison
Doris Hegseth-Ures
Curt Heisler
Gibert Holmes
Margaret Huffer
Robert Hunziker
Christopher Ireland Jenny
Jerilynn Lucia Johnson
Melody Johnson
Laney Jones
Mary Kay Jones
Peggy Jones
Julie Judge
Kathy and Peter Judge
Kurt Koenig
Edward Kinney
Lori Kipp
John Klein
Bridget Klein
Jason Konkel
Tim Laufenberg
Yvonne De Leon
Fernardo De Leon
Hannah Levy
Elizabeth Lewis' mother
Sean Linehan
Dawn Longero
Alyson Lowery
Danielle Mandella
Catharine Martinet
Elizabeth Mayer
David McAfee
Karen Melvin
Nancy Melvin
Nome Mentch
Jessica Mobley
Loretta Morris
All Mothers
Lynette Moulton
Kimberly Myers
Patrick Nash
Joe Odonnell
Michele Denise Olson
Jennifer Ortman
Dellene Ott
Pamala
Gino Panelli
Scott "eDog" Peterson
Karen Porterfield
Tim Prater
Jon Prater
Dea Roanhaus
Ann and Rob Robinson
Katie Robinson
Pamela Rockhold
Tom Rolefson
Stanley Roshwald
Joseph Marden Sinnaeve
Anabel Stenzel
Robin Stephenson
Pamela Stroud
Erin Phillips Taylor
Tara Telford
Pat and Frank Thibault
June Thompson
Ariel Tonkel
John Trask
Louis Anthony Trigueiro
Todd Trisch
Bea Mae Ures
Aurore and Jerome Vaeth
Joy Villasenor
Erynn Vondell
Tom Walton
Sean Waltrip
Tara Weir
Hayley Carol Wester
Claire Wineland
Jakub Wisniewski
Estelle Zuckerman

Pet Memorial

Lola Garlow (Dog)

Tributes

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

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

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

Honoring Our Community Heroes

At the 37th National CF Education Conference in July, CFRI proudly honored four remarkable people for their outstanding contributions to the CF community. We are grateful for their time and commitment to those living with cystic fibrosis.

Alicia Maciel

David Stuckert Memorial Volunteer of the Year Award — *Alicia Maciel, MBA*

Alicia Maciel's impact upon CFRI is profound. The mother of two sons, one of whom has cystic fibrosis, Alicia has been a highly involved volunteer for many years. Alicia has volunteered as an editor of CFRI's Spanish language newsletter for nearly nine years, assisting with content and ensuring accurate translations. She serves on CFRI's Diversity and Inclusion Advisory Committee where she has played a pivotal role in CFRI's reach to the Hispanic/Latinx community. She has participated in our diversity films on CF in the Hispanic/Latinx community, recording podcasts in Spanish to help Spanish-speaking members of our community access CFRI's resources. She helps to coordinate diversity workshops for our community members and has facilitated a webinar for CF social workers on mindfulness and DEI work. Alicia also serves on CFRI's Embrace Mothers Retreat Committee, where she plays a pivotal role in assisting with event planning and content. Alicia is generous with her time and expertise in supporting her fellow CF community members and is an outstanding CFRI volunteer.

Kate Yablonsky

CFRI CF Professional of the Year Award — *Kate Yablonsky, LCSW*

Kate Yablonsky, LCSW joined the Stanford Adult CF Team as the CF Social Worker in 2018. Before this, she was a social worker at Lucile Packard Children's Hospital in the Pediatric Stem Cell Transplant Program, before moving to the CF center. Kate sees her patients beyond their cystic fibrosis diagnosis. Originally from Pittsburg, Pennsylvania, Kate earned her undergraduate degree at New York University and her Master's in Social Work from UC Berkeley. She is known for her caring kindness and respect for her patients, as well as her patience and humor. Kate has been involved with CFRI for many years. She is a co-facilitator of CFRI's CF Adult Support Group and the two CF Caregivers Support Groups. She has presented at CFRI's conference as well as in CFRI webinars. Kate is always generous with her time. Kate honors her patients' lived experience with CF and recognizes the resilience, self-knowledge and courage of the adults she works with. Kate is an exemplary social worker, who uplifts those around her.

