

Inflammation in CF: Finding the Balance *By Siri Vaeth Dunn, MSW*

The immune system plays a vital role in responding to inflammation, a critical aspect of CF lung disease. As discussed by Dr. Jennifer Taylor-Cousar during her fascinating and comprehensive presentation, “A Story of Friends, Foes & Happy Mediums: Inflammation in CF,” at CFRI’s 29th National CF Family Education Conference, it can both help and hinder efforts to keep lungs clear and infection free.

Our immune system dictates our reaction to the microbes we are constantly exposed to. “Innate immunity” allows the body to quickly respond to infections and foreign bodies by producing and mobilizing immune cells and proteins, but this rapid response can damage normal tissue due to their lack of specificity. “Adaptive immunity” allows for a more precise response, but can take days or weeks to develop. Ideally, the immune system needs a balance: an overreaction can lead to autoimmune diseases, while a limited reaction can lead to infections and cancer.

In applying this to the CF airway, Dr. Taylor-Cousar noted that numerous studies show that the inflammatory response in the CF lung begins early in life. Many of the infants



The inflammatory response in the CF lung begins early in life.

in the large Australian Respiratory Early Surveillance Team for CF study were found to have “significant pulmonary pathology” at the time of diagnosis through newborn screening. Even within patients whose cultures are free of bacterial infections, neutrophil counts and interleukin 8 levels are elevated.

Researchers seeking an accurate measurement of inflammation levels found that patients with higher levels of sputum inflammation had significantly lower lung function. Another study found that inflammatory markers in bronchoalveolar lavage (BAL) fluid increased with the number of pathogens.

Continued on page 4



Paul Quinton, PhD

CFRI Funded Research: Past Progress and Future Promise — Part 1

By Julie Desch, MD

This is the first of two articles based upon Dr. Desch’s September 2016 Discovery Series presentation. Part one will focus on CFRI-funded research discoveries. Part two will focus on current and future research.

CFRI was founded in 1975 by a group of parents whose children with cystic fibrosis (CF) were not expected to reach adulthood. At the time, there was little understanding of the disease and only minimal supportive therapy was available. Forty-one years later, CFRI has been acknowledged in over 200 scientific publications, having provided almost \$9 million in CF research awards. CFRI-funded research has led to seminal discoveries that greatly contributed to today’s CFTR modulating drugs, and CFRI-funded researchers continue to pave the way in the search for CF treatments and a cure.

Continued on page 4

CFRI Community Winter 2016

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Letter from the Executive Director

Dear Friends,

It is a tremendous honor to lead CFRI, an organization that has meant so much to me for a very long time. Many of you know that I first became involved with CFRI as a volunteer over 26 years ago. As the mother of an adult daughter with cystic fibrosis – who today is doing well after receiving the gift of a double lung transplant – CFRI offered me the power of knowledge and the power of community.

Over the years, CFRI has grown exponentially in every way. In addition to expanding research funding, we have launched and expanded psychosocial support, education and advocacy programs. With only 30,000 people diagnosed with CF in the United States, it is incumbent upon us to draw in our community and to craft programs that meet our unique needs.

In 2017 we will continue to make changes. CFRI's 2017 conference – our 30th year! – will be live streamed in its entirety and available at no cost to individuals with CF. We will be launching a series of podcasts, "CF Community Voices," that will expand our collective knowledge and perspectives on multiple CF-related topics. We are fully committed to being your partner in living, and want to address our community's diverse needs.

As such, if there are programs or services that you wish CFRI would offer to address unmet needs, I'd love to hear from you. If you have any thoughts or ideas to share, please email me at suehlandgraf@cfri.org.

In closing, I know you join me in wishing a fond farewell to Scott Wakefield, CFRI's Programs and Operations Associate, who retired in October. Scott, the father of an adult son with CF, volunteered for many years with CFRI prior to joining the staff.

I wish you a joyous and healthy holiday season.

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,

I hope this note finds you and yours well. As the year draws to a close, I am pleased to report that CFRI has had another very successful year. Financially we are on solid ground, thanks to the support of our corporate partners and community members.

With your commitment to CFRI we were able to expand our service delivery in 2017, increasing our CF Quality of Life programs, funding researchers across the United States, launching an advocacy campaign, and providing numerous educational programs and resources.

Continued on page 5

A Faster Way to Test Drugs: The Research of Jeffrey Wine, PhD

By Valerie Baldwin, MS

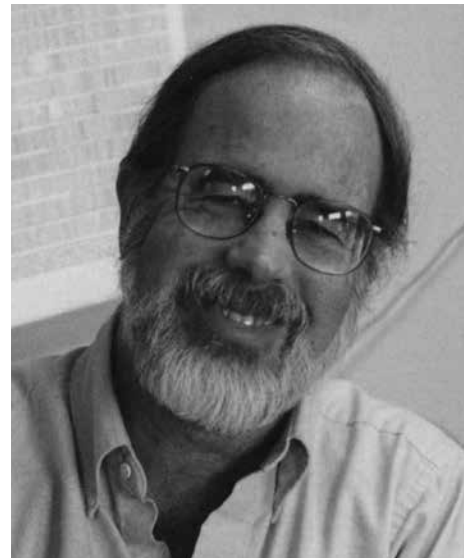
Exciting new drugs that precisely target the underlying cause of cystic fibrosis (CF) are now available, and more are on the way. The faster we can get them to those with CF with specific targeted mutations, the less suffering there will be among those with this challenging disease. But testing new drugs can take years, delaying delivery to those who will be helped. What if there was a faster and more accurate way to circumvent this laborious process? Dr. Jeff Wine believes he has the answer. As he described during his presentation at CFRI's 29th National CF Family Education Conference, Dr. Wine and the team at his Stanford lab – with support from a research award from CFRI – have been studying sweat glands. Because sweat glands in CF do not work properly, can we simply test these glands to see if the patient has responded to a new drug? The “sweat test” has been used for years to determine if an individual has CF. Dr. Wine is ready to move beyond this and expand its use to test the efficacy of new drugs.

The human body evolved to develop a cooling mechanism of pumping water onto our skin that evaporates and keeps us cool. This mechanism is facