

Yoga: A Friend for Life

By Lucy Barnes

Yoga has long been my personal sanctuary. I rediscover myself on the mat every time I practice. Not only does it help me physically by clearing my lungs during the poses, it also helps me mentally and spiritually. For these reasons, I decided to pursue yoga teacher certification and share its benefits with others. I have cystic fibrosis (CF), so I wasn't sure how my daily health regimen would fit into the time-consuming schedules of the programs I researched. I never let CF get in the way of fulfilling my dreams and enrolled in the Soma Yoga Institute, a three-week intensive therapeutic yoga teacher training. Hawaii here I come!

First, I had to organize my medical supplies. With over 30 pills and at least two respiratory treatments a day, I made a three-week supply of "pill packets" and prepared a mini-cooler for my Pulmozyme. I packed all my medical equipment in a large carry-on and brought my Vest. I also brought my favorite navy blue yoga mat.

After arriving in Hilo, we were driven to a rural part of the island. "If there's a medical emergency," I thought, "I'll just have to wing

it as there seems to be no cell reception or town close by." I did not pass this along to my mother. We arrived at Kalani retreat center and unloaded. With my medications and respiratory treatments in mind, I had requested a private room. How-

ever, my room was far from private. My wall was all-window and looked out over the entire community. "Terrific," I thought. Regardless,

I had to take care of myself, so I shed my self-consciousness and did a treatment first thing. No one seemed to notice.

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Lucy Barnes practicing as the sun sets

Photo by Mac Holt



CFRI-funded researchers and Research Advisory Committee Members

CFRI-Funded Research: Past Progress and Future Promise — Part 2

By Julie Desch, MD

This is the second of two articles based upon Dr. Desch's September 2016 Discovery Series presentation. To watch the full presentation, go to www.youtube.com/user/cfri2010/

When CFRI first began its research program, the CFTR gene had not been discovered, few therapeutic options were available, and there were more questions than answers for those living with cystic fibrosis (CF). Since then, pivotal discoveries in the field of CF have been made by CFRI-funded researchers. Currently, these clinicians and scientists pursue their research nationwide via three granting

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CFRI Community Spring 2017

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Letter from the Executive Director

Dear Friends,

I hope this note finds you and your loved ones well. CFRI celebrated a record-breaking end to 2016, as our revenues surpassed all previous totals in our 42-year history. We continue to focus on implementing our ever-growing programs to fund research and provide education and support to our cystic fibrosis (CF) community.

This was made possible due to significant support from our individual donors and corporate and foundation partners, as well as the generosity of two women who left a legacy that improves the lives of those living with CF. Irene Pappas and Julie Judge were sisters. Julie's children, Peter and Kathy, both had CF and it was important to the sisters to leave a legacy to support the CF Quality of Life (CFQoL) program to honor Peter and Kathy. Both bequeathed significant funds to support CFRI's CFQoL psychosocial and patient assistance programs for those impacted by CF.

Please consider including CFRI in your estate planning. If you have questions or wish to discuss this further, please email me at suehlandgraf@cfri.org. I would love to talk about the impact you can have now and into the future.

Of course, we have many other opportunities for you to support CFRI. Whatever you choose, your participation is vital. In addition to funding researchers nationwide, this year we are offering our new CF Community Voices podcast series, caregiver support groups, MBSR classes, retreats for mothers and adults with CF, and our National CF Family Education Conference. Our "Many Voices ~ One Voice" advocacy and awareness campaign will be active: as changes are made to national health care policy, we need your voices to be heard!

Cystic fibrosis remains a harsh and challenging disease. Each one of us plays a key role in the search for a cure.

Together, let us replace thistles with flowers.

Warmly,



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



Sue Landgraf



Bill Hult, President

News from the Board

Dear CFRI Community,

2017 is off to a fast start. We are in excellent fiscal shape, having just completed the strongest financial year in our history. Highlights from our audit will be included in CFRI's Annual Report, which will be included in the next edition of CFRI Community. We are thrilled to be funding new and exciting research projects across the country while expanding our broad range of programs for the CF community. Together, we are partners in living.

In January, CFRI's Board of Directors held a Strategic Planning retreat, at which we examined our organizational identity, our competitive advantages, our role on the national front, and our three-year goals.

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cfri | Spring 2017

Yoga: A Friend for Life

Continued from front cover

We all met for dinner that night and immediately bonded. Anxious with anticipation, we were instructed to meet for meditation at sunrise the next day. Sunrise came quickly as we walked in silence. I thought I had meditated before; after 20 minutes I realized I had not. Breakfast followed and then three hours of morning practice. Every day we had a lunch break during which I did my afternoon treatment. We then gathered for afternoon practice and curriculum studies. Dinner never came soon enough so I always packed plenty of snacks. My fellow yogis laughed and wondered how I ate so much but was so small. I explained the reason was cystic fibrosis. Every evening we sat in the hot tub and talked underneath the stars. I usually left early to do another treatment before bed.

This was my daily schedule for three weeks. Busy as it was, I have never experienced anything as profound. I met incredible people from all over the world with life circumstances different than mine, but equally defining. One of my closest friends was an over-50-feminist rock star from New York. A survivor of breast cancer, she and I immediately bonded over our similar humor. A couple from Canada became my surrogate parents, while I connected

equally in different ways with five women my age. Although CF was initially a concern, this feeling dissolved as I realized everyone has their own hardships to overcome. What a beautiful thing to recognize.

On the last day, after graduation, a storm hit and we were instructed to stay inside and prepare to evacuate. I thought this hurricane might be the medical emergency I had jokingly imagined on that first day driving to Kalani. Unphased, we gathered at the hot tub one last time. It was pouring rain, branches were falling, and I felt at peace. At peace with my life being different than others and grateful for this. On the flight back to California my heart felt full. Looking at my yoga mat, I reflected on the three weeks I spent studying and realizing a long-



Lucy and her fellow yogis

held dream alongside the demands of my healthcare, yet feeling in perfect harmony. I thank yoga daily for this feeling, for the self-confidence it inspires, and for my overall acceptance of what is in front of me.

Life is uncertain for everyone and that is what keeps it magical. I am now working in a yoga studio and sharing what I learned with others. For all these reasons and more, I know yoga will be my lifelong friend.

Namaste.

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. Topics in 2017 will include reproductive health, GI issues, fitness, relationships, humor, and parenting. Each month two new episodes will be 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. 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, and Proteostasis Therapeutics.



In Memory of

November 1, 2016 — January 31, 2017

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- **ATTEND A CFRI FUNDRAISING EVENT OR HOLD YOUR OWN!** Whatever your interest, we have an event for you! Or come up with an idea and we will support you through our Reaching New Heights Campaign.
- **TRIBUTES IN HONOR OF AND IN MEMORY OF** When you make a gift to CFRI in honor or in memory of a loved one, that person's name will appear in our newsletter, and an acknowledgement is sent to the person you designate.
- **GIFTS OF STOCK TO CFRI** You do not pay capital gains tax on appreciated stock, and receive an income tax charitable deduction for its fair market value on the date of the gift. For more information, please contact us.
- **CHARITABLE PLANNED GIVING** Planned giving offers benefits for donors that often include increased income, substantial tax savings, the opportunity to meet your philanthropic goals, and 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.

News from the Board

Continued from page 2

Moving forward, we will continue implementing strategies to further CFRI's research, education, advocacy, and support programs.

CFRI-funded research has played a key role in the development of new therapies.

In her cover article, Dr. Julie Desch, Chair of CFRI's Research Advisory Committee, describes what projects we are currently supporting. 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 | Board President

In Honor of

November 1, 2016 — January 31, 2017



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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

CFRI-Funded Research: Past Progress and Future Promise — Part 2

Continued from front cover

structures: the Elizabeth Nash Memorial Fellowship (ENMF), New Horizons (NH) Campaign, and Special Circumstance grants.



