cfri community
41 Years of Research, Education & Support
Fall 2016

Emily Schaller's Mission to Rock CF

By Amy Baugh and Siri Vaeth Dunn, MSW

Emily Schaller is a rock star, both figuratively and literally. She is, among other things, a drummer, comedian, adult with cystic fibrosis (CF), founder of the Rock CF Foundation, marathon runner, and source of inspiration for many. Emily provided the perfect inspirational closing presentation to CFRI's 29th National CF Family Education Conference. Her sense of humor and upbeat and positive attitude radiated as she shared her life story of living with – and thriving with – CF.

When Emily's mother first held her in her arms, she knew that something wasn't right. Within a few months, Emily was diagnosed with failure to thrive due to her poor weight gain. When the doctors suggested that it might be CF, like so many others, her family was shocked: they did not know what CF was and there was no family history of the disease. After a sweat test at an accredited CF center, the CF diagnosis was confirmed. At that time the life expectancy for a child with CF was around 18, and the news was devastating.

Emily's parents were determined that she would have a "normal" childhood. With two older brothers, Emily skateboarded, played t-ball and joined the family band. During her early teenage years, while many new drugs and therapies were developed, at the same time Emily had her first "tune-up," and noticed that she had a hard time keeping up with her peers. Her hospital stays became more frequent, until she was inpatient for three to five weeks several times per year.

Emily Schaller rocks CF

After high school, Emily had a short stint in college, but soon left to play in a band, work retail, and to live what she called "the CF cycle," in and out of the hospital. At this time she was a self-proclaimed couch potato, but she was becoming "sick of being sick." She knew she needed to make a change, and exercise was that change. On a trip out to California to attend her brother's wedding, she met triathletes and marathon runners, and this proved to be the motivation she needed to start her running and

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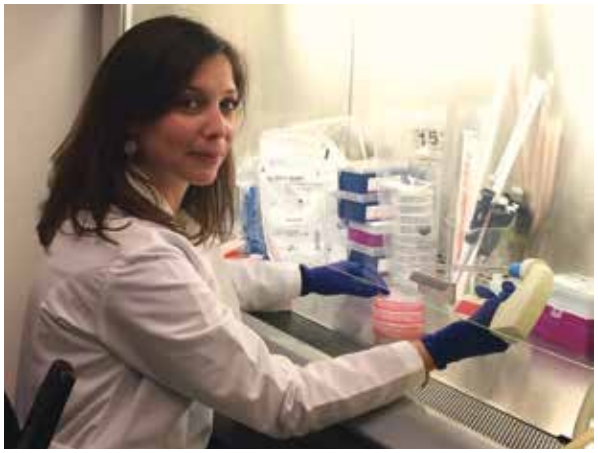

Carolin Boecking, MD, in the lab

A Meeting of the Minds: CFRI-Funded Research Track 2016

By Doug Modlin, PhD and Julie Desch, MD

CFRI has distributed over 9 million dollars in research grants since 1975, contributing to a series of basic research findings that have paved the way towards successful therapeutics and improved quality of life for those with CF. Each year, current and past grant recipients present their research findings at CFRI's National CF Family Education Conference to an audience of CF researchers, healthcare providers, interested people with CF, and their families.

The Elizabeth Nash Memorial Fellowship (ENMF), named for Elizabeth Nash, a PhD geneticist with CF who volunteered extensively for CFRI, was created in

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Fall 2016

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Letter from the Executive Director

Sue Landgraf

Dear Friends,

I hope this finds you and yours well. CFRI is a constant hub of activity, as our dedicated staff and volunteers expand our research, education, advocacy, and psychosocial support programs. While there has been tremendous progress in the field of cystic fibrosis (CF), our community's needs are diverse and significant. I am proud that CFRI is on the cutting edge of service delivery to those impacted by this challenging disease.

Our 29th National CF Family Education Conference, Riding the CF Wave, was an outstanding success, and in this newsletter you will read summaries of many of the presentations (to be continued in our winter edition). Thanks to those who attended, and to our generous sponsors and exhibitors who made it happen. The conference truly felt like an embracing CF village for our community.

We remain strongly committed to CF research, and have recently extended a nationwide call to our medical and scientific community, seeking CF research funding proposals. We continue to invest in the highest quality scientific research that will broaden treatment options, improve quality of life, and expand the search for a cure. I look forward to keeping you updated on this next cycle of funding.

CFRI's psychosocial programs continue, including our online MBSR classes, CF Caregiver Support groups, retreats, and counseling program; evaluations show that we are helping members of our community to reduce their anxiety and depression. Similarly, our advocacy program, described by Bill below, is empowering thousands of people, and raising awareness of CF at both the state and national level.

As the mother of an adult daughter with CF, I understand the heartbreak and triumphs that accompany life with CF. I am extremely honored to be a part of this caring community.

Warmly,

Sue

Sue Landgraf | *Executive Director and mother of an adult daughter with CF*

Bill Hult, President

News from the Board

Dear CFRI Community,

I am delighted to share that CFRI's Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Campaign is a tremendous success. A recent analysis of our impact found that since the campaign launched in February, CFRI has sent 18 "calls to action" to our advocates, who responded by sending over 6,200 letters to their national and state legislators, seeking support for issues relevant to the CF community. Our social media efforts to promote our advocacy campaign have reached 30,000 people. CFRI's Change.org petition to encourage access to lifesaving CF medications brought us over 8,500 new constituents. We are a caring and committed community!

Cystic fibrosis is considered a "Rare Disease" by the U.S. Government, meaning one which impacts

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New Drugs in CF Pipeline Make Ride Towards a Cure More Navigable

By Bridget Barnes

The CF community has been riding the wave toward a cure for cystic fibrosis (CF) for decades, and Dr. Jordan Dunitz clearly charted the latest advances in his presentation, "Curing CF: Are We There Yet?" at our 29th National CF Family Education Conference. As Director of the Minnesota CF Center and Adult CF Program, Dr. Dunitz highlighted the dramatic discoveries made in the past few years for a select group of patients. "If you're one of those people who read the last chapter of the book, we are not there yet, but we can see it from here. It is a time to be very optimistic as patients, caregivers and providers."

