

From Small Town Advocacy to Statewide Change

By Stephanie Hammar

On April 13, 2017 I walked into our small town high school in Wisconsin looking forward to a college prep meeting for my daughter, Taylor. Upon entering, I immediately noticed a strong odor and loud noises. After inquiring, I was informed that a referendum-approved construction project had started early. I had voted yes for the referendum to improve our school, because prior to the election, parents and community members were told the construction would take place during summer months when school was out of session. No one had been notified that construction was beginning in a building filled with students. As Taylor has cystic fibrosis (CF), seeing the dust and knowing of the mold and other pathogens it likely contained, I feared for my daughter.

That April day, many children went home sick or were pulled out of school by their concerned parents. After multiple parental complaints, the County Health Department inspected the school, which shut down construction for the day with an order to air out the building. That single day of construction resulted in three children sickened by physician-confirmed carbon monoxide exposure.

Citing our daughter's needs as outlined in her 504 plan, my husband and I attempted get the construction stopped yet we were ignored by the school board and administration. We were vilified by some of these individuals who publicly posted letters stating that no one was in harm's way and that the negative "buzz" created in the community was unnecessary and exaggerated. Our family was slandered, and we were victims of malicious town gossip spread on

Continued on page 4



Taylor Hammar advocates at the Wisconsin State Capitol



AKM Shamsuddin, PhD in his lab

Pharmacology of CFTR HCO₃ Secretion in Native Small Airways: Implications for Cystic Fibrosis

By AKM Shamsuddin, PhD | CFRI New Horizons Research Program Principal Investigator

Cystic fibrosis (CF) is a genetic disease affecting multiple organs including the airways, pancreas, reproductive organs, intestines and the sweat glands. Severe infections in the small airways by opportunistic bacteria is a primary cause of morbidity and mortality in CF. Recent studies have indicated that the inability of the mutant ion channel protein called CFTR, which acts as a pore to allow

two important chemicals called chloride and bicarbonate to pass across the airway epithelial cells results in abnormal mucus secretion, physical obstruction, secondary infections and eventual destruction of the small airways.

Over the past three decades, great emphasis has been placed on the abnormal transport

Continued on page 8

CFRI Community

Spring 2018

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Letter from the Executive Director

*"You will either step forward into growth
or you will step back into safety."*

— Abraham Maslow

Dear Friends,

I hope this note finds you and your loved ones well. CFRI ended 2017 having accomplished its goals and expanded many of its programs. We are already off and running to ensure another year of successes. With your support, we will address the multi-faceted needs of our community, whether through the funding of innovative research, the provision of educational and psychosocial support programs, or engaging our community to raise awareness of the needs of those impacted by cystic fibrosis (CF). We are your partner in living, and we are so grateful for your sustained involvement.

In 2018 we are thrilled to expand our Partners in Living Initiative CF Quality of Life (CFQoL) programs to expand the level of support we offer members of our community, including new CF-focused online mindfulness classes, a top-notch conference, and of course, our CF Summer Retreat for adults with CF and the Embrace Mothers Retreat.

Our CF research awards program will expand in 2018 to fund some of the most brilliant minds in the field. Our "Many Voices ~ One Voice" advocacy and awareness campaign will be increasingly active, with events ranging from California to Washington DC. Please join us and raise your voice!

This growth requires a shifting of responsibilities among CFRI's strong team. Siri Vaeth has now moved into the newly-created Associate Director position to work with me and our community members to bring our goals to fruition.

We have many opportunities for you to support CFRI; your participation is vital. Cystic fibrosis remains a harsh and challenging disease. Each one of us plays a key role in the search for a cure.

Together as a CF community, let us step forward into growth.

Warmly,



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



Sue Landgraf, Executive Director

News from the Board

Dear CFRI Community,

CFRI has been a hub of activity, as 2018 jumped out with a fast and very productive start. We remain in excellent fiscal shape, thanks to the generous support of members of our community and our corporate partners. Highlights from our audit will be included in CFRI's Annual Report, which will be in the fall edition of CFRI Community. We are thrilled to be funding innovative research projects across the country while expanding our broad range of programs for the CF community. Together, we are partners in living.

CFRI-funded research has played a key role in the development of new therapies. As I write this, members of the Research Advisory Committee are vetting proposals from researchers across the country who have submitted requests for funding through our Elizabeth Nash Memorial Fellowship Program and New Horizons Program. The incredibly high caliber of the proposals will make the selection very challenging!