Julie Desch, MD

With funding from the ENMF, Stanford University Post-Doctoral Fellow, Andrey V. Malkovskiy, PhD, with Principal Investigator Carlos Milla, MD, is using Raman spectroscopy to test the hypothesis that the thiocyanate (SCN⁻) signal of the solid salivary mucus fraction may be a biomarker that could serve to quantitate the degree of rescue of CFTR function in response to novel drugs, as well as a potential additional means to determine residual function in patients with questionable CF diagnoses.

At the Mayo Clinic, ENMF researcher Noud Van Helmond, MD, and Principal Investigator Michael Joyner, MD, are testing the idea that administering nebulized albuterol, a bronchodilator, during exercise improves drug delivery.

New Horizons researchers include Jeff Wine, PhD, whose sweat bubble ratio assay led to a very precise method to measure CFTR function using what he calls the C/M ratio. Dr. Wine's ratiometric analysis has tremendous promise to accurately measure the effects of current and up-coming CFTR modulators.

Another NH researcher, Paul Beringer, PharmD, of the University of Southern California, is studying rhesus theta defensin-1 (RTD-1), a protein found in non-human primates, which exhibits antibacterial activity against drug resistant *Pseudomonas aeruginosa* in patients with CF.

Several airway regions have the capacity to both absorb and secrete, and while not clearly understood, the net balance between these ion transport processes is believed to control airway surface liquid volume. New Horizons Researcher Guillermo Flores Delgado, PhD, at UC San Diego's Quinton Lab, seeks to clarify these processes, potentially enhancing development of new CF therapies.

Peter Haggie, PhD, of the University of California San Francisco, is studying W1282X-PTC, a premature termination mutation which does not respond to available CFTR modulators. Dr. Haggie seeks to extend screening to identify novel CFTR1282-targeted correctors, potentiators

and synergizers, and characterize the mechanism of action of CFTR1282-targeted modulators. He also seeks to develop human primary cell models to test efficacy of targeted modulator combinations.

Through CFRI's Special Circumstances funding, Sara Modlin has investigated the beneficial effects of osteopathic manipulative treatment in the prevention of distal intestinal obstructive syndrome (DIOS).

Cystic fibrosis newborn screening (NBS) programs have led to the identification of CFTR-related metabolic syndrome, which has an uncertain prognosis that creates challenges for patients, families and CF centers. Funded through a CFRI Special Circumstances grant, Danieli Salinas, MD, of Children's Hospital Los Angeles and the USC Keck School of Medicine, is developing a wearable "sweat chip" for infants that may serve as a confirmatory diagnostic tool and provide insights into future disease symptoms.

CFRI's research funding provides future promise of new therapies, and a cure. There are many other areas of research to further explore, including: the role of bicarbonate; ENac channel studies; CFTR trafficking and degradation; therapies to break through bacterial biofilms; new treatments for emerging antibiotic-resistant pathogens; and of course, DNA and mRNA editing so as to fix a mutated gene or correct the RNA message.

We are grateful to those who support CFRI's research programs. Together, we can continue our progress and fulfill our promise to improve the lives of those living with cystic fibrosis.

CF Summer Retreat: Outside Expectations Please Join Us! July 30 – August 5, 2017

CFRI's CF Summer Retreat, held at Vallombrosa Center in Menlo Park, California, provides a safe environment for people who share common experiences with CF. This is a fun and meaningful event which enhances positive coping skills and provides social support, information and resources. At the Retreat, you'll find exercise, rap groups, presentations by experts, humor, and more. Adults with CF, their family members, friends, and health care providers are encouraged to attend. Register for whichever days fit your schedule. Rooms are available at Vallombrosa Center; scholarships available. To ensure good health for all, please use proper hygiene practices. All participants and guests with CF must comply with CFRI's Infection Control Guidelines. See www.cfri.org for more information, or call 855.237.4669. Sponsored by AbbVie.