"When I started treating CF, the cycle of infection was an endless feedback loop, but we didn't know why," Dr. Dunitz explained. "We knew CFTR (cystic fibrosis transmembrane conductance regulator) was defective and a protein, but not what it did." Over time, CFTR was discovered to be a chloride channel, which in normal airway cells creates mucus that is watery and floats on top of the cilia lining the lungs. In CF, the mucus is sticky, trapping bacteria in the airways and causing infection.

Jordan Dunitz, MD

Focusing on the CF drug development pipeline, Dr. Dunitz noted the benefits and challenges of recently approved medications. The Cystic Fibrosis Foundation Therapeutics Network "has developed lots of drugs for different purposes, from nutrition all the way up to the recent CFTR modulators Kalydeco and Orkambi which correct malfunctioning CFTR. By addressing the modulators we will hopefully prevent disease progression." Yet Dr. Dunitz noted, "as excited as we are by CFTR modulators, the reality is we also need all of the traditional drugs for adults."

Anti-infectives inhaled Levofloxacin (already approved in Europe and Canada) and Arikace recently completed Phase 3 trials, receiving encouraging results. Dr. Dunitz is most excited about a new antibiotic Gallium, which kills resistant *Pseudomonas*, is effective against biofilms and is FDA approved for intravenous administration.

Restoring airway surface liquid to the cell, a promising new inhaled medication, P-1037/VX-371, functions as a sodium channel inhibitor. A Phase 2a study is ongoing while a study in combination with Orkambi is currently enrolling. Data will be available in a year.

"There are about 2000 different mutations which work in 5 or 6 different ways," Dr. Dunitz explained when reviewing the molecular consequences of CFTR mutations and the impact of CFTR modulators, Kalydeco and Orkambi, which are being used by a select group of patients. Kalydeco, a potentiator, "opens up the channel so chloride can go through." Orkambi, a combination corrector/potentiator corrects the defective protein and transports chloride to the cell surface. With Orkambi, "all patients remain on all their lung medications and must maintain standard therapies," Dr. Dunitz explained. VX-661 is currently being studied in an effort to improve upon Orkambi as it has a longer half-life, less drug-to-drug interactions, and no side effects.

Two Phase 2 studies are underway with a new CFTR modulator, N91115, looking at safety and effectiveness for people with one or two copies of F508del. An oral medication, N91115 increases S-nitrosoglutathione (GSNO) concentrations, which have a key role in modulating protein function. Another Phase 2 study of N91115 added to Orkambi in homozygous adults with F508del is currently enrolling participants.

An Ataluren Phase 3 efficacy and safety trial for patients with "nonsense" mutations not receiving TOBI is ongoing and results look promising. QBW251 (potentiator), Riociguat (improves CFTR function), and QR-010 (repairs RNA) are also on the horizon.

As Primary and Co-Investigator for a number of Phase 2 and 3 trials, Dr. Dunitz encouraged participation in clinical trials, without which no CF medications would be available. "The bottom line is we want a lifelong cure for all patients and we need everyone who can to participate in clinical trials. So please be optimistic and participate!" Dr. Dunitz concluded.

To find trials currently enrolling go to clinicaltrials.gov.

News from the Board
Continued from page 2

less that 200,000 people in our country. As such, CF is often overlooked for funding and research. We have to be very vocal to have our issues and needs addressed, and we can only do so if we unite to speak as one unified voice. If you have not participated as an advocate, please respond to the next call to action. They are fast and easy; by participating, you are making a difference for our community. Please join us!

Peace and good health,

Bill Hult | *Board President*

A Meeting of the Minds

Continued from front cover

1999 to encourage promising post-doctoral researchers to enter the field of CF by funding cutting-edge research at established CF labs in California. This year, ENMF applications were accepted from across the country and funding was raised from $40K to $60K per year for two-year projects.

CFRI-funded researchers and RAC Committee members

Four ENMF fellows spoke at this year's conference. Yan Wei Lim, who worked in Dr. Forest Rohwer's lab at UCSD, presented her findings in a talk entitled "Polymicrobial Infections in CF: The Need for Personalized Medicine." Dr. Lim discussed her in-vitro airway model designed to better understand the metabolic behavior of microbial communities in plugged CF airways during periods of exacerbation. As sputum samples do not always reflect what is happening in small airways, this work provides valuable insights that could lead to better treatment strategies during CF exacerbations.

Carolin Boecking, MD, who worked in the laboratory of Dr. Walter Finkbeiner at UCSF, presented her work on 3D cell cultures of airway surface cells. This is an improved in-vitro model for CF airways, and could provide the basis for novel high throughput screening assays for the development of new drugs designed to restore function to CF airway cells.

Andrey Malkovskiy, PhD, a post-doctoral fellow working at Stanford University with Dr. Carlos Milla, presented his project identifying thiocyanate content in saliva as a biomarker of CFTR function. A reliable saliva biomarker for CFTR would provide a non-invasive way to monitor the effectiveness of drugs designed to restore CFTR function.

Dr. Michael Tracy, an ENMF Fellow working in the lab of Dr. David Cornfield at Stanford University, studied the dynamic changes seen in microbial populations in CF airways as an indicator of disease severity. His research has shown that increased disease severity appears to be correlated with lower bacterial richness and diversity. Additionally, Dr. Tracy observed that the predominant bacterial species varies from individual to individual and that when exacerbations occur, bacterial diversity goes down and the individual's predominant (and often more problematic) bacteria dominate.

In 2006, CFRI developed the New Horizons Research Campaign to provide seed funding for promising new lines of basic and clinical research, which could lead to new treatments or a cure and had good prospects for follow-on funding from the NIH or CFF. In 2016, the New Horizons research grant amount was increased from $60K to $70K for each year of the two-year grant period.

AKM Shamsuddin PhD (UCSD), who received a New Horizons research grant in 2014, presented interesting findings suggesting that the human small airway consists of separate secretory and absorptive cells which maintain proper balance of airway surface liquid (ASL). It is currently thought that small airway cells are both secretory and absorptive and that a clear understanding of ASL production and regulation - key to developing therapies that target individual cell types with the potential to restore normal ASL, mucus secretion, mucociliary clearance, and immune function – is lacking.

Our last speaker was Dr. Danieli Salinas, who received a Special Circumstance grant in 2015. Special Circumstances grants are occasionally available in situations that fall outside of ENMF or New Horizons funding. Dr. Salinas is developing a "wearable" sweat testing device that would allow infants to move freely during the test and does not require injection of sweat gland stimulating drugs. Development of such a device could allow doctors to determine whether or not children who screen positive for CF with rare mutations go on to develop clinical cystic fibrosis.