Bill Hult, President

Continued on page 5

cfri | Spring 2018

Flying with CF: Key Things to Remember

By Siri Vaeth, MSW

The X-ray conveyor belt at the airport is moving steadily forward. An endless stream of shoes, laptops, handbags, and carry-on suitcases enter the tunnel and then emerge. And then it all comes to a grinding halt. The Transportation Security Administration (TSA) officer reverses the belt, looks at the item on the screen and then moves it to the side, simultaneously signaling for further examination by a colleague and the owner of the bag. And so my daughter Tess follows the agent carrying her Vest to a separate table where it will be removed, examined, and swabbed for explosives. Meanwhile the process is repeated with her nebulizer compressor. Anyone with cystic fibrosis (CF) who has travelled with their medical equipment knows this scenario. For those of you who have not travelled recently, or who are planning a first getaway with your child with CF, here are some tips and pointers to make the process as seamless as possible.

Most importantly, never check your medications and medical equipment with your bags. Always carry these items on the plane with you, as a lost or damaged bag could immediately derail all planned activities while you scramble to locate specialty pharmacies and medical equipment suppliers. Even if you carry on your equipment, it is always a good idea to know in advance where the closest CF center and pharmacy are located at your destination.

It is highly recommended that you request an annual letter from your physician on official letterhead to carry with you that states your or your child's diagnosis and lists the required medications.

According to the TSA website – which provides a wealth of information for travelling with medications and medical equipment – it can be very helpful to notify the officer at the security checkpoint that you have medically necessary liquids, medications and equipment. This can include ice packs used to keep your medications cold. Medically necessary liquids “in reasonable quantities,” such as vials of inhaled medications and insulin are exempt from the standard limitation of 3.4 ounces or 100 milliliters, though the TSA stresses that they are still able to screen these liquids for explosives.



There is no limitation on carrying medications in pill form. While the TSA does not require passengers to carry their medications in prescription bottles, to avoid any issues, it is recommended that you keep them in their original containers with the prescription label. This is especially important if you are traveling overseas, but also in the U.S. because states have varying laws related to the transporting of medications.

Medical equipment, including vests, compressors/nebulizers, CPAPs and BiPAPs should be carried on the plane for your own protection. The TSA site notes that these should be removed from their cases when they are sent through the X-ray, and that it may be safest to place it in a clear plastic bag to protect it from other bacteria and pathogens. The tubing and nebulizers can remain in the case. It is likely that the machines will still be swabbed for explosives, which requires removal from the plastic bag.

TSA agents handle a wide range of items, many of them with questionable cleanliness. Should your equipment need to be examined, always ask the officer to replace his/her gloves prior to the check. For those who are worried about irritating the TSA officer, I have asked agents at several airports if passengers who request this are seen as problematic, and universally, all have stressed that Tess should always request the new gloves for her protection.

If you are planning to travel overseas, it is important to confirm in advance if there are any restrictions on medications you will be bringing into the country. A recent article in the New York Times noted that many medications used in the United States are banned or restricted in other countries, including over-the-counter drugs. The author noted that even Tylenol PM tablets may not be brought into Japan, as they contain 25 mgs of diphenhydramine, exceeding the 10 mg limit per tablet enforced in that country. With the wide range of medications used by individuals with cystic fibrosis that may be unattainable in other countries, it is best to research in advance and arrive prepared.

As a rule, Tess has been treated with courtesy by the TSA officers who wave her to the side each trip. Should you have concerns about the screening process at a U.S. airport as it pertains to your medications or equipment, or if you need special accommodations, you are able to request a TSA Passenger Support Specialist, who is specially trained to address the needs of those with disabilities and medical needs.

One final tip: Always ask to pre-board the plane so that you can wipe down your seat area with antibacterial wipes.

With preparation, the stresses associated with flying with CF can be minimized, leaving you better able to enjoy your trip.

From Small Town Advocacy to Statewide Change *Continued from front cover*

social media purporting we were using our sick daughter to penalize the school. My husband, who has been a teacher at this school for 16 years, was put under intense scrutiny and it was clear that his job may be in jeopardy.

The personal and financial agendas of the school administration clouded the reality that doing construction of this magnitude in an occupied building is a significant health risk to students and staff, especially those most vulnerable. This was a major renovation of a very old building: ceilings were being ripped down while machinery tore up old flooring and cement was poured. One day, signs were posted stating that on that same day, “asbestos removal may be occurring adjacent to your working area; however, all federal regulations will be adhered to.” There was no notice, no discussion, and no risk mitigation plan. The administration had a timeline and an agenda to complete the construction quickly, and it appeared nothing was going to stand in the way.

