

## CFRI's 30th National Cystic Fibrosis Family Education Conference: Speaker Abstracts

At CFRI's annual National CF Family Education Conference, Soaring to New Heights, held July 28 to July 30, 2017, nationally-renowned speakers from across the country shared their expertise and experience on a wide range of CF-related topics. Nine of these presentations were recorded and are available for viewing on CFRI's YouTube channel. The abstracts below provide a brief overview of each talk, followed by a link to the specific presentation.

### Lessons from a CF Cornerman

Ray Poole, MBA — Fort Lewis, Kentucky

As the author of *Lessons from a CF Cornerman: 38 Lessons I Learned During my Wife's Illness and Lung Transplant*, Ray shares the lessons he learned during the life journey he has travelled with his wife Rebecca, who faced a rapid decline in health and months on a ventilator before receiving a double lung transplant in 2015. When Ray and Rebecca started dating, life expectancy for those with CF was 30 years. As they became more serious, he had to come to terms with this, as he learned that CF is not always

as it seems from the outside and involves constant thinking and problem solving. Ray discussed these lessons in the context of how he learned them. Many of Ray's lessons are universal and speak to the many

challenges facing caregivers and loved ones of those dealing with CF.

Some of the lessons that Ray shared include the value of trusting your instincts and the

*Continued on page 3*

## Small Molecule Screening Approaches to Validate CF-Relevant Drug Targets

By Peter M. Haggie, PhD — University of California, San Francisco

Mutations in the cystic fibrosis transmembrane conductance regulator protein (CFTR) cause the disease cystic fibrosis (CF) that, in its most severe form, is associated with life-shortening lung disease. CFTR conducts chloride and bicarbonate ions across cell membranes. CF disease manifestations are believed to result from defective ion transport which leads to altered lung function, infection, exaggerated inflammation and consequent lung pathology. As such, identification of small molecules that restore

function of mutant CFTR proteins and correct ion transport is a major strategy for CF drug development.

First generation drugs with proven clinical efficacy are now available that directly target certain CFTR mutants with defective ion transport function ('gating defects,' e.g. G551-CFTR) or defective cellular processing ('trafficking defects,' e.g. Fdel508-CFTR). However, development of therapeutic approaches for most less-common mutations

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Dr. Peter Haggie in his lab



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## Letter from the Executive Director

Dear Friends,

What an incredible time in the world of cystic fibrosis (CF) research! At this moment, nearly three dozen treatment options are in many stages of development. These therapies address many aspects of the disease, including restoring CFTR function, improving mucociliary clearance, providing new anti-infective options, and addressing nutrition and CF-related gastrointestinal issues. It is projected that in the not-too-distant future, 90% of those with CF will have CFTR modulating therapies available to them. As we cautiously but optimistically anticipate these developments we must ask: What will this mean for our CF community and its needs? What will CFRI's role be?

We recently distributed a survey to our community, asking you what you want and need from CFRI, and where we would best focus our efforts moving forward in the changing landscape of cystic fibrosis. The response was resounding and consistent: Stay the course. Keep offering our research, education, psychosocial support, and advocacy programs, and if possible increase and expand all of them. We heard you loud and clear. We will continue to offer our current programs, but will make adjustments to expand our community's ability to participate via live streaming and online programming. We will continue to fund innovative research, and will increase our advocacy efforts to ensure issues impacting the CF community – including access to therapies, affordable insurance and quality care – continue to be addressed.

CFRI is your partner in living. Thank you for being an active member of our dynamic community.

Warm regards,



Sue Landgraf | CFRI Executive Director and Mother of an Adult Daughter with CF



Sue Landgraf

## News from the Board

Dear CFRI Community,

I am delighted to share that CFRI's clean audit has been completed, documenting that last year was CFRI's most successful financial year in its organizational history. As you will note in the enclosed annual report, thanks to the generous support of our sponsors, grant funders and donors, we raised just shy of \$1.7 million dollars. We are thrilled by this growth because it represents a correlating expansion in CFRI's programs to the CF community. While we are fiscally responsible in maintaining a financial reserve, we translate our funds to life changing programs and services, including funding innovative research, offering conferences, podcasts, retreats, MBSR classes, counseling services, educational materials, advocacy campaigns, and more.