Research track attendees provided positive feedback, noting the research talks were enjoyable and increased their understanding of cystic fibrosis and the current state of CF research.

There is No Health Without Mental Health

By Siri Vaeth Dunn, MSW

"We need to treat the whole person. Wellbeing includes both physical and mental health; we need to integrate these two to have the very best health outcomes." In her inspiring presentation at CFRI's 29th National CF Family Education Conference, Alexandra Quittner, PhD, spoke passionately about this issue. Those diagnosed with a chronic disease, or who care for a child with a chronic disease, are more likely to face depression and anxiety. "It is time to turn the concept of mental health on its head, and see these symptoms as common and normal."

Anxiety and depression can affect one's behavior, mental health impacts adherence, and ultimately, health outcomes. Individuals with cystic fibrosis (CF) who are depressed are less likely to go to clinic, more prone to exacerbations, and more likely to have a decrease in lung function, weight and quality of life. Because CF is a capricious disease, depression and anxiety can emerge unpredictably at the time of a new diagnosis of CFRD, a new pathogen in the lungs, or the first hospitalization.

Dr. Quittner oversaw The International Depression/Anxiety Epidemiological Study (TIDES), which screened for depression and anxiety among nearly 6,100 patients and over 4,100 caregivers in nine countries. The results found rates of depression and anxiety that were two to three times higher than among the general population. There was a strong concordance of symptoms: adolescents were nearly five times more likely to report depression and anxiety if their parents were elevated for these symptoms. "We need to pay attention to the parents as well!"

TIDES led to national guidelines for annual depression and anxiety screening using the GADS-7 and PHQ-9 questionnaires. If levels are mild, mental health CF team members can check in and offer resources. If symptoms are more serious, the mental health team member can do further assessments and refer to a mental health specialist.

In addition to education, screening and intervention, Dr. Quittner hopes there will be a greater focus on prevention and other strategies, including addressing painful medical procedures, training mental health professionals about CF and evidence-based treatments for depression and anxiety, as well as training CF physicians to prescribe medications for depression and anxiety. This includes making CF physicians aware that CFTR modulator therapies can interact with anti-depressants and decrease their effectiveness. There is a need for a referral center for parents and families, and to find and train mental health professionals in the communities where patients and families live.

Alexandra Quittner, PhD

Quittner shared her own center's recent screening results, where the GADS-7 and PHQ-9 surveys are uncovering higher rates of depression and anxiety than were seen in TIDES. At least 1.5% of CF deaths are attributed to suicide, and the PHQ-9 assesses risk. In Dr. Quittner's center, most individuals are not actively suicidal, but the screening has led to disclosures by teens that they are cutting themselves to deal with depression and anxiety.

Even when teens push their parents away, Dr. Quittner stressed the importance of this relationship. "The best predictor of adolescent adherence is the level of parent-teen conflict. Good parent-teen relationships translate to better adherence."

As those with CF get older, adherence often declines. Patient and caregiver depression and anxiety is directly related to medical adherence. Studies of parents of children with chronic illness found higher levels of conflict about child rearing, greater division of parenting tasks and fewer positive daily interactions. Dr. Quittner encouraged parents to take time for themselves, accept tangible support, and seek therapeutic services when needed.

In closing, Dr. Quittner encouraged those impacted by CF to work on realistic goals, set time aside to do at least one relaxing activity each day, share the stress with others, and to include fun. "Small changes lead to big effects."

Adversity and Hope

By Isabel Stenzel Byrnes, MSW, MPH

Ginny Dieruf opened CFRI's 29th National CF Family Education Conference with an inspiring presentation about her daughter Cody, with cystic fibrosis (CF). Ginny is the founder and, until recently, executive director of the Cody Dieruf Foundation, which raises money for CF families in rural Montana to receive financial assistance, travel expenses for CF care, and scholarships. Ginny and her family are from Bozeman, Montana, where the nearest CF Center is 700 miles away.

Ginny delivered a passionate story. Because rural doctors were less familiar with the disease, despite years of symptoms, Cody wasn't diagnosed with CF until she was 9 years old, and had already lost 25% of her lung capacity. Ginny recalled the CF doctor's advice: "Don't believe everything on the internet. Don't treat her any differently than you would your other child." The doctor also told Cody, "You can do anything you want. Most importantly, keep up your dance." Cody was a ballet dancer. Her dancing saved her life: clearing her lungs, strengthening her muscles, while giving her a passion, improved self-esteem, and a place of belonging.

Cody had multiple hospitalizations, a port, stomach tube, and she knew her CF made her different. Cody and Ginny cried and talked about how CF was hard. But CF also expanded Cody's awareness of life; even as a teenager she decided that, "beauty can be found in anything if you look at it from the right angle… I want to fill every day with as much beauty as I can because I know this body and these minutes are not forever." Eventually, CF robbed Cody of dance. She then set her mind on going to college, stating, "CF may rob me of my body but never my mind." Ginny taught Cody to take ownership of her CF, and to become independent in her care, so she was able to attend college at Lewis and Clark in Portland, Oregon.

Cody Dieruf

Ginny Dieruf

Cody's health declined rapidly during her senior year in college. Ginny shared Cody's courage to face and embrace the finality of her life. She described her daughter as critically ill yet still smiling, calm and surrounded by friends and teachers. She shared the intimacy of laying with her daughter in her final days, as her family gathered to say goodbye. On April 28, 2005, at the age of 23, Cody breathed her last breath.

Ginny walked the audience through the grief facing a "Codyless" world. She felt angry because Cody had to suffer; because she was 11 days shy of graduating from college. Ginny questioned if she could handle this challenge, feeling so helpless and hopeless. Ginny forgot what beauty looked like or joy felt like. Eventually, Ginny noticed "signs" from Cody. She realized she couldn't stop life, and decided to "embody all I loved about her. Cody didn't wear her disease on her sleeve, so I wasn't going to wear my grief on mine. I will honor her determination, grace and courage. I will spread awareness of CF."

Ginny is able to continue Cody's legacy by supporting the CF community in Montana as well as here at CFRI. She shared, "Cody didn't choose CF, but chose how to live her life. That is a choice we all have here. We have an opportunity to choose how we're going to show up in this battle with CF." The intention of CFRI's conference is to share hope amidst adversity with our community. Highlighting how a mother can survive and thrive after the loss of her daughter to CF is a vital manifestation of strength, resiliency and hope.

Sex Hormones and Their Impact on Gender Disparities in CF Health

By Siri Vaeth Dunn, MSW

While cystic fibrosis (CF) is equally prevalent in males and females, women consistently experience worse outcomes than men. This discrepancy exists even when factoring in other co-morbidities such as nutrition, genotype and pathogens. It has long been hypothesized that sex hormones play a role in CF outcomes, but until recently there has been little substantiating data. Dr. Raksha Jain, MD, MSCI, Director of the Adult Cystic Fibrosis Program at University of Texas Southwestern Medical Center in Dallas, Texas, and a leader in this field of inquiry, provided a compelling overview of sex hormones' key significance at CFRI's 29th National CF Family Education Conference. Observing that in the general population, women consistently have a longer life expectancy than men, Dr. Jain noted, "CF leaves a relative seven-year disadvantage for females that we don't fully understand." A 1997 examination of sex-based survival differences in CF found that the median age of survival was 28.4 years for males, and 25.3 years for females. By 2014, the median age of male survival had increased to 38.7 years, but the gender gap remained, with women's life expectancy at 36 years. There are many theories regarding this discrepancy, including size and nutritional status, adherence to therapies, co-morbidities, and physical activity level. While all may play a role, Dr. Jain strongly believes that sex hormones are significant contributors.

The major female sex hormones are estrogen (E2) and progesterone. When women with CF have good nutrition, their hormone levels mimic those of women without CF; men with CF tend to have lower levels of testosterone than those without CF. Estrogen, progesterone and testosterone are present in lung tissue, bronchial epithelial cells, macrophages, and neutrophils. Irish scientists found that estrogen appeared to increase the conversion of *Pseudomonas* to its mucoid form. Other studies have demonstrated that E2 inhibits cilia beat frequency in the laboratory, and inhibits non-CFTR calcium mediated chloride channels on alveolar epithelial cells, leading to less airway surface liquid and thick sticky mucus.

Dr. Jain's female patients often comment that they feel better during different times of their menstrual cycle. Studies on hormonal fluctuations in women have found that women with CF have an increased rate of CF exacerbation post-puberty compared to males, and that pulmonary exacerbations are associated with increased E2 levels.

Estrogen plays a role in inflammation. Dr. Jain and her team found that female CF mice died earlier and had more difficulty clearing bacteria in response to *P. aeruginosa* lung infections than males. Mice supplemented with estrogen fared worse, as it induced a pro-inflammatory response in the presence of *P. aeruginosa*, activating neutrophils and degranulation, but impeding phagocytosis (which removes cell debris), thereby clogging the lungs. When treated with estrogen blockers, the mice fared better.

In light of these studies in the lab, can hormone modulation serve as a therapeutic target for CF patients? Dr. Jain is conducting a study of female patients on oral contraceptives. While not yet completed, early indications show a slight improvement in lung function and quality of life. With this encouraging news, Dr. Jain cautioned that there remain many questions about the systemic impact of oral hormone therapy on hemoptysis, clot formation (important in light of catheters), bone density, and drug interactions. She asked, "Can we develop an estrogen receptor antagonist that would be nebulized? How do we get this past the biofilm and impact what we need to impact?"

While there has been focus on female hormones, Dr. Jain noted that it is important to study whether testosterone should be administered to men with CF. "We need to narrow the sex-based disparity, and improve the health of both men and women."

Raksha Jain, MD, MSCI

CF Pioneers Live in 3-D *By Danielle Mandella*

It's hard to believe this year's CFRI Summer Retreat Blockbuster: Live in 3-D has come and gone. For over 30 years, adults living with cystic fibrosis (CF) and their friends, family and caregivers have come together in a safe environment to learn from each other and bond over shared experiences. Born in 1986, as awareness of cross infection risks arose, I did not attend.

I first heard about Retreat in an online support group. My friend Eric told me that some participants have attended for years. This retreat is where they grew up learning to find acceptance and encouragement in their daily battle with CF.

Any nerves about potential cross infection, especially as a post-double lung transplant patient, were outweighed by my growing need to be part of the learning and healing process I had missed out on as a child and hadn't been able to fully satisfy online. I first attended Retreat in 2011 and have returned every year since. Arriving for the first time was like meeting a long lost family. A connection like I had never experienced before was formed instantly with everyone I met.

Daily "rap sessions" allowed me to share deeply held emotions about my CF that I'd never expressed to anyone. Educational presentations from CF and lung transplant experts from globally recognized care centers gave me hope. This year, Dr. Jasleen Kukreja, a cardiothoracic transplant surgeon at UCSF, presented on ECMO technology that has allowed her team to extend the time patients can survive while waiting for new organs.

During mealtime, non-CF volunteers served participants with CF in order to maintain CFRI's Infection Control Policy. An alternating CF/non-CF seating pattern was followed to maintain the required six-foot distance between participants with CF, while encouraging everyone to develop new friendships.

Through daily arts and crafts, meditation, and yoga, I felt myself relax into a newfound state of acceptance of CF. The exercise activities like U-Jam and Bubble Ball benefited my physical health in a way that was much more fun than feeling self-conscious at the gym alone.

My first year at Retreat, I found lifelong friends who are now a vital part of my emotional support system. I always look forward to greeting old friends and seeing new faces. This year, I met new friends from Washington, Pennsylvania and Maine, who were able to attend thanks to generous scholarships created by two families in memory of former Retreat participants, the Kriss Benson Memorial Retreat Fund and the family of Kelly Colgan.

The phenomenal truth is that adults with CF are living longer. We are at the forefront of this wonderful evolution. We are the Adult CF Pioneers, and there is no group of people I would rather have by my side (or six feet away) in the face of cystic fibrosis.

Awards Night at the retreat, attended by those with CF and their friends and family.

Tributes

Our *"In Memory of"* and *"In Honor of"* pages provide the opportunity to honor a person, family, or special event, 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 acknowledgement of your gift to the person you designate.