Our family was left with no choice than to pull Taylor out of school and hire an attorney to protect her health. The attorney gave the school a “cease and desist” construction letter, which was ignored for five days during which she was at home and missing school. Finally, the school responded they would meet with us, which resulted in a horrific arrangement as Taylor was singled out and placed in the school library because it had a separate HVAC system. She was forced to leave school at 11:00 each morning to accommodate their construction plans.

You can imagine the heartache this caused a young teenage girl. Not only was she separated from her peers and social interactions she also wasn’t given proper instruction nor had access to a bathroom that was safe for her to use. I will never forget the evening when Taylor looked at me with tears welling in her eyes and said, “Mom, you always did a good job never making me feel different for having cystic fibrosis, but this has made me feel so different and so sad.” That was my tipping point. The arrangement wasn’t working. Taylor’s education was suffering, and no



Open ceilings, ripped up flooring and large amounts of dust at the school construction site

one had the right to take away all we had done to allow her to live and feel as normal as possible despite having CF. No one. Something had to change.

Our lawyer went back to the school asking that the construction be done when school was out for the summer as originally planned. Our daughter’s physician wrote a letter to the school and community documenting the severe risk of exposing those with CF – as well as those with other health issues – to the dust, mold and other pathogens circulating during construction.

Again, we were ignored.

That is when I went public and with the help of CF public policy advocates, including those at the Boomer Esiason Foundation, Senate Bill 427 was created. This bill mandates that schools doing renovation in excess of \$10,000 must give two-months’ notice to students, parents, and staff while also outlining a risk mitigation plan.

In Wisconsin, we have laws regarding construction in hospitals and daycare centers, but nothing for schools. Beyond the harm to Taylor and my family, the entire student body and staff were put at risk. During this construction, children in the school needed emergency medical appointments for asthma attacks, including my son. While construction workers were protected with

hard hats and face masks our children walked around vulnerable and exposed. School doors were left propped open, and the learning environment was polluted with dust and potential pathogens, to say nothing of the noise and distraction which impacted some of our most vulnerable children with learning disabilities, autism, and other special needs. Adequate notice, planning, and risk mitigation preparation could have remedied all of this.

Senate Bill 427 still has a long road ahead until it is officially law, but we will not rest until we know we did everything in our power so that another child’s health isn’t recklessly disregarded and that no one goes through the heartache we did. Every child has a right to a safe school environment, and as parents we have a right to know if and when the safety and health of our children is jeopardized. Unfortunately, until SB 427 passes, the experience with our school could happen in any school district in Wisconsin. Please join us in helping make Senate Bill 427 law in Wisconsin. Consider researching whether your state has laws to help insure that schools are a healthy environment in which attendance, achievement, and safety are promoted above all else.

Please join me in protecting and advocating for our children!

CFRI's Many Voices ~ One Voice CF Advocacy and Awareness Campaign: The Power of a Unified Community

By Siri Vaeth, MSW

CFRI's Many Voices ~ One Voice Campaign was launched in 2016 to provide an easy and impactful means for members of our community to contact their elected officials and other decision makers so as to educate them about the challenges of life with cystic fibrosis (CF) and to encourage improved access to affordable quality medical care and new therapies. 2017 brought a roller coaster of emotion and intense activity due to multiple efforts to revamp healthcare policy and legislation at the federal level. Through "Calls to Action" emailed to our community members, we encouraged our constituents to communicate issues and concerns to their elected officials. Throughout the year, our message was consistent: should the Affordable Care Act (ACA) be repealed or altered, any new legislation must maintain the vital ACA protections that help our CF – and rare disease – communities. And our community responded, sending over 23,000 emails and faxes from across the country to their representatives. We are a strong community when we raise our voices together.

We need you! We encourage everyone to participate in our Many Voices ~ One Voice Campaign, whether through letter writing or participation in one of our awareness events. With only 30,000 people diagnosed with cystic fibrosis in the United States, we are considered a "rare disease" by the government (defined as impacting less than 200,000 in the country). With such a small community, it is imperative that we unite and make our voices heard to ensure our healthcare concerns are addressed.

CFRI has further expanded its advocacy and awareness efforts this year. We follow legislation at the state and national levels, which impacts our community, and will

continue to call upon our CF community to share its stories and opinions with their elected decision makers. We are once again working with California State Senator Bill Monning to declare May 2018 as CF Awareness Month in the state, and will collaborate with community members in other states to have similar state resolutions passed. In late February we joined our rare disease partners to advocate in Washington DC during Global Genes' Rare Disease Week on Capitol Hill, and will work with the California Rare Disease Caucus in the coming months.

CFRI is very honored to host an externally-led Patient Focused Drug Development hearing with representatives of the Food and Drug Administration (FDA) on October 29, 2018. The goal of this day-long meeting in Maryland, which will be live streamed, is to increase FDA decision makers' understanding of CF and the need to fast track potential drugs. CFRI will invite individuals with CF and their loved ones to share their perspectives with the FDA, including their daily healthcare experience, currently

available treatments, the need for and access to new therapies and medical options, and the role the FDA can play in bringing new drugs to market quickly. We encourage your participation via live stream; we will share the log in information as we get closer to the event.

CFRI is proud to be a founding member of the Cystic Fibrosis Engagement Network, along with the Laura Bonnell Foundation, Boomer Esiason Foundation, CF Rocks, and the Cystic Fibrosis Lifestyle Foundation. The Cystic Fibrosis Engagement Network serves as a leading educational and advocacy organization focused on policy matters impacting cystic fibrosis patient access to optimal care. CFEN will be an active participant in the externally-led Patient Focused Drug Development meeting.

Please join us. Together we can have a tremendous impact. For more information, please go to our website, and click on the "Advocacy" tab.



News from the Board

Continued from page 2

In his cover article, CFRI-Funded researcher AKM Shamsuddin, PhD, provides a wonderful overview of the inspired work that is improving lives and creating new therapies.

As a member of CFRI's community, you are a part of this innovative work. Thank you for your ongoing support. With your help we will continue to move closer to a cure, while enhancing the lives of those living with cystic fibrosis.

Peace and good health,

Bill Hult | President, CFRI Board of Directors

Embrace: A Retreat for Mothers of Those with CF

The fourth annual retreat for mothers of children and adults diagnosed with cystic fibrosis (CF) will be held May 4th – May 6th at Vallombrosa Center in Menlo Park, California, where women can enjoy art projects, yoga, journaling, support groups, CF resources, celebrations, and needed respite time. The retreat provides creative strategies for coping with the challenges of the CF journey while creating a lasting support network.

Last year, women travelled from throughout the country to attend this powerful event. Participants may stay onsite, or “commute” each day. Registration for those staying onsite is \$150, which includes two nights at Vallombrosa, meals, workshops, and events. Registration for commuters is \$75, which includes meals, workshops and events. Please join us! For more information, call 650.665.7576, or go to www.cfri.org.

Sponsored by Vertex Pharmaceuticals, AbbVie and Gilead Sciences.



Living Mindfully with Cystic Fibrosis: New Class for 2018

Over the past three years, CFRI’s online Mindfulness Based Stress Reduction (MBSR) classes have helped over 200 people reduce the depression and anxiety so common among those with cystic fibrosis (CF) and their family members. Taught by Julie Desch, MD, the MBSR classes have brought together an online global CF community who, while thousands of miles apart, join together for weekly yoga, meditation, mindful practices, and discussion.

This year Dr. Desch, who herself has CF, has created a new “Living Mindfully with CF” class. The class integrates principles of MBSR, including yoga, breathing exercise, and mindfulness practices, but will more specifically apply these principles and practices to life with CF.

Classes are free, thanks to our generous funders. In the online platform, attendees can see and hear each other, and there is the opportunity for break out discussion groups during class. The first session began in February and quickly exceeded our goal for registrations. The next class will be held in the summer of 2018, with the final class of the year offered in the fall. Please watch our website and weekly newsletters for upcoming dates.

CFRI is extremely grateful to Julie Desch, who generously donates her time and expertise to support our CF community in reducing depression and anxiety, and in bringing mindfulness to the cystic fibrosis journey.

Living Mindfully with CF is made possible thanks to grants from Vertex Pharmaceuticals, Gilead Sciences and Genentech.

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



www.donatelife.net

In Honor of

November 1, 2017 — January 31, 2018

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Sandra Aguirre
Sadie Anderson
Brittany Armstrong
Haleigh Baker
Kyle Baker
Bridget Barnes
Lucy Barnes
Nicholas Barnes
Jamie Barry
Joseph Batchelder
Makinnon and Marin Baugh
The Baugh Family
Maggie-Faye Bendz
Michael Benedetto
Alison Best
Francine Bion
Kara Borowski
Brian Burks
Linda Burks
The Burks Family
Isabel Stenzel Byrnes
Stacy Carmona
John Robert Christie
Shaun Collins
Lauren Colonna Cooper
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Eliza Williams
Ashley Wilson
Nina Wine
Jonathan Witzcak
Amanda Wood
Katiana Wosina
David Zweier

In Memory of

November 1, 2017 — January 31, 2018

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Gianna Altano
David and Jodi Armknecht
Elizabeth Arvidson
Sue Asti
Cara Baysinger
Anne Beltrame
Irvin Beltrame
Brett Bennett
Bill Berkson
Neha Bode
Toby Boyes
Greg Brazil
Cheri Brower
Evelyn Brugger
Jerry and Jane Burroni
Peter Byram
Agnes Calleri
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Sonya Chartrand
Eugene "Frenchie" Choiniere
Auntie Janet Clark
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Melody Johnson
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Julie Judge
Kathy Judge
Peter Judge
Tom Judge
Richard Kastle
Blake, Stan and Shirley
Kelley
Judith Huddleston Kellogg
Joan Killian
Kathleen "Kitty" Kiou
Lori Kipp
Bridget Klein
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Roy and Mary Tripp
Jill Tulcin
Daniel Turner
Fernando Vela
Cindy Vidak-Haley
Betty Vitousek
Tara Weir
Maurice Wernli
Hayley Carol Wester
Pamela Whitehurst
Dr. Wise and his son Arthur
Cynthia Witman

CFRI's CF Community Voices Year Two: Podcasts Created By & For the CF Community



CF Community Voices was created to share both factual information and personal insights about a wide variety of topics that impact our CF community. Launched in January 2017, the response to the series exceeded expectations, with 31 podcasts generating 3,650 views and listens. Topics in 2017 included reproductive health, GI issues, fitness, mental health, advocacy, CF pathogens, and CF clinical trials.

This year there will be four filming events at CFRI's office, to which our community is invited to hear our presenters and meet others impacted by CF. The remaining majority of the podcasts will be filmed "in the field," where individuals with CF, researchers, clinicians, and family members can be interviewed in their workplaces, labs, vineyards and homes.

You can watch or listen to the podcasts on CFRI's Podbean and YouTube sites. The Podbean site (www.cfri.podbean.com) allows you to download episodes to enjoy in the car or while

exercising. We are delighted to share our community's diverse voices throughout the year. If you prefer YouTube, go to <https://tinyurl.com/y989lynx>. Generously sponsored by Vertex Pharmaceuticals, Chiesi USA, and Gilead Sciences.

Pharmacology of CFTR HCO₃ Secretion

Continued from front cover

of chloride as a primary defect in CF while paying little attention to the devastating role played by another equally important chemical – bicarbonate – as evidenced by the destruction of the pancreas, a tissue that is primarily involved in bicarbonate but not chloride transport.

Recent new evidence also indicated that bicarbonate-deficient fluid secretions by the CF-affected organs are responsible for the formation of mucus plugs in the lumen. Interestingly enough, newly developed CF drugs were shown to significantly improve the chloride transport. However, whether these drugs can also restore the bicarbonate transport in the CF small airways, which seems to be necessary for optimal therapeutic benefit is unknown. In view of these early observations, we proposed to investigate how this important anion, bicarbonate, is managed by the epithelial cells of the small airways in health and disease with the ultimate objective of pharmacologically correcting the defect in CF.

Studies of small airways in their natural state (native) have been rare and difficult due to the tiny size and fragility of the tissue. Even though small airways account for the largest portion of the total surface

area of the conducting structures of the lung, characterization of the bronchiole epithelial ion transport functions has been limited by the complex anatomy and relative inaccessibility of these structures, especially in humans. To date, we have a very limited understanding of how the airways so precisely maintain the volume (critical thickness) of airway surface liquid (ASL) in a steady state so that the airways normally are never desiccated nor obstructed with excessive fluid and mucous.