CFRI's Many Voices ~ One Voice CF Advocacy and Awareness Campaign – Uniting Our Community to Protect Vital Healthcare Protections

In 2016, CFRI's Many Voices ~ One Voice provided a means for our community to contact their elected officials to encourage them to improve access to quality medical



care and new therapies. As 2017 dawned, we encouraged our community to educate their representatives about the vital protections within the Affordable Care Act that help our CF – and rare disease – communities,

and to urge them to include these in any subsequent healthcare-related legislation.

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 raise our voices to ensure that our healthcare concerns are addressed. CFRI is proud to be one of the founding members of the new Cystic Fibrosis Engagement Network, along with the 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. Please join us. Together we can have an impact. For more information, please go to our website, and click on the “Advocacy” tab.

2017 Mothers' Day Tea Fundraiser Brings Awareness & Hope!

It is an annual tradition that involves hundreds of people, promotes awareness of cystic fibrosis (CF) around the globe, and ultimately raises nearly \$150,000 to support CFRI's vital services to the CF community. CFRI's annual Mothers' Day Tea has long been a success thanks to the participation of our incredible community.

Please join us as a 2017 Tea Sender! Call the friendly staff at CFRI – we will provide everything you need for this spring's kick-off, including invitations and teabags. Donors give in their honor – and memory – to further CFRI's outstanding research, education and support programs, so as to improve the lives of those with CF.

If you prefer to participate online, invite your friends and family to a virtual tea! Go to



www.cfri.org and click on the “Fundraising” tab to find all the information you need.

There is tremendous hope that a cure will be found, but CF remains the most common fatal genetic disease in the U.S. Please join us as a Tea Sender. Call CFRI at 650.665.7576, email cfri@cfri.org, or sign-up online at www.cfri.org.

SAVE THE DATE

CFRI's CF Community Voices Video/Podcast Series

Monthly Events at CFRI, Palo Alto, CA
Check website for upcoming dates
To download episodes go to
www.cfri.podbean.com

Sponsored by Vertex
Pharmaceuticals, Chiesi USA,
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CF Caregivers Support Groups

Fourth Tuesday of Every Month
March 21 • April 18
May 16 • June 20
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

Please RSVP

CFRI Mothers' Retreat

May 5 – May 7, 2017
Vallombrosa Center, Menlo Park, CA

Register Now!

Sponsored by
Vertex Pharmaceuticals,
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CFRI Community Celebration Event

May 10, 2017
PBM Showroom, Mountain View, CA

Online MBSR Classes

June 22 – August 17, 2017
September 28 – November 16, 2017

CFRI 30th National CF Family Education Conference Soaring to New Heights

July 28 – July 30, 2017
Pullman San Francisco Bay
(formerly Sofitel), Redwood City, CA
Register Now!

See back cover for
speakers and sponsors

CFRI Summer Retreat

July 30 – August 5, 2017
Vallombrosa Center, Menlo Park, CA

Register Now!

Sponsored by AbbVie

For information or to register for
these events, please email
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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: 855.cfri.now

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

July 28 – July 30, 2017

Pullman San Francisco Bay
(formerly Sofitel)
Redwood City, CA

Our 30th annual conference offers outstanding speakers, receptions, support groups, work-shops, and the opportunity to connect with your CF community from across the country. Join us!

Speakers Include:

- Cathy Chacon., RN
- John Clancy, MD
- Luke Hoffman, MD, PhD
- John Mark, MD
- Jay Poole, MS
- Carol Power, RRT, CPFT
- Paul Quinton, PhD
- Kristin Riekert, PhD
- Karen Von Berg, DPT
- Claire Wineland

CFRI-Funded Researchers:

Presentations on Sat/Sun by Researchers from Stanford, UC San Francisco, UC San Diego, University of Southern California, and the Mayo Clinic.



Early Bird Registration: \$185 per person (until 6/28/17)

Regular Registration: \$215 per person (6/29/17 and after)

Registration includes conference meals, reference materials, presentations, receptions, and support groups.

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.

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