Laura Mentch

CFRI Partners in Living Award in Memory of Anabel and Isabel Stenzel — *Laura Mentch, EdM*

Laura was diagnosed with cystic fibrosis at the age of 50, after years of being told that allergies and asthma were the cause of her repeated lung and sinus infections. After her diagnosis, Laura immediately engaged with the national CF community, including with CFRI's Retreat and conference. Laura has lived on both the East and West Coasts, but now hails from Bozeman, Montana. Prior to her CF diagnosis, Laura received her graduate degree, married, and raised three children while working as a health educator – with a strong emphasis in sexual and reproductive health. Laura serves on the Board of Directors of the United States Association of CF Adults (USACFA) CF Roundtable, as well as the Cody Dieruf Foundation in Montana. In 2023, she began co-facilitating CFRI's support group for Adults with a Late CF Diagnosis. CFRI's Board of Directors celebrates Laura and her many contributions to the cystic fibrosis community.

John LiPuma

Paul M. Quinton Cystic Fibrosis Research Legacy Award — *John LiPuma, MD*

John LiPuma is Research Professor of Pediatrics and Communicable Diseases, and Division Director, Pediatric Infectious Diseases Research Program at the University of Michigan. His research laboratory focuses on bacterial infections of the airways in persons with cystic fibrosis. His laboratory has developed novel methods of bacterial genotyping to study the molecular epidemiology of CF- related respiratory tract pathogens, as well as numerous genetic-based methods for bacterial species identification. His interest in bacterial taxonomy has contributed to the description of dozens of novel bacterial species. His work focusing on bacterial pathogenesis has utilized cell culture and animal models of infection. Recent research employs culture-independent microbial community profiling, including the use of next generation DNA sequencing, to understand the airway microbiota in CF. His laboratory serves as a national reference laboratory for the Cystic Fibrosis Foundation, and maintains an extensive culture collection that includes approximately 40,000 bacterial strains. Dr. LiPuma was previously the recipient of CFRI research awards, which supported his research on the epidemiology of *Burkholderia Cepacia*. Dr. LiPuma is recognized as one of the most impactful researchers in CF microbiome studies with a research record second to none in the world of CF microbiology.

Community Abounds at the 40th Annual Golf Tournament for CFRI

On August 12, dedicated golfers gathered for the 40th annual Cystic Fibrosis Benefit Golf Tournament at the beautiful Cinnabar Hills Golf Club in San Jose, California. Participants enjoyed friendly competition while supporting the search for a cystic fibrosis (CF) cure. Participants had an incredible day, netting over $71,000 for CFRI's research and programs. Of this total, $15,000 is being matched by CFRI's Jessica Fredrick Memorial CF Research Challenge Circle and designated for CFRI's research grant awards.

The event is deeply personal for the event co-chairs, Scott Hoyt and Mike Roanhaus – both have daughters living with cystic fibrosis. CFRI is extremely grateful to the dedicated mem-bers of the event committee – Scott, Mike, Tina Capwell, and Ralph Swanson – and the many participants whose support advances cutting-edge research and much needed support pro-grams for those living with CF. We also thank the long-time major sponsors of the event – Star One Credit Union, the Kirkorian Family Foundation, as well as the Roanhaus family. Dates for 2025 will be announced soon!

Jessica Fredrick Memorial CF Research Challenge Circle andFund

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

— Albert Camus

Members of CFRI's Jessica Fredrick Memorial CF Research Challenge Circle give generously to inspire others to join the search for new CF therapies and a cure. This year, Circle members will contribute nearly $100,000 so as to match – dollar for dollar – donations from individuals committed to CF research. Together, these donations are used for our CF research awards.