By virtue of reading this newsletter, you are involved with CFRI. If you seek to become more engaged, we welcome you! Whether hosting or volunteering at special events, sending emails to your elected officials, serving as a CFRI ambassador wherever you live in the world, or attending our conference or other events, we ask you to join us. Together, we are a strong community. Together we can improve the lives of those living with cystic fibrosis.

Peace and good health,



Bill Hult | President, CFRI Board of Directors



Bill Hult, President





Ray Poole, MBA

significance of simply showing up. He discussed how asking questions and advocating holds importance even if you are not a medical expert. Ray also addressed interpersonal challenges that often surface during stressful times and the importance of not letting others bring you down. He emphasized that if you have the opportunity, try to laugh and understand that “every day may not be a good day, but it is good to have that day.” Ray’s overarching message is to recognize what we can control and what we cannot, and to put forth our best effort to stay positive for one another.

To watch Ray Poole’s presentation, go to <http://tinyurl.com/yd7wzt48>

### What Gets in the Way? Understanding and Supporting Treatment Adherence in Cystic Fibrosis

Kristin A. Riekert, PhD —  
The Johns Hopkins School of Medicine

The cystic fibrosis (CF) treatment regimen is complex and time-consuming. Thus it is no surprise that, on average people with CF complete only about half their daily treatments. The extent to which a person with CF completes prescribed treatments (i.e., is adherent) is associated with having fewer pulmonary exacerbations and lower lung function, hospitalization rates and healthcare costs. There are many barriers and facilitators that affect a person’s ability and motivation to complete prescribed treatments. Despite the importance of adherence to health, there are few empirically validated interventions for chronic disease management generally or for CF specifically.

In this talk, what is known about various barriers to getting CF treatments done, and strategies that can be used to improve adherence were reviewed, and the Success with Therapies Research Consortium (STRC) and its mission were introduced. In addition, the initial CF self-management studies that are being conducted were described.

To watch Dr. Riekert’s presentation, go to <http://tinyurl.com/y75aeu4p>



Kristin Riekert, PhD

### CF Research Update 2017: Crossing the Bridge to a Cure

John P. Clancy, MD —  
Cincinnati Children’s Hospital

Cystic fibrosis (CF) research and care is in the midst of a dramatic transformation. Our understanding of CF and the genetic defects that lead to CF has grown substantially over the past two decades and is now able to inform therapies that target the root cause of disease. Specifically, therapies that improve the function of disease-causing CFTR mutations are available to a growing number of individuals with CF based on their CFTR genotype, and the pipeline of



John Clancy, MD

research to expand these treatments to the vast majority of them is moving extremely fast. Hand-in-hand with the development of these CFTR modulators, additional approaches that seek to improve the function of common and uncommon CFTR mutations are entering clinical trials, providing confidence that CFTR-focused therapies will ultimately be available to all individuals with CF. Research is also advancing to help determine whether cells derived from individuals with CF that have rare CF-causing mutations in CFTR can detect modulator activity and inform clinical trials. New treatments for CF are not only focused on CFTR; numerous strategies that target other common challenges in CF including infection, inflammation, mucus, and nutrition are underway, ensuring that individuals at any stage of disease have new treatments on the horizon. Indeed, these are exciting times in CF, and with the advent of these novel new therapies we truly are building a bridge to a cure.

To watch Dr. Clancy’s presentation, go to <http://tinyurl.com/y8r67elc>

### CF Beyond the Lungs: The Role of Physical Therapy

Karen von Berg, PT, DPT —  
The Johns Hopkins Hospital



Karen von Berg, PT, DPT

Today, more than half of the people living with CF are over the age of 18. The improved health, quality of life, and life span of people with CF has created a need for a physical therapist as an integral member of the CF care team. Historically, physical therapy (PT) primarily functioned to prevent and treat the basic lung defect via airway clearance and aerobic exercise. Physical therapists

*Continued on page 4*

are now assessing and treating multiple body systems to optimize movement and promote healthy physical activity. In addition to clearing secretions from the airways, physical therapists are looking beyond the lungs to address the secondary impairments of CF: assessing and treating endurance, strength and flexibility; managing posture, pain and urinary incontinence; and, ultimately guiding patients through the physical challenges of growing up and growing old with CF.

To watch Dr. von Berg's presentation, go to <http://tinyurl.com/y82odbu7>

### What to Expect When You're Expectorating: The Bugs and Drugs of CF Respiratory Infections

Lucas Hoffman, MD, PhD —  
University of Washington School of Medicine / Seattle Children's Hospital

Bacteria and other microbes play important roles in many of the manifestations of cystic fibrosis (CF). For example, the airways of people with CF usually become infected with a variety of different microbes, and antibiotics are often cornerstone members of the treatment regimens for people with



Lucas Hoffman, MD, PhD

CF lung disease. A great deal of research has focused on the microbiology of the CF lung since the earliest descriptions of this disease, identifying not only which microbes cause these infections, but also how they contribute to lung disease and how best to use our available treatments. However, despite this extensive work, we have not yet been able to clearly define

how microbes contribute to lung disease, or how to predict which antibiotics will most effectively treat it.

Recently, advances in microbiological laboratory techniques have taught us a great deal about the pathophysiology and microbiology of CF lung disease. In this talk, some of the recent advances in our understanding of CF airway infection were discussed, including how these infections begin, how they might contribute to disease, and how they change upon treatment. In addition, new findings from studies of CFTR modulators were described that have revealed the close relationship between CF and bacteria, and how microbiology may change with these promising treatments.

To watch Dr. Hoffman's presentation, go to <http://tinyurl.com/y9ddkprk>



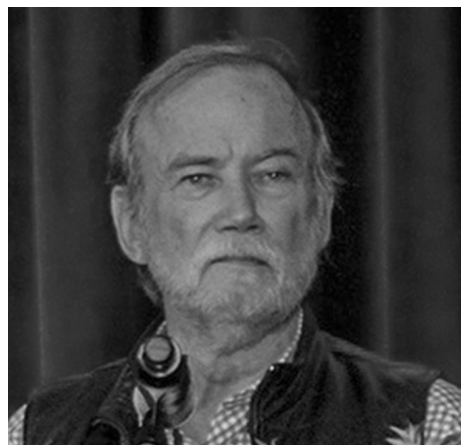
Cathy Chacon, RN

### Beyond CF: Adult Health Issues in CF

Cathy Chacon, RN — National Jewish Health

More than half of individuals with cystic fibrosis (CF) in the United States are over the age of 18. The median predicted age of survival is approximately 40. With many new and exciting therapies on the horizon, it is expected that the life span of those with CF will only increase in the future. CF care teams are challenged by new adult issues to consider and what health screenings are needed for their patients as they age. Multiple health evaluations and adult issues were discussed in this presentation, including colonoscopy and mammography screening, as well as nutrition, bone health, diabetes-related health issues, and mental health screening.

To watch Cathy Chacon's presentation, go to <http://tinyurl.com/y938vrs1>



Paul Quinton, PhD

### Forty Years of CF Research: Past Progress and Future Promise

Paul Quinton, PhD — UC San Diego

Since CFRI was founded over 40 years ago by a group of parents whose children with cystic fibrosis (CF) were not expected to survive childhood, funding innovative CF research has been at the core of its mission. CFRI's first research grant cycle included funding for Paul Quinton, who in 1982 first identified that the chloride transport in CF sweat ducts was defective. Since its earliest modest research grants, CFRI has provided nearly \$9 million in CF research funding, and has helped to support a thriving CF research community. There are now over 200 scientific publications that credit CFRI for funding. Multiple seminal discoveries have been made by CFRI-funded scientists, including insights and breakthroughs that led to better treatments and new drugs such as kalydeco, lumacaftor, and others in the pipeline including tezacaftor. CFRI-funded researchers have expanded our understanding of CF through innovative developments with Calu-3 cells, CF cell lines, the cellular processing and degradation of the CFTR molecule, the involvement of inflammation and antioxidants, early airway damage, the lung and gut microbiome, host/bacterial interaction, particularly in *Pseudomonas* infections, alternate pathways associated with chloride channel function, mucus gland regulation and secretions, new 3D cell culture techniques to assess CFTR function, biofilms and nitrite sensitivity and interaction with lung epithelium, and the impact of ABPA and *Burkholderia*. This abbreviated list only hints at the impact that CFRI-funded research has had in understanding CF. In sharing past and present research accomplishments,



Dr. Quinton provided a glimpse of a future made possible with CFRI-funded research.

To watch Dr. Quinton's presentation, go to <http://tinyurl.com/ycm8uh33>

## Mind-Body Therapies in Cystic Fibrosis Care

John Mark, MD — Stanford Medical Center

Complementary health includes modalities and products with a history of use or origins outside of conventional Western medicine. Integrative Medicine (IM) is the combination of conventional and complementary health therapies. IM makes use of all appropriate therapeutic approaches, healthcare professionals and disciplines, and integrates them to achieve optimal health and healing. The use of complementary modalities such as supplements, herbal remedies, traditional

Chinese medicine, and mind-body therapies is common among people with chronic respiratory conditions. Studies show that 60% to 80% of children and adults with cystic fibrosis (CF) may use some form of complementary health therapies.

Mind-body therapies focus on the interaction between the mind and the body, with the intent to use the mind to influence physical functions and directly affect health. These therapies may include meditation, mindfulness, hypnotherapy, imagery, music/art therapy, and breathing exercises used in martial arts and yoga. In this presentation, Dr. Mark discussed the use and evidence supporting mind-body therapies in cystic fibrosis care. One possible mechanism is that mind body therapies may be effective by reducing stress and inflammation in patients with CF. Suggestions and thoughts using this integrative approach in incorporating various mind-body therapies with conventional CF care were made.

To watch Dr. Mark's presentation, go to <http://tinyurl.com/yg8kbt6c>

## Belonging and Identity: Growing Up With CF

Isa Stenzel Byrnes, LCSW, MPH — Mission Hospice, Redwood City, CA

A longtime member of the cystic fibrosis (CF) community, Isabel integrated her personal experience as an adult with CF



Isa Stenzel Byrnes, LCSW, MPH

and recipient of a double lung transplant with her professional experience as a social worker and counselor, to speak about what makes life with CF worth living. In particular, to commemorate the 30th anniversary of the conference, she explored attitude and the role that belonging and community play in the development of identity as a person with CF. Key objectives for the talk included: to provide a psychosocial overview of an individual living well with cystic fibrosis; to offer suggestions of ways parents can raise their children to develop a confident and secure identity with CF; and to offer suggestions for involvement and connection to the CF community that can foster support, belonging and confidence.

To watch Isa Stenzel Byrnes' presentation, go to <http://tinyurl.com/yaoj7xy2>



John Mark, MD

## Small Molecule Screening Approaches

Continued from front cover

represents a major unmet need in the field. For instance, CFTR mutations termed premature termination codons (PTCs) prevent complete synthesis of the CFTR protein and therapeutic strategies for this type of mutation have focused on promoting translational read-through to facilitate synthesis of full-length protein. To date, such approaches have been unsuccessful in clinical trials leading to the termination of drug development programs.

Ongoing studies conducted at UCSF focus on the W1282X-CFTR mutation, the third most common mutation in pan-ethnic U.S. CF subjects and an extremely prevalent mutation in Ashkenazi Jewish subjects. Small molecule screening approaches using transfected cell models were used

to identify small molecules that enhance trafficking and activity of truncated CFTR produced by the W1282X mutation (termed CFTR1281), thus demonstrating the feasibility of a novel therapeutic paradigm for W1282X-associated CF. Significantly, the combination of a novel potentiator and the approved drug ivacafor/VX-770 were able to fully restore channel activity.

Although CFTR1281 correctors and potentiators that work in transfected cell models were discovered, in initial studies these molecules were ineffective in primary or reprogrammed nasal epithelial cell models derived from a single CF subject homozygous for the W1282X mutation. However, we plan to expand these studies to other CF subjects that carry the W1282X-CFTR mutation in an effort to establish a new therapeutic paradigm. Using similar approaches to

the W1282X-CFTR targeted studies, we are also investigating whether other rare CF mutations are amenable to existing drug combinations, or to the newly identified dual-potentiator approach.

As with many CF-related research projects, these studies are only possible through the collaborative efforts of scientists, clinicians, and in this instance, experts in drug development and cell culture models.

Dr. Haggie is the recipient of a research grant through CFRI's New Horizons Research Program.



# CFRI CF Summer Retreat: A Place of Belonging

By Colleen Lewis

The summer of 2016 was rough for me, but CFRI's retreat lifted my spirit. I had just moved into my parents' house after living independently for 10 years, and I was having a really hard time coping.

I had connected on Instagram with another young woman with CF who was my age and going through a similar struggle, and she told me about the retreat. She also informed me about the travel scholarships that were available so that I could afford to get there. Of course I was immediately skeptical, wondering, "How could we possibly stay infection safe?" and, "Will I be okay spending a week away with total strangers?" Through our discussion, all my hesitations and questions were put to rest. I applied, got accepted, and ended up spending a week connecting with the most welcoming and understanding group of people that I've ever met.

I don't quite know how to express how being in a room with others who have cystic fibrosis feels. Online connection is great, but being physically present with a group of your peers – it's simply unparalleled. I've never felt so in place.

The week was spent sharing meals, having group discussions and conversations,

learning about things that could be beneficial additions to your care plan, or the future of CF treatment in general, working out, enjoying the beautiful

retreat center, and "crafting." I put that in quotes because I usually just showed up to the craft room and ate snacks while others did the creative stuff. All of the scheduled activities were flexible like that. And there were plenty of snacks!

The retreat is open to adults with CF\*, their families, and closest friends. I plan on returning for many years to come, and I hope some new faces will come join us to experience the vibes. You'll belong.



Colleen Lewis, enjoying the CF Summer Retreat

*\*Adults with CF must follow CFRI's cross-infection control policies and procedures, which include a sputum culture, medical release form signed by one's physician and a liability release. To see the complete policy, go to [www.CFRI.org](http://www.CFRI.org).*

CFRI's CF Summer Retreat was generously sponsored by Gilead Sciences and AbbVie, with additional support from Genentech, Alcresta Pharmaceuticals, Allergan, and Kroger Specialty Pharmaceuticals.

## 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 acknowledgment of your gift to the person you designate.

Please mail your contributions to:

**CFRI**

1731 Embarcadero Road, Suite 210  
Palo Alto, CA 94303



[www.donatelife.net](http://www.donatelife.net)

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May 1, 2017 — July 31, 2017



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# In Memory of

May 1, 2017 — July 31, 2017

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Joe Wright



# 33rd Annual Golf Tournament Benefitting CFRI A Record Setting Event!

The legendary Pasatiempo Golf Club – a “top-100” course – hosted 135 golfers on August 7, who enjoyed friendly competition while supporting the search for a cystic fibrosis (CF) cure. The 33rd annual benefit event for CFRI broke all previous records – selling out and raising over \$78,000! Of this total, \$15,000 was matched by CFRI’s Jessica Fredrick Memorial 2017 CF Research Challenge Circle. All proceeds will fund CF research grant awards.