Please mail your contributions to:

CFRI
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Suite 210
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In Memory of

May 1, 2016 — August 31, 2016

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Marcus Adelman
Sonya Akister
Gianna Altano
Paul Anderegg
David Armknecht
Jodi Armknecht
Theodore Armon
Ann Baker
Ronald Baldwin
Ann Baldwin
Matthew Baptiste
Anne Beltrame
Irvin Beltrame
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Lorene King
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Jessica Mobley
John Moran
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Lynette Moulton
Kimberly Myers
Sherman Naymark
Frank Nieto
Darius Noori
Danny and Kevin O'Brien
Michele Olson
One of my students
Jennifer Ortman
Lisa Pearne
Patrick Peters
Sean Peterson
Eva Pira
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Lyle Vadneis
Rory and Jerry Vaeth
Joy Villasenor
Viola Wastell
Nicky Wastell
Tara Weir
Hayley Wester
Cynthia Witman

In Honor of

May 1, 2016 — August 31, 2016

SHL ACFAC
Chelsa Aboud
Gordon Adelman
All parents who live every day fighting the fight to help cure/save their child
Chace Anderson
Jessica Arvidson
Kyle Baker
Bridget Barnes
Lucy Barnes
Darlene Batchelder
Joseph Batchelder
Batchelder Family
Makinnon Baugh
Amy Baugh
Marin Baugh
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Joseph Fraker
Emily Fredrick
Alicia Fusco
Sean Gallagher
Larissa Giuliano
Elyse Elconin Goldberg
Stanley Goldberg
Antonio Gonzalez
Rose's Grandson
Gianna Gutierrez-Serrato
Sonya Hagget
Erika Harrington
Lani Hernandez
Susan Hoffman
Courtney Hollis
Erinn Hoyt
Kristen Hoyt
The Hoyts
Noelle Hunt
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Barbara Jensen
Darren Johst
Michelle Jones
Peggy Jones
Laine Jones
Franny Kiles
Edward Kinney
Julie Ann Kobernus
Riley Kobler
Eleanor Kolchin
Bill Kolchin
Jason Konkel
Kristen Favero Konvolinka
Steven Kusalo
Sally Kusalo
Susan Lane
Sharon Le Berthon
Theresa Le Berthon
Maeve Leonard
Joseph Librers
Michael Livingston
Alyson Lowery
Janet Lowery
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Carolyn Martin
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Carly McReynolds
Mikey
Maia Miller
Emma Miller
Hannah Mitchell
Anna Modlin
Paul Mohabir, MD
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Emily Schaller's Mission to Rock CF

Continued from front cover

exercise routine. On her first attempt to run, she set out to run two miles, but after one block she had to stop. She persevered, and after three months of running she saw a huge jump in her lung function. At this point she knew that running and exercise was the key to having better quality of life.

Emily started biking, and has participated in triathlons, half marathons, and 500-mile bike rides. In 2007, Emily started the Rock CF Foundation. Through her foundation, Emily heightens public awareness and raises funds to increase the quality of life for everyone with CF. Emily created an internationally-acclaimed line of merchandise to help fulfill the mission of Rock CF, and she has been the focus of articles in many publications including Runner's World, FORBES, the New York Times, Washington Post, USA Today, and NPR.

Emily's goal is to raise CF awareness and positivity. She wants to change the lives of those with CF for the better, and to promote the benefits of exercise in their lives. Her foundation sends running shoes to people with CF and signs them up for a race of their choice. Whether or not one has CF, Emily is truly inspirational. Emily says that she is the healthiest she's ever been, because she is literally "outrunning CF."

Emily Schaller

Recognizing Our Extraordinary Community Heroes

By Siri Vaeth Dunn, MSW

CFRI is proud to honor the following individuals who have made extraordinary contributions to the cystic fibrosis (CF) community. Awards were presented at our 29th National CF Family Education Conference and our fall gala at Nestldown.

The 2016 CFRI CF Professional of the Year Award was presented to **Meg Dvorak, LCSW.** A licensed clinical social worker at the Adult Cystic Fibrosis Center at Stanford, Meg facilitates a monthly online support group for CF adults, helped develop a peer mentoring program for CF adults, and partnered with the Stanford Adult CF Advisory Board to create and moderate a Stanford sponsored Facebook page for CF Adults. She has given numerous presentations both nationally and locally, including at CFRI's Discovery Series. Meg is an active member of CFRI's CF Quality of Life Program: A Living Legacy to Peter and Kathy Judge and an outspoken advocate for the CF community as well as for CFRI.

The 2016 Dave Stuckert Memorial Volunteer of the Year Award was presented to **Robin Modlin, MA.** The mother of a 35-year-old woman with CF, Robin has been involved with CFRI for decades as a Board member, facilitator of support groups, newsletter committee member, fundraiser and more. She has shared her talent as a Soul Collage® workshop leader at numerous CFRI events. She spearheaded the creation of "Embrace: A Retreat for Mothers of Children and Adults with CF," which was described as 'life changing" and "transformative" by those who attended.

The 2016 CFRI Partners in Living Award in Memory of Anabel Stenzel was awarded to **Beth Sufian, JD.** As an attorney and an adult with CF, Beth has inspired others for decades. She is Director of the CF Legal Hotline, which has received over 40,000 calls from the CF community, and she is the Director of the CF Social Security Project, which has successfully obtained social security benefits for over 1,000 individuals with CF. Beth has also generously shared her time with CFRI as a conference presenter, newsletter contributor and Summer Retreat supporter.

The 2016 Cystic Fibrosis Champion Award was presented to **Julie Desch, MD.** Julie received her medical degree from Stanford University School of Medicine. She has been a dedicated CFRI volunteer for many years, currently serving as Chair of the Research Advisory Committee, leading CFRI's online Mindfulness Based Stress Reduction classes, presenting at CF Discovery Series and retreats, and writing for CFRI Community. She formerly served on CFRI's Board of Directors and Medical Advisory Board. As a woman with CF, Julie inspires others to embrace fitness, and to seek strategies to improve one's quality of life.