Our Circle is named in memory of Jessica Fredrick, who lost her battle with CF at the age of 21. There is still no cure for CF. We need your help to improve and save the lives of our loved ones. Please join this inspiring group! Become a member of the Jessica Fredrick Memorial CF Research Challenge Circle by making a minimum gift of $2,500. You will inspire others to make the dream of a CF cure a reality.

If you are unable to join the Circle, please consider making a gift to the Research Challenge Fund, which will be designated for CF research awards. By giving all to the present, you are generously supporting the future hopes of those with CF.

SAVE THE DATES!

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

Practical Mindfulness
Beginning Tuesday, October 29
Six-week online Mindfulness course for the CF community with Dr. Julie Desch.

CF Virtual Support Groups
See dates on page 4

Dance Like a Fool
Six-hour dance-a-thon to support CFRI's Wellness Programs
February 21, 2025

CF Spring Retreat
A virtual retreat for adults with CF, their friends and family
March 2025

Purple Power Challenge
Color your hair purple and challenge your friends to raise CF awareness!
May 2025

Embrace Mothers' Retreat
An in-person retreat for mothers of children and adults with CF
May 2 – 4, 2025
Vallombrosa Retreat Center
Menlo Park, CA

CFRI 38th National CF Education Conference
Date to be announced soon!
Held as a hybrid event (virtual and in-person)

CF Summer Retreat for Adults with CF
August 2025
More details coming soon!

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

How Everyday Molecules and Bacteriophages Can Help Eradicate Tough CF Infections

Continued from Cover

In the Whiteson lab at UC Irvine, teams of brave students search wastewater samples from several treatment plants in Southern California to find phages that can target resistant bacteria from people with CF, including bacteria like *Stenotrophomonas maltophilia* and *Pseudomonas aeruginosa*. Samples from the wastewater treatment plant in Escondido, CA have been particularly rich in *Stenotrophomonas* phages – that is where most of the several dozen new phages discovered at UCI came from.

With the help of medical collaborators, we have been collecting bacterial isolates from people with CF and testing whether our phages can kill them. Often there are some bacteria that the phages cannot kill. To boost the phages' potential to kill some of the more difficult strains of bacteria, we are combining phages, antibiotics and other helper molecules into cocktails and testing them under conditions that mimic CF airway environments. So far, we have tested a variety of alcohols along with 2,3-butanedione (diacetyl), 2,3-butanediol, essential oils, and other everyday molecules, including fatty acids.that range from small, acidic molecules such as acetic acid (vinegar) to larger carbon chains resembling soap. Many of these molecules are known to inhibit bacterial growth and have been used since medieval times. Fortunately, chemist and CFF post-doctoral fellow Dr. Sage Dunham has helped us past many hurdles, especially related to the solubility of the compounds we want to work with.

We have found that all tested fatty acids slow the growth of *S. maltophilia*, but short-chain fatty acids (SCFAs) rely heavily on pH to work and don't help phages much. In contrast, medium-chain fatty acids (MCFAs) can stop growth independent of pH and work synergistically with phages. Octanoic acid, a type of MCFA, seems to enhance the effectiveness of phages across different types of bacteria, including both gram-negative ones like *S. maltophilia* and gram-positive ones like *Enterococcus*. We are now expanding our tests with MCFAs to conditions that better mimic the CF infection environment, such as different oxygen levels and artificial lung fluid, and applying them to other CF pathogens like *Staphylococcus aureus* and *Pseudomonas aeruginosa*.

CFRI's 37th National Cystic Fibrosis Education Conference

Continued from Cover

miracle resurrection through a double lung transplant. Together, they defy the odds and are fueled by hope, gratitude and a quest for meaning and healing.

Robin Modlin

Follow them as they meet a Tibetan lama who opens their world with ancient healing rituals, have an audience with the Dalai Lama, and in one of her darkest hours, Anna experiences a healing blessing from a magical blue budgie. With her newfound lungs, Anna triumphs, realizing unexpected dreams and invites exciting adventures into their lives.

Love, Courage, and Miracles is more than a story. It is a testament to the unbreakable bond between a mother and daughter entwined with the challenges of a devastating disease. Their journey is a powerful narrative of survival and living life to the fullest, showcasing the transformative power of love, acceptance, and hope.