Team Becca 2017

The event is deeply personal for the event co-chairs, Scott Hoyt and Mike Roanhaus. Scott, Pasatiempo Golf Club Manager and former CFRI Treasurer, has two daughters with CF, one of whom received a life-saving double lung transplant in 2016. Mike, current Secretary and past President of CFRI’s Board of Directors, is the father of Becca, who also lives with CF. Star one Credit Union stepped up their sponsorship level to \$7,500 and became the tournament sponsor. The other Major sponsors continued to be the Mike

and Dea Roanhaus family, HDR Architecture, the Kirkorian Family Foundation, and the Scott and Anne Hoyt family. Says Scott, “Thanks go to everyone that donated, sponsored, participated, volunteered, and contributed to the success of this event. The tournament committee feels so blessed to have this level of support.”

CFRI is extremely grateful to Scott, Mike, and the other dedicated members of the



Team Hoyt 2017

golf committee: Francine Bion, Tina Capwell, Dea Roanhaus, and Ralph Swanson, plus the many event participants who are supporting cutting-edge research for those living with cystic fibrosis.

## CFRI and Me: PARTNERS for LIFE – Some Easy Ways to Deepen Your Relationship

- **VOLUNTEER** in the CFRI office, or at a CFRI event. Maybe host your own event, serve as an Ambassador, or lend your IT skills. The sky’s the limit as to what’s possible. If you have some time, the desire, and an idea, just let us know and we’ll help you make it work.
- **ATTEND a CFRI FUNDRAISING EVENT**, or hold your own! Check out our listings at [cfri.org](http://cfri.org). Or we’ll help you through our Reaching New Heights Campaign.
- **TRIBUTES: In Honor Of and In Memory Of. RECOGNIZE a LOVED ONE** with your choice of gift. CFRI will then send an acknowledgement letter to your designee.
- **GIVE STOCK to CFRI**. Donating appreciated stock avoids paying capital gains taxes had the stock been sold. You’re also entitled to an income tax charitable deduction for the stock gift date’s fair market value.
- **PLANNED GIVING** potentially offers increased income, tax savings, the opportunity to meet your philanthropic goals, and the satisfaction of making a significant gift to CFRI during your lifetime.
- **BEQUESTS**: Include CFRI as a beneficiary in your will or living trust. At the time of your passing, your designated amount would come to CFRI – tax-free to your heirs and CFRI.
- **VEHICLE DONATIONS**: Donate your unused car/RV/boat to CFRI. Your contribution is tax-deductible, and we will coordinate the transfer of property..

For more information, please contact **Tony Adessa, CFRI’s Development Manager**: 650.665.7586 or [tadessa@cfri.org](mailto:tadessa@cfri.org).



## SAVE THE DATES!

### Mindfulness Based Stress Reduction Online Class for Those with CF & CF Caregivers

September 28, 2017

First Class

6:00 pm – 8:00 pm PST

Eight-Week Course

### CFRI's Moonlight Masquerade A Gala to Support CFRI Programs

October 28, 2017

Hillsborough Racquet Club

Hillsborough, CA

See back of newsletter for details

### 2017 CF Caregivers Support Group

(Attend in Person or By Phone):

Oct. 17, Nov. 21, Dec. 19

Times:

CF Caregivers of Children

5:00 pm – 6:00 pm PST

CF Caregivers of Adults

6:00 pm – 7:00 pm

For location or call-in number, go to [www.cfri.org](http://www.cfri.org)

### Embrace: CFRI Mothers' Retreat

May 4, 2018 – May 6, 2018

Vallombrosa Center

Menlo Park, CA

### 31st National CF Family Education Conference Bridges to the Future

August 3 – August 5, 2018

Pullman SF Bay

Redwood City, CA

### CFRI's CF Summer Retreat

August, 2018

Vallombrosa Center

Menlo Park, CA

For information or to register; for these events, please email

[cfri@cfri.org](mailto:cfri@cfri.org)

or call 650.665.7559.