Congratulations to these outstanding individuals

Photos from top: Meg Dvorak, LCSW; Robin Modlin, MA; Beth Sufian, JD; Julie Desch, MD

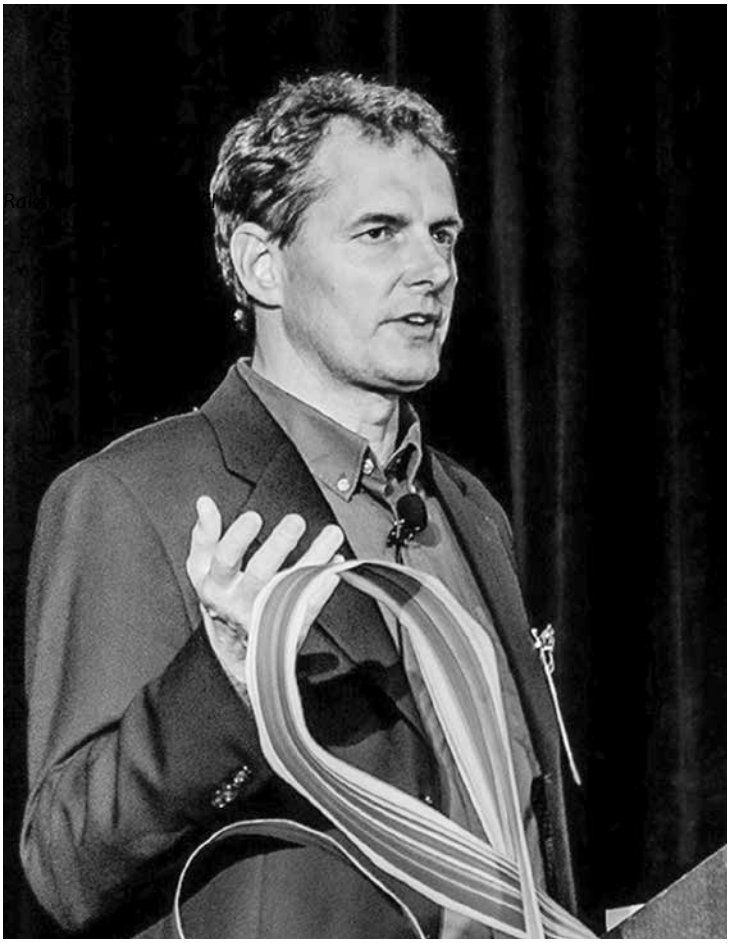
A CF Patient's Perspective on Genome Editing: Opportunities and Challenges for Cystic Fibrosis

By Reid D'Amico

Until the summer of 2015, those of us with two copies of the F508del mutation found ourselves on a dizzying cycle of treatment regimen after treatment regimen. We spent hours every day trying to stay healthy because therapies were simply designed to treat the underlying symptoms. Each new F508del cystic fibrosis (CF) therapy approved seemed only to serve as a bucket to remove water from our sinking ship. Finally, in July 2015, we had a new treatment that would actually help patch the hole. But what if we could move beyond patching this metaphorical hole, and actually stop producing faulty ships? The answer lies within correcting the problem at its source: the DNA.

At CFRI's 29th National CF Family Education Conference, Matthew Porteus, MD, PhD, of Stanford Medical Center, took on the radical concept of gene editing through the lens of CF. Dr. Porteus' research projects were the first to demonstrate that gene correction could be achieved in human cells at frequencies that were high enough to potentially cure patients, and he is one of the pioneers and founders of the field of genome editing. His talk eloquently mixed science and advocacy into a deliverable message that left the crowd hopeful yet aware of the hurdles that remain.

Matthew Porteus, MD, PhD



Many of us in the CF community have likely heard of CRISPR technology, but what exactly is it? Clustered regularly interspaced short palindromic repeats (CRISPR) work by delivering Cas9 nuclease and appropriate guide RNA into the cell, where they can then locate the gene of interest. Once there, this technology can allow for genes to be edited, yielding a therapeutic benefit.

Applied to cystic fibrosis, CRIPSR works by honing in on the specific site of interest in the patient's DNA and then reverting the pathological CF variant (mutation) to a non-pathological variant. Another strategy of CRISPR can be used to create a new therapeutic phenotype of the cell. For CF, this might mean both reverting a pathological variant, as well as putting back a fully functional copy of cDNA into the precise location. The use of CRISPR for genome editing serves as breakthrough technology for more than just CF. With the power to potentially correct diseases like sickle cell disease, hemophilia, and muscular dystrophy, members of the genetic disease population look to this technology with unwavering hope.

While this technology is not yet ready to enter clinical trials for the treatment of cystic fibrosis and other diseases, we have already defined the challenges. The delivery of genome editing technology into the body will need to be well studied for each disease it serves to treat. For CF specifically, the lungs are fortunately an easier target than most organs, since nebulizer treatments directly contact the organ of interest. But the challenge of genome therapy does not end at the drug delivery; there is still a great need to uncover the biological questions: How many cells will need to be changed in order to gain a therapeutic benefit? What cells will need to be targeted? Will there be an immune response or any off-target effects? Until these questions are answered, we will not see CRISPR-based therapeutics in clinical trials. However, the field of genome editing is exploding, with more cross-disciplinary fields spearheading its research. With the brightest minds of each academic discipline working together towards a common goal, I am more at ease with the future of medicine. On the cusp of the revolutionary genome-editing era, those of with cystic fibrosis – regardless of mutation - find ourselves closer than ever to a cure.

32nd Annual Golf Tournament Benefitting CFRI A Record Setting Event!

The legendary Pasatiempo Golf Club – a "top-100" course – hosted 144 golfers on August 1, who enjoyed friendly competition while supporting the search for a cure for cystic fibrosis (CF). The 32nd annual benefit event for CFRI broke all previous records – selling out and raising $71,000. Of this total, $19,000 will be matched by CFRI's Jessica Fredrick Memorial 2016 CF Research Challenge Circle and designated for CF research grant awards.

Team Becca came out in force to support CF research

The event is personal for the event co-chairs: Scott Hoyt, manager of Pasatiempo Golf Club and former CFRI Treasurer, has two daughters with CF, one of whom recently received a life-saving double lung transplant; Mike Roanhaus, current Secretary and past President of CFRI's Board of Directors, is the father of Becca, who lives with CF. The tournament has a loyal following, with the largest group in attendance, "Team Becca," comprised of many of Mike's fraternity brothers from college. Major sponsors included the Mike and Dea Roanhaus family, HDR Architecture, Star One Credit Union, the Kirkorian Family Foundation, and the Scott and Anne Hoyt family.

CFRI is extremely grateful to Scott Hoyt, Mike Roanhaus, and the other dedicated members of the golf committee, Francine Bion, Dea Roanhaus, Tina Capwell, and Ralph Swanson, and the many event participants who are supporting cutting-edge research and much needed support programs for those living with CF.