Modeling Epithelial Immune Cell Interactions in Cystic Fibrosis

Amy Ryan, PhD —
University of Iowa, Iowa City, IA

Amy Ryan

Mucociliary clearance is a key mechanical defense mechanism of human airways, and clearance failure is linked to major respiratory diseases, including cystic fibrosis. Despite Highly Effective Modulator Therapy (HEMT) benefits, persistent lung inflammation and compromised pathogen clearance in people with CF (pwCF) suggests inadequate targeting of lung innate immunity or potential drug tolerance. These issues highlight a need to further understand the interplay between immune cells and airway epithelial cells during injury, repair, and regeneration.

Our research focuses on developing models to elucidate these dynamics. We have recently generated lung-on-chip models incorporating CF primary bronchial epithelial cells and elucidated the structural parameters of airway epithelia that predict clearance function in both ex vivo and in vitro tissues. From these we developed physics-based models to translate measurable parameters to quantitatively benchmark the human-relevancy of mucociliary clearance in experimental models, and to characterize distinct disease states.

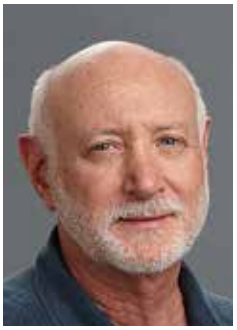
Furthermore, we have engineered ΔF508 mutant THP-1 cells, using CRISPR/Cas9 technology, to investigate the role of CFTR (Cystic Fibrosis Transmembrane Conductance Regulator) in innate immune functions. We compared isogenic wild-type, ΔF508 mutant, and CFTR knock-out THP-1 cells, differentiated into macrophage-like cells, and tested their responses with CFTR modulators (ivacaftor, elexacaftor, tezacaftor). Our findings indicate dose-dependent effects of these modulators on inflammatory responses, TNFα release, phagocytosis, bacterial killing, cell migration, and expression of pro-inflammatory markers in both ΔF508 and wild-type macrophages. Notably, lower concentrations of modulators attenuate inflammation, while higher doses, especially in combination, may exacerbate immune dysfunction.

These insights into how HEMTs impact macrophage function highlight potential mechanisms underlying immune complications observed in CF patients despite treatment. Future investigations incorporating patient-derived macrophages could reveal additional therapeutic targets to mitigate these challenges. Moving forward, our integrated approach combining physics-based models, gene-edited immune cells, and lung-on-chip technologies promises to deepen our understanding of inflammation's role in airway stem cell function and functional mucociliary clearance. This multidisciplinary framework holds promise for advancing personalized cellular therapies for CF and other lung diseases.

Aging in the New Age of Cystic Fibrosis

Richard Moss, MD —
Stanford University, Palo Alto, CA

In the 15 years since the clinical trials of Kalydeco® (ivacaftor) in G551D-carrying people with CF (~4% of the total CF popula-



Richard Moss

tion) showed a potential transformative early benefit, confirmed and vastly expanded by the effects of the triple drug Trikafta® (elexacaftor/ tezacaftor/ ivacaftor, ETI) on 85-90% of people with CF in the Global North, the entire worldwide CF community has come to realize that we have entered a new age, where the potential of a full lifespan is now predicted for those diagnosed, eligible and on CFTR modulator treatment from an early age. What the rosy predictions may neglect is the realization that aging with, instead of prematurely dying from, CF presents its own set of formidable new challenges, for lifelong "highly effective" CFTR modulator therapy [HEMT] with ETI is not a cure. Aging on top of defective, not fully corrected CFTR function and established disease impacts on many organs despite HEMT, recent studies confirm, is associated with a panoply of many CF- (and transplant-) related complications and early vulnerability to an expanding array of age-associated diseases such as diabetes, a variety of cancers, cardiovascular disease, obesity, osteoporosis, and other health challenges. The huge issue of the ineligible minority with HEMT-unresponsive CFTR mutations remains a new mountain to climb. In addition, there is increasing recognition of the further problems of HEMT intolerance and heterogeneity of response, CF underdiagnosis in much of the world and among many ethnicities (partly due to genotypic heterogeneity and partly to many socioeconomic factors), lack of access to HEMT in many countries and exorbitant lifelong cost. In this overview talk, Dr. Moss addresses many of these aspects of our new age of CF, and presents CFRI's new programmatic efforts to raise expertise of caregivers for aging CF patients as well as providing accurate information and empowerment to all people with CF everywhere.