## CFRI's CF Community Voices: Podcasts Created By and For the CF Community

CFRI's CF Community Voices was created to share information and insights about a wide variety of topics that impact our CF community, including reproductive health, GI issues, fitness, relationships, and parenting. Each month two new episodes are posted, providing perspectives

from a "professional expert," (respiratory therapist, dietician, social worker, pulmonologist, researcher, etc.), and from a "personal expert," i.e. individuals with CF, or parents, spouses, partners or siblings of those with CF.

Episodes are available on CFRI's podhosting site: [cfri.podbean.com](http://cfri.podbean.com). You can watch or listen at the site, or download to your phone or tablet to enjoy in the car or while exercising. Episodes are also posted on CFRI's YouTube channel. The response has been phenomenal, and we look forward to sharing our community's diverse voices throughout the year. Generously sponsored by Vertex Pharmaceuticals, Chiesi USA, Gilead Sciences, Genentech, and Proteostasis Therapeutics.

## CFRI's Many Voices ~ One Voice CF Advocacy and Awareness Campaign Increases Its Impact

CFRI's Many Voices ~ Once Voice Campaign kicked off nearly two years ago, and its impact continues to grow. A Change.org petition drew 5,000 new constituents into our fold, while 40 Action Alerts to our community resulted in over 6,000 letters to elected officials in the United States Senate, House of Representatives and Food and Drug Administration (FDA), as well as to elected officials in select states across the nation. These past months brought stress to many in our CF community, who feared that proposed changes to current healthcare law would be catastrophic for those facing the expensive and complex care that cystic fibrosis requires. CFRI has consistently informed its community of developments in this area, and remains on-message that any change in healthcare legislation must include protections for the cystic fibrosis and rare disease communities. Our therapies are costly, and the need for affordable insurance and specialized care is paramount. Thank you to everyone who participated in our calls to action!

With approximately 30,000 people diagnosed with cystic fibrosis in the United States, it is imperative that we raise a unified voice for increased research and access to care. We have recently released a moving advocacy film, developed to educate those who are unfamiliar with CF, and inspire them to join our advocacy efforts. Please watch and share the link with others. Without heightened awareness about cystic fibrosis, we will remain a lesser priority for research funding and support at the state and national levels. With your support our impact will grow. Join us!

To watch the video, go to: <https://tinyurl.com/yakz3hfs>









# Recognizing Our Extraordinary Community Heroes

By Siri Vaeth Dunn, MSW

CFRI is proud to honor the following people who have made extraordinary contributions to the cystic fibrosis (CF) community. Awards were presented at our 30th National CF Family Education Conference on July 29th, 2017.

**A Special Recognition Award** was presented to **CFRI's Research Advisory Committee (RAC)**, whose members utilize their clinical, scientific and personal expertise with cystic fibrosis to ensure that CFRI's research funding is directed to the most promising scientific projects. RAC members vet letters of inquiry and full proposals, and provide CFRI's Board of Directors with vital information to make informed funding decisions.

**The 2017 David Stuckert Memorial Volunteer of the Year Award** was presented to **Barbara Curry**, who became involved with CFRI over 20 years ago after her grandson's diagnosis with CF. Barbara has been involved with nearly every aspect of CFRI, serving on the Conference, Gala and Mothers' Day Tea Committees, and annually raising approximately \$60,000 through her Mothers' Day Tea invitations. A tireless CF advocate, Barbara Curry personifies the qualities of the award's namesake.

**The 2017 CFRI CF Professional of the Year Award** was presented to **Ahmet Uluer, DO**, Director of the Adult Cystic Fibrosis Program at the Boston Children's and Brigham and Women's Hospital CF Center, where he is the co-director of the Therapeutic Development Network. Dr. Uluer's clinical and research interests include all aspects of CF care, quality care initiatives and outcomes, successful transition from pediatric to adult-centered care, and improving consistency in CF care. Dr. Uluer serves on CFRI's Medical Advisory Board. A caring and dedicated clinician, Dr. Uluer holds both the physical and mental health of his patients at the forefront of his work.

**The 2017 CFRI Partners in Living Award in Memory of Anabel Stenzel** was awarded to **Elyse Elconin-Goldberg**, who has inspired others with CF for decades. Elyse credits physical activity as key to maintaining her lung function as she worked, married, and raised her children. Elyse received a life-saving double lung transplant in 2013. She serves on CFRI's Board of Directors, Gala Committee, and CF Quality of Life Advisory Board. She has been a Discovery Series presenter, CF Community Voices podcast speaker, CFRI advocacy film participant, newsletter contributor, and advocate. Elyse embodies the qualities exemplified by Anabel, including courage, determination, adherence to medical regimen, community service, and positive coping.

**The Inaugural Paul M. Quinton Cystic Fibrosis Research Legacy Award** was awarded to its namesake, **Paul Quinton, PhD**. This award recognizes CFRI-funded researchers whose work has impacted the field, increased our understanding of the disease, and advanced our ability to progress in our search for a cure. Dr. Quinton is Emeritus Nancy Olmsted Chair in Pediatric Respiratory Medicine in the School of Medicine at UC San Diego. An early recipient of CFRI research funding, Dr. Quinton discovered the basic defect in chloride permeability that characterizes the dysfunction of CF affected tissues. His lab has further explained CF pathology, and has helped develop improved sweat tests for diagnosing CF and possibly assisting in assays of therapeutic drug effects in vivo. Dr. Quinton is a mentor to many, and an inspiring friend to the CF community.



From top:  
Barbara Curry, Ahmet Uluer,  
Elyse Elconin-Goldberg,  
Paul Quinton

## CFRI's 30th National Cystic Fibrosis Family Education Conference: Soaring to New Heights

July 28 – July 30, 2017

Thank you to our generous sponsors & exhibitors who made this event possible!

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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.*

For their generous support of **CFRI Community**, special thanks to:

**Vertex Pharmaceuticals,  
Genentech, Gilead Sciences,  
AbbVie and Chiesi USA**

Visit our website at:  
**www.cfri.org**

for more information about us  
and about cystic fibrosis.

**Call toll free: 855.cfri.now**



## CFRI's Moonlight Masquerade ~ Buy Your Tickets!

Saturday, October 28, 2017 from 6:00 pm to 11:00 pm (dancing from 9:30 pm – 11:00 pm)

*At the beautiful and historic Hillsborough Racquet Club in Hillsborough, California.*

Enjoy gourmet delicacies, fine wines and fabulous entertainment. Celebrate progress in the field of CF research and therapies. Honor our 2017 CF Champion, Dr. Rick Moss of Stanford.

Bid in our exciting auction. End the night on the dance floor.

This is a 21-and-over event. Individuals with CF must adhere to CFRI's gala-specific infection control procedures. Go to [www.cfri.org](http://www.cfri.org) for time-sensitive information.

**Cost:** \$165 per person / \$150 per ticket with the purchase of two or more.

Sponsorship packages are available.

For more information go to [www.cfri.org](http://www.cfri.org), or call 650.665.7576.

Generously sponsored to date by **Vertex Pharmaceuticals, AbbVie, Chiesi USA, Novartis Pharmaceuticals, Gilead Sciences, Genentech, and NBC Bay Area.**

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