SEEKING PARTICIPANTS FOR THE ROSES PROJECT

We know the current treatment regimen for individuals with CF can be time-consuming and complex. CFRI is honored to partner with Alexandra Quittner, PhD, at the University of Miami to seek participants for the ROSES (Raising Optimism, Strength, Expectations, & Success) Project. We want to learn how busy individuals are able to fit their treatments into daily routines. What works for you may help Dr. Quittner and her team to develop effective interventions for others. There are two components to the ROSES study, and we are seeking participants for both.

In the first study, you will be asked to complete a brief online survey about your (or your child's) health care regimen, and how burdensome or time consuming you find the regimen. You will receive a $30 gift card for your participation.

The second study seeks to determine what factors help people complete their treatments. As a participant, you will be asked to complete questionnaires about your background, perspective on managing CF, and your quality of life, which will take approximately 30 minutes. You will need to sign a medical release form so Dr. Quittner and her team can collect basic medical data from your CF center. After completing the questionnaires, you will be asked to complete a brief phone diary (10-15 minutes) over three days asking about your daily activities. You can receive up to $130 for your participation in this study.

You may participate in one or both studies. If interested, please email ROSES@miami.edu or call 305-284-6986.

Thank you for your consideration!

CFRI's Many Voices ~ One Voice CF Advocacy and Awareness Campaign

Our Many Voices ~ One Voice Campaign focuses on educating and engaging those impacted by CF, the general public and legislative sectors to broaden understanding of the challenges faced by the cystic fibrosis community. Living with CF presents a multitude of challenges – physical, emotional, and financial. Barriers to medical care and therapies must be reduced; funding to find a cure for CF must be increased. Our community deserves a better quality of life. We need your voice to make this happen. Please contact cfri@cfri.org to get involved! *Sponsored by Vertex Pharmaceuticals and Genentech*

Breaking News: An Analysis of the New Social Security Rules for Cystic Fibrosis

Beth Sufian, center, with her team from Sufian & Passamano, LLP.

Beth Sufian, Director of the CF Social Security Project®, presented at CFRI's 29th National CF Family Education Conference about new Social Security disability rules for people with CF to a standing room only crowd. Ms. Sufian, an attorney and 51-year-old adult with CF, has won thousands of Social Security cases for people with CF.

Ms. Sufian explained that beginning October 7, 2016, the Social Security Administration will change its criteria to determine if an applicant is eligible for benefits, found in the Social Security Medical Listing at Section 3.04. For more than 20 years, eligibility rules allowed an applicant to medically qualify for Social Security benefits if the applicant had either: (A) low FEV1; (B) six physician interventions in 12 months; or (C) use of inhaled or IV antibiotic for pulmonary infection once every six months.

Effective October 7th, §3.04B, which allowed a person with six physician interventions in 12 months to meet the medical criteria for benefits and was a flexible standard, will be deleted. Many applicants with CF became eligible for Social Security benefits under this section.

Another significant change is the removal of the former §3.04C from the rules. This section provided that a person using inhaled or home IV antibiotics (of any duration) to treat a persistent pulmonary infection once every six months met the eligibility criteria. In practice, Social Security also required a showing of significant daily treatment time. Many people with CF qualified for benefits under the old §3.04C. Unfortunately, this criteria will also be entirely deleted.

The new rules retain low FEV1 as an eligibility requirement, but this requirement has been substantially reformulated, and is now based on age and gender.

Social Security looks at medical records within the 12 months prior to the application. Under the new rules a person may be eligible in five other ways: (1) at least three hospital stays; (2) an embolization for hemoptysis; (3) treatment for a collapsed lung; or (4) on a ventilator for at least 48 hours. The fifth way to quality requires a combination of any two of the following: home IV use for at least 10 days; CFRD; use of a feeding tube, or embolization to treat hemoptysis.

The new rule has a welcome addition addressing post transplant care, as it establishes a presumption of disability of up to three years post transplant. This does not mean that people will lose benefits at their three-year post transplant anniversary, but they must show why they are unable to work full time in order to continue benefits. Even if a person does not meet one of the new criteria, the law will still permit the applicant to show that his combination of symptoms is as severe as the listed criteria.

Sufian stressed the importance of medical records when applying for Social Security benefits or completing a Continuing Disability Review. It is helpful if medical records contain information about the length of and number of breathing and airway clearance treatments, the need for naps during the day, issues with coughing up blood or stomach problems, issues with memory, concentration or stamina. Any information that supports a finding that the person cannot work full time is helpful.

The CF Social Security Project® will continue to represent individuals with CF in an initial application and in a Continuing Disability Review. The CF Legal Information Hotline®, funded by a grant from the CF Foundation, will continue to provide information about Social Security benefits, insurance, employment and education and can be reached at 1-800-622-0385 or by email at CFLegal@sufianpassamano.com

Make A Wish Brings Joy to Children With CF

Did you know that all children between the ages of 2½ and 18 years old who have cystic fibrosis with respiratory involvement are eligible for a wish through Make-A-Wish? This experience can help children feel stronger and better able to battle their disease. Health professionals say the wish experience works in concert with medicine to make their patients feel better both emotionally and physically. To refer a child living with CF, please contact your local Make-A-Wish chapter: http://wish.org/refer-a-child

Save The Dates

CF Discovery Series: Live and Live Streamed!

October 13, 2016
6:00 pm – 7:30 pm PST
CF Pipeline
Dennis Nielson, MD, PhD

November 10, 2016
6:00 pm – 7:30 pm PST
Fungi in CF: Observers or Actors?
Rick Moss, MD

CFRI Office, Palo Alto, CA

Mindfulness Based Stress Reduction

Online Class for Those with CF & CF Caregivers

Thursdays, 7:00 pm – 9:00 pm EST
(3:00 pm – 5:00 pm PST)
Eight-Week Course
Begins October 20, 2016

CF Caregivers Support Group

New Dates, Times and Locations!

Dates:
October 18, November 22, December 20

Times:
CF Caregivers of Children
10:30 am – 11:30 am PST
CF Caregivers of Adults
6:00 pm – 7:00 pm

Location
3rd Floor Conference Room
730 Welch, Palo Alto, CA
Free Parking!
Or participate by phone
Call CFRI for details

CFRI Mothers' Retreat

May 5, 2017 – May 7, 2017
Vallombrosa Center
Menlo Park, CA
Register Now!

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

Become a CFRI Partner in Living!