Culture Shift: CF Lung Infections in the Modulator Era

Lucas Hoffman, MD, PhD —
University of Washington, Seattle, WA

CFTR modulator therapy has dramatically changed the pace, course, and overall

Lucas Hoffman

nature of CF lung disease for many, but not yet all, people with CF. Even before these transformative treatments were introduced, the "ecology" of CF airway infections – the types and prevalences of different bacteria in the respiratory samples from people with CF - had changed considerably over the years as treatments, social practices, and hospital policies changed. At the same time, our understanding of how microbes infect people with CF in the first place, and how those microbes adapt and change during infections, has grown enormously, aided by new technologies, concepts, and insights from a variety of fields. We are only now updating these models of CF lung infection pathogenesis in the context of CFTR modulator treatments, with some studies suggesting the need for large-scale revisions of how we diagnose, treat, and think about these infections, guided both by ongoing research and what our patients are telling and showing us.

In this presentation, Dr. Hoffman reviews the "cast of characters" - the microbes that are most frequently detected and other less common but equally important ones - involved in CF airway infections. We'll see how these infections have changed over the years, as treatments and policies have changed. He talks about the benefits and risks of current treatments, especially antibiotics, and the meaning of antibiotic resistance, and how these concepts might change in the context of CFTR modulators. In addition, Dr. Hoffman discusses the implications of the ongoing decreasing rates of expectoration among many people with CF, a trend that preceded the introduction of highly-effective CFTR therapy but that has greatly accelerated since. In particular, he reviews what this trend means for diagnosing CF respiratory infections, as well as work on the horizon to improve detection of infections in this new era.

Sexual and Reproductive Health in CF

Natalie E. West, MD, MPH —
Johns Hopkins University, Baltimore, MD

With improved therapies, people with cystic fibrosis (CF) are living longer and healthier

Natalie E. West

lives. People with CF have an increasing number of questions regarding their sexual and reproductive health. This talk will summarize important issues during puberty, adulthood, and menopause that specifically affect people with CF.

A wide range of sexual and reproductive health topics including puberty, transgender and gender nonbinary identities, contraception, cyclical hemoptysis, fertility, contraception, and parenthood will be addressed.

More people with CF are expressing the desire to become pregnant, as people with CF are living longer lives. In the last 4 years, the pregnancy rate of women with CF has tripled in the United States. The impact of highly effective modulators has improved the health of many people with CF, which is allowing them to consider all reproductive options. Care during pregnancy, management of CF medications during pregnancy, and outcomes with the use of highly effective modulator therapy during pregnancy and lactation will be discussed, as there are retrospective studies available, as well as a large ongoing prospective pregnancy clinical trial. 95-97% of men with CF have congenital bilateral absence of the vas deferens, which leads to infertility in men with CF. Assisted reproductive technology is available which can be used to assist in having biological children.

Other options for family building include fostering, adoption, and surrogacy. Gaps in knowledge, current evidence, and management strategies to optimize care in people with CF will be discussed. The impact of the approval and increased use of highly effective modulator therapy on sexual and reproductive health care needs and outcomes remains to be seen. However, due to the positive impact on health and longevity, it is expected that people with CF will increasingly face concerns and decisions. Optimizing sexual and reproductive health care as the face of CF changes is imperative to meet these emerging needs throughout the lifespan.

Continued on page 14

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Panel: Coping with Cancer and CF

Elyse Elconin Goldberg, MA; Thomas Horal; Colleen Lewis; Christine Nash, MBA — *Los Gatos, CA; San Jose, CA; Philadelphia, PA; Lafayette, CA*

Moderated by Jean Hanley, MD — *Manhattan Beach, CA*

Elyse Elconin Goldberg

Thomas Horal

Colleen Lewis

Christine Nash

As adults with cystic fibrosis are living longer, additional health complications are emerging. Some of these are related to having CF; others are made more complex by a CF diagnosis. There is increased awareness of the higher risk of certain cancers for adults with CF, most notably gastrointestinal cancers. There is a higher risk of pancreatic cancer; the risk of colon cancer for those with cystic fibrosis is five to ten times higher than that of the general population. Breast cancer rates are higher for women with CF, with evidence of the role of sex hormones, particularly estrogen, impacting the pathophysiology of CF.

For individuals with CF who have received a double lung transplant, the risk grows significantly; colon cancer risks are over 25 times higher than the general population due to the immunosuppressants required to ward off organ rejection. With the immune system suppressed, cancers are more likely to develop and spread, most significantly GI, esophageal and skin cancers. In this session, panel participants share their personal experiences with diverse cancer diagnoses. A sibling will describe her brother's battle with pancreatic cancer, while three adults with CF will describe their individual journeys with breast cancer, skin cancer and colon cancer. Awareness, detection and early intervention are key. Panelists will share insights and perspectives on detection and treatment, as well as the mental health implications of this dual diagnosis.

Jean Hanley

Panel: Advocacy, Access and Health Equity in Cystic Fibrosis

Rachel Alder; Jaelyn Cooper, MHA; Alicia Maciel, MBA; Abhijit Tirumala — *Salt Lake City, UT; Little Rock, AR; Brea, CA; Saratoga, CA*

Moderated by Kimberly Morse, MSW, LCSW — *Children's Hospital Los Angeles, Los Angeles, CA*

Rachel Alder

Jaelyn Cooper

Alicia Maciel

Abhijit Tirumala

Despite the fact that cystic fibrosis occurs in every race and ethnicity, there remains a misperception – both in the general public, and among medical care providers - that the disease only impacts people of European descent. As a result, many people of color with CF are misdiagnosed for years and are thereby unable to benefit from CF therapies and care. 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. Current CF therapies were largely approved through clinical trials with very few people of color participating. For CF patients and families for whom English is not a first language, it may be challenging to access resources and support. During this dynamic panel discussion, we will hear from members of our CF community who will share their personal experiences and insights navigating bias to develop productive partnerships with care teams and fellow community members so as to improve medical care and quality of life. All panelists provide examples of optimal care and interactions, while stressing the importance of self-advocacy and community engagement.

Kimberly Morse

Exploring Nucleic Acid Based Approaches to Treat People with CF

Jennifer Taylor-Cousar, MD, MSCS — *National Jewish Health, Denver, CO*

Jennifer Taylor-Cousar

Cystic fibrosis (CF) was first described as a clinical entity by Dr. Dorothy Andersen in 1938. At that time, people with CF unfortunately did not survive past early childhood. In subsequent years, the establishment of comprehensive care and treatments directed at the signs and symptoms of CF improved the quantity and quality of lives for people with CF. In 1989, the CF transmembrane conductance regulator (CFTR) gene was discovered; it was thought that the development of gene therapy to cure CF would be imminent. However, in early gene therapy clinical trials, ineffective vector (transport mechanism)

transduction (transfer of the corrected gene) into lower airway cells along with immune-mediated side effects temporarily prevented advancement of this approach to treating CF.

While deficits in early gene therapy technology precluded its initial development for CF, focus shifted to addressing the downstream protein dysfunction caused by variants in the CFTR gene. Since 2012, four CFTR protein modulators have been approved. In populations comprised primarily by people of European descent, >90% of people are variant eligible for CFTR modulators. However, side effects and access preclude CFTR modulator use by some variant-eligible people with CF. Critically, there are also people with CF whose variants make them unable to benefit from CFTR modulators. To achieve effective therapies for all people with CF, nucleic acid based therapies are being developed.

The goal of nucleic acid based therapies (NABT) is to deliver the correct instructions to the cell for making a functional CFTR protein. Examples of nucleic acid based therapy include gene editing (making specific changes to the gene), gene therapy (replacing the entire gene), mRNA [messenger ribonucleic acid] therapy (using the corrected blueprint for the protein) and antisense oligo nucleotide (ASO) therapy (using a very small amount of matching RNA to correct the blueprint). The various approaches are each associated with advantages and challenges including potential variant-agnostic treatment (e.g. therapies that are effective regardless of CFTR variant), differences in delivery requirements for each potential therapy, potential immune reactions to therapeutic delivery of the therapies, and possible barriers for redosing. Nonetheless, gene therapy, mRNA and ASO treatments are currently in clinical trials for pwCF.

In this session, Dr. Taylor Cousar reviews lessons learned from historical NABT efforts, pre-clinical data supporting renewed clinical investigative efforts, and ongoing clinical trial designs and updates.

Strategies to Address Medical Trauma

Samantha Johnson, MA, CCLS;
Kate Yablonsky, LCSW —
Stanford Children's Medicine, Palo Alto, CA; Stanford Health Care, Palo Alto

Over the course of a lifetime with chronic illness and interaction with the medical

Samantha Johnson

Kate Yablonsky

system, people with cystic fibrosis and their families are at high risk of experiencing medical trauma. This is an under-discussed but very real form of trauma that can have a significant impact on quality of life. In this session, a pediatric Child Life Specialist and Adult CF social worker review signs and symptoms of medical trauma and discuss strategies for people with CF and their loved ones across the lifespan to effectively process and integrate these experiences.

Living Proof: Nearly Seventy Years with Cystic Fibrosis

Luanne McKinnon, PhD —
Albuquerque, NM

Luanne McKinnon, PhD (b. 1955) has cystic fibrosis and is a thirteen-year survivor of a successful bilateral lung transplant. Her presentation, "Living Proof: Nearly 70 Years with Cystic Fibrosis" is a colorful recounting of her life with CF, from a diagnosis in 1969 through the arc of CF care that, like a travel log, leads us from Texas to Europe to New York City, Scotland and France, then New Mexico to Palo Alto. She will speak about her uncanny good fortune to live at a time, in the long history of CF, in which research and healthcare have mitigated so much suffering. Ms. McKinnon's presentation weaves a brief historical account of the discovery of CF in 1938 into the broader, compassionate scope of living under the "double rainbow" of hope and doing the work required to be here now.

Luanne McKinnon

"Living Proof" is presented in two parts. Part 1 is a personal testimony. Part 2 is an imaginative piece about the life of her mother's sister who died in 1935 from symptoms echoing CF. Inspired by the late Isa Stenzel Byrnes, who during one of her last creative writing workshops posed the question, "How do we honor those we have lost?" Ms. McKinnon will share an excerpt from her memoir-in-progress entitled, *Pneuma, Latin for soul and breath*. The CFRI audience is the first to hear this.

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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.

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

CFRI's New Teen Guide: Available in English and Spanish

CFRI is excited to announce the release of *A Teen's Guide to Cystic Navigating Fibrosis: Resources & Tools for Physical, Emotional & Mental Wellbeing*. This comprehensive guide for teens with cystic fibrosis, spearheaded by CFRI's Diversity and Inclusion Advisory Committee, was created with the input of teens and young adults with CF. It offers tips, tools and resources to cope with the many issues faced by teens with CF, including peer pressure, treatment frustrations, mental health, self esteem, and healthy relationships. It also includes the lived experiences of teens from underrepresented groups who had the additional challenge of feeling "rare within rare." The booklet is available in English and Spanish. It is available for download on CFRI's website, and printed copies are available at no cost to teens, families, and CF centers.

To request your copy, email — **cfri@cfri.org**.

"A Teen's Guide to Cystic Fibrosis" was created with grants from Viatris, Vertex Pharmaceuticals, and Gilead Sciences.