With the support of a New Horizons research grant from CFRI, our team in Dr. Paul Quinton's Lab at the University of California San Diego (UCSD) designed and developed a special 'mini'-Ussing chamber (area ≈ 1 mm²) and optimized the experimental system in order to measure the basic physiological properties of electrolyte transport across native, intact, freshly dissected, human small airways. Using our novel mini-Ussing chamber we will test the hypothesis that CFTR mediated HCO₃ secretion in native small airways is defective in CF. A recent study with the application of CFTR potentiator drug VX-770 (Ivacaftor) showed promising results with respect to lung function in ΔF508 homozygous individuals. Also a recent study in our lab on the native human sweat ducts indicated that CFTR potentiator, VX-770 (Ivacaftor) and corrector,

VX-809 (Lumacaftor) increased CFTR- HCO₃ conductance in normal but not in CF ducts. We will determine the efficacy of the CFTR corrector and potentiator drugs on the bicarbonate transport by human and pig native small airways.

We believe that these studies will significantly enhance our understanding of the role of bicarbonate in CF pathology and determine the efficacy of newly identified CF drugs in restoring this abnormal bicarbonate transport function in CF.

AKM Shamsuddin, PhD



Perspectives from a Respiratory Therapist

By Kristin Shelton, RRT

Kristin Shelton began her career as a respiratory therapist in 1980, when she was a trainee at the Children's Hospital at Stanford (CHAS) while attending the Respiratory Therapy program at Foothill College. Kristin is beloved by her cystic fibrosis (CF) patients at Lucile Packard Children's Hospital at Stanford. She serves on CFRI's Board of Directors, Conference Committee and Medical Advisory Board.

What first drew you to the field?

My older sister was a student in the program. She encouraged me to pursue respiratory therapy because it was a field that was growing, paid well, and provided the ability to work evenings or night shifts while attending college during the day.

When did you know that you wanted to focus on working with CF patients?

When I began working at CHAS, I immediately admired the spunk and resilience of the people I came to know with CF. In those days, the hospital policies and environment encouraged patients to dress in "street clothes" versus hospital gowns, and go through normal daily activities like school and such. They were allowed to leave the hospital for short periods of time as long as their therapy was not interrupted.

What was it like when you started out? What therapies were available?

We had nebulizers and some bronchodilators. A CF physician developed a special formulation (Harvey's Mix) for the nebulizer that had a mixture of bronchodilators, antibiotics and other items I don't recall. Everybody received chest physiotherapy by hand or with a mechanical percussor. There were no oximeters, Pulmozyme, TOBI, Cayston, or vests.

What have been the most rewarding aspects of your work?

Watching babies with CF grow to be amazing adults!

What have been the most challenging and/or heartbreaking?

Challenging: Working with families that have multiple challenges and the toll it takes on those with CF. Heartbreaking: Losing those same amazing people to the ravages of cystic fibrosis.

How did you keep from "burning out" in light of the losses you experienced?

I always tried to remember that my presence is a source of support to families that have known me and learned to count on me through the years.

What do you tell people who ask you what the best form of respiratory therapy is?

The best airway clearance is the one you can get your child (or you) to perform!

What tips do you have for parents whose kids are resisting adherence?

Get the family involved in the entire process. Do not isolate a person with CF in their bedroom; bring them to the family room and play a board game or watch a favorite show together during the treatment. Make



it a family affair. Ask the person what you can do to help make the process easier or more tolerable.

What are some of the best tips you've heard from parents and patients to stay adherent to the regimen?

I think my favorite tip is from a mom who would only let her child watch TV while he did his treatments. He would ask for a treatment so he could have television time! I love it when parents tell me that treatments are such a part of their life and routine that their children don't know life without the therapy. Unfortunately, CF never takes a holiday.

Not every CF RT gets involved with the CF community like you – i.e. volunteering with CFRI, participating in The Breathing Room, etc. What drew you in?

Volunteering and participating in CF activities has been a large source of support for myself. I get energized by watching those with CF thrive and survive.

What gives you hope for the future?

When I began this journey, the median life expectancy for CF was 18 years, now it is 47 years. That is a lot to celebrate!



Every Day is Mother's Day! 2018 Mother's Day Fundraiser Kicks Off!

Our Mother's Day fundraiser provides vital funding for CFRI's multifaceted programs. We need you to reach our goal of \$125,000. Contact us at CFRI, and we will provide you with everything you need, including the beautiful invitation (at left) created by eight-year-old Gianna, who lives with cystic fibrosis (CF). Mail the invitations to your family and friends, encouraging them to reflect upon their loved ones with cystic fibrosis and to support CFRI's outstanding research, education and support programs, so as to improve the lives of people with CF. Also invite your friends and family online! To participate, please call us at 650.665.7576, email cfri@cfri.org, or sign-up online at www.cfri.org.

CFRI's New Website Adventure with Taproot!

CFRI is extremely proud to have been selected as a Taproot Foundation Service Grant recipient. As a recipient, CFRI is fortunate to receive the pro bono services of a

highly skilled group of passionate professionals who are helping us to recreate our website to better represent CFRI's diverse work and serve as a more useful tool for our

cystic fibrosis (CF) community.

The new website will meet many needs. It will serve as a resource for CF researchers and those who wish to receive current research updates. It will help us to spearhead advocacy efforts to engage

our community in ensuring our voices are heard at the regional, state and federal levels on issues that impact access to care and therapies. The new website will promote CFRI's educational and psychosocial programs and services, while fostering a caring and connected community. It is also hoped that the site will heighten public awareness of cystic fibrosis and serve as a platform to help increase financial support for our vital programs.

We will share the good news as soon as the new site is launched. It promises to be more visually engaging, easy to navigate, inspiring, and a vital resource. CFRI is extremely grateful to the Taproot Foundation and our phenomenal team of pro bono professionals who are helping us to bring this exciting project to fruition.



TOP TEN LIST: CFRI's CF Summer Retreat 2018

CFRI's 2018 CF Summer Retreat will take place at Vallombrosa Center in Menlo Park, California from Thursday, August 16 to Tuesday, August 21, 2018, with the theme, "Take Back the Future: A CF Odyssey." The retreat provides a safe and welcoming environment aimed at enhancing positive coping skills for people living with cystic fibrosis and their family members, friends and caregivers. Participants must be at least 18 years old and adhere with CFRI's Infection Control Policy. Activities include daily exercise, arts and crafts, rap sessions, and educational presentations by experts in the CF field.



Top Ten Reasons To Attend Retreat As Shared By Past Participants in Random Order:

- Having a safe space to share your thoughts and feelings related to CF. Listening and learning with CF peers.
- Soaking in the peaceful, relaxing environment. It's like a vacation.
- Enjoying activities at whatever pace and involvement level feels comfortable.
- Learning about the latest treatments and scientific research related to CF.
- Strengthening bonds with siblings/friends; getting a deeper glimpse into their lives and better understanding some of the difficulties they deal with.
- Getting insight and experience from other CFers who have gone through the same situations. Realizing you aren't the only one helps in navigating the process and healthcare systems.
- Feeling heard and seen by people you have struggles in common with; a weeklong reward for a year well lived surviving this disease.
- Bacon... jerky... cheese snacks... caramels... s'mores.
- Spending time with awesome people, leading you to understand how much of a superstar you actually are.
- Coming away from retreat feeling like an even better you!
- RETREAT Bonus: Renew friendships. Experience new friendships. Try something new. Rap Sessions. Education. Art projects. Togetherness.

For more information, please visit www.cfri.org or contact Mary Convento at 650.665.7559 or mconvento@cfri.org. Registration opens soon! We hope you can join us! The CF Summer Retreat is generously sponsored by Gilead Sciences and AbbVie.

Counseling Support Expanded!

CFRI is thrilled to announce that our very successful counseling support program has expanded in 2018. Thanks to our generous funders, we are now able to provide financial support for eight sessions of counseling with the licensed therapist of your choice. Participants must have cystic fibrosis (CF) or be a direct family member of someone with CF (parent, sibling, spouse



/partner) and live in the United States. This is the fourth year that CFRI has offered this program, and it has proven to help reduce depression and anxiety for those who participate. For more information, email Siri Vaeth, MSW, at svaeth@cfri.org.

CFRI's Partners in Living Initiative CF Quality of Program – A Living Legacy of Peter and Kathy Judge, is generously funded by Vertex Pharmaceuticals, Gilead Sciences, Global Genes, Genentech, and individual donors.



CFRI and You: Partners for Life

Some Easy Ways to Deepen Your Relationship

- **COME to a CFRI FUNDRAISING EVENT**, or hold your own! 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! Check out our listings at cfri.org, or think “out of the box” and we’ll help you make it happen.
- **NEW MONTHLY GIVING PROGRAM: Champions of Hope!** Donations to Champions of Hope will provide a new, predictable revenue stream to support research to find a cure for CF and enhance CFRI’s programs in CF education, support and advocacy. To participate, go to our website or contact Tony Adessa (see below).
- **TRIBUTES In Honor Of and In Memory Of:** Recognize a loved one with your choice of gift. CFRI will promptly send an acknowledgement letter to your designee.
- **GIVE STOCK to CFRI.** Donating appreciated stock avoids capital gains taxes incurred had the stock been sold. You’re also entitled to an *income tax charitable deduction* for the stock gift date’s fair market value.
- **PLANNED GIVING** offers benefits that can include increased income, substantial tax savings, opportunity to meet your philanthropic goals, and the satisfaction of making a very significant gift to CFRI during your lifetime.
- **BEQUESTS:** Include CFRI as a beneficiary in your will or living trust. At the time of your passing, your designated amount would come to CFRI, tax-free to your heirs and CFRI.

For more information, please contact Tony Adessa, CFRI’s Development Manager: 650.665.7586 or tadessa@cfri.org.

SAVE THE DATES!

CFRI’s CF Community Voices Video/Podcast Series

April 12, 2018

CFRI Office, Palo Alto, CA

To download episodes, go to

www.cfri.podbean.com

Sponsored by Vertex Pharmaceuticals, Chiesi USA, and Gilead Sciences

CF Caregivers Support Groups

Third Tuesday of Every Month

March 20 • April 17 • May 15

June 19 • Aug 21 • Sep 18

5:00 pm – 6:00 pm PST:

Parents/Caregivers of Children

6:00 – 7:00 pm PST:

Parents/Partners/Spouses of Adults

Participate in person or by phone

Sponsored by Vertex Pharmaceuticals,

Genentech and Gilead Sciences

Embrace Mothers Retreat

May 4 – May 6, 2018

Vallombrosa Center, Menlo Park, CA

Register now!

Sponsored by Vertex Pharmaceuticals,

AbbVie and Gilead Sciences

Volunteer Appreciation & CF Awareness Event

May 9, 2018

PBM Showroom, Mountain View, CA

Online MBSR Classes

Dates for summer and fall classes to be announced.

Sponsored by Vertex Pharmaceuticals,

Genentech and Gilead Sciences

CFRI’s 31st National CF Family Education Conference

Bridges to the Future

August 3 – August 5, 2018

Pullman San Francisco Bay

Redwood City, CA

Register Now!

Please see back cover

CFRI’s CF Summer Retreat

August 16 – August 21, 2018

Vallombrosa Center, Menlo Park, CA

Register now!

Sponsored by AbbVie and Gilead Sciences

CFRI’s Enchanting Adventure at Nestldown

September 29, 2018

Nestldown, Los Gatos, CA

Purchase tickets or

participate as a sponsor!

Sponsored to date by Vertex Pharmaceuticals, AbbVie and Chiesi USA

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



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CFRI's mailing list is confidential. We do not sell our list, nor do we give out any names or addresses under any circumstance.

CFRI Mission

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 31st National Cystic Fibrosis Family Education Conference: *Bridges to the Future*

August 3 – 5, 2018

**Pullman San Francisco Bay
Redwood City, CA**

Our 31st annual conference promises to be our most exciting thus far, offering outstanding speakers, receptions, support groups, workshops, and the opportunity to connect with your CF community from across the country. **Join us!**

General Session Presenters To Date Include:

- Elaine Chen, MD
- Reid D'Amico, PhD Candidate
- Manu Jain, MD
- Jasleen Kukreja, MD
- Rick Moss, MD
- Chelsea Toth, DSW
- Alan Verkman, MD, PhD

CFRI-Funded Researchers Track Presenters:

- Guillermo Flores Delgado, PhD
- Peter Haggie, PhD
- Nam Soo Joo, PhD
- Kenichi Okuda, MD
- AKM Shamsuddin, PhD

Generously sponsored by: **Vertex Pharmaceuticals, Genentech, Gilead Sciences, Chiesi USA, AbbVie** and the **Boomer Esiason Foundation**

Cystic Fibrosis Research, Inc. a 501(c)(3) nonprofit organization Federal EIN# 51-0169988



Early Bird Registration: for the full conference (on or before 6/22/18) **\$185 per person**

Regular Registration: (7/23/18 and after) **\$215 per person**

Registration includes all conference presentations, meals, reference materials, receptions, and support groups. Limited scholarships are available.

Research Track Registration: **\$125 2-day / \$75 1-day**

Research Track registration includes lunch.

To ensure good health for all, please use proper hygiene practices. All participants/guests with CF must adhere to CFRI's Infection Control Guidelines. See www.cfri.org for specifics.

For more information, visit www.cfri.org or call **855.cfri.now**.