Your Support Can Change Lives

DONATE TO THE JESSICA FREDRICK MEMORIAL 2016 CF RESEARCH CHALLENGE FUND Your gift will be matched 1:1 by the Jessica Fredrick Memorial 2016 CF Research Challenge Circle to fund CFRI's research grant awards.

ATTEND A CFRI FUNDRAISING EVENT OR HOLD YOUR OWN! Whatever your interest, we have an event for you, including concerts, golf tournaments, and other opportunities. Or come up with an idea and we will support you.

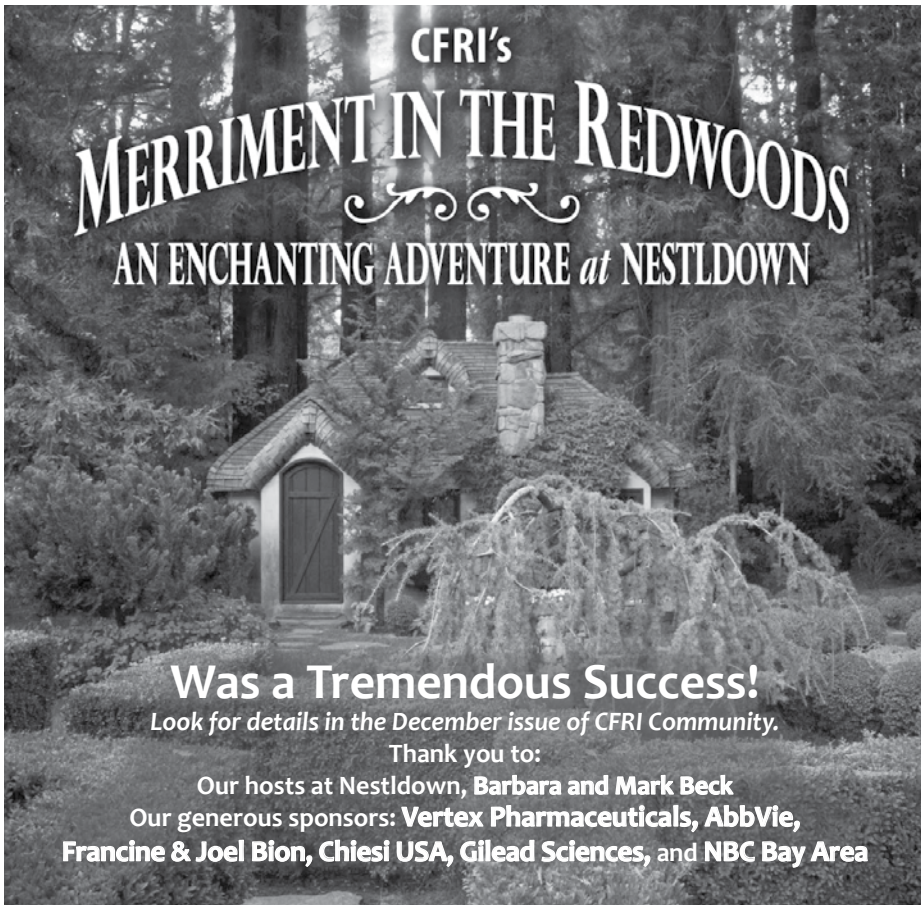
TRIBUTES IN HONOR OF, AND IN MEMORY OF Any gift to CFRI can be made in honor or in memory of a loved one, friend or colleague. That person's name will appear in our newsletter; if requested, an acknowledgement will be sent to the person you designate.

GIFTS OF STOCK TO CFRI Donating a gift of appreciated stock is easy and rewarding. You do not pay capital gains tax on stock that has appreciated over the years, and you will receive an income tax charitable deduction for the fair market value of the stock on the date of the gift.

CHARITABLE PLANNED GIVING Planned giving offers benefits for donors that often include increased income and substantial tax savings, while providing the opportunity to meet your philanthropic goals and provide positive tax benefits.

VEHICLE DONATIONS If you have a car, boat, RV, or motorcycle that you no longer need, please donate it to CFRI. Your contribution is tax-deductible, and we will coordinate the transfer of property.

For more information please contact Mary Convento at 650.665.7559 or mconvento@cfri.org



29th National CF Family Education Conference a Success!

CFRI recognizes the generous sponsors and exhibitors whose support made our 29th National Cystic Fibrosis Family Education Conference possible.

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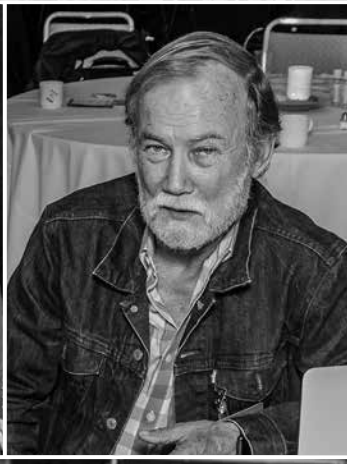

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CFRI Mission

Cystic Fibrosis Research, Inc. exists to fund research, to provide education and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease.

CFRI Vision

As we work to find a cure for cystic fibrosis, CFRI envisions informing, engaging and empowering the CF community to help all who have this challenging disease attain the highest possible quality of life.

Visit our website at:
www.cfri.org
for more information about us and about cystic fibrosis.
Call toll free: 1.855.cfri.now

CFRI's Cystic Fibrosis Quality of Life Program
A Living Legacy of Peter & Kathy Judge

Financial Support for Individual Therapy

Funding is still available for individual counseling! CFRI will underwrite six sessions of counseling with a licensed therapist. This nation-wide service is available to children and adults with CF, as well as to their family members, until funds are expended.

Mindfulness Based Stress Reduction (MBSR) Online Class

Open to participants nationwide, CFRI's online MBSR class combines body awareness, meditation and yoga to help those impacted by CF to address anxiety, depression, pain, and stress. The next 8-week class begins in October.

CF Caregivers Support Group

CFRI hosts two monthly CF Caregivers Support Groups: one for parents of children with CF, and another for parents of adults with CF. Attend in person (Palo Alto) or participate via conference call. Facilitated by a licensed clinical CF social worker, the group provides peer-to-peer support to help families cope with the daily challenges of life with CF.

Sponsored by ***Vertex Pharmaceuticals, Genentech*** *and* ***the Allergan Foundation***

For their generous support of ***CFRI Community***, special thanks to: • **Genentech, Inc.** • **Vertex Pharmaceuticals** • **Gilead Sciences** • **AbbVie** • **Chiesi USA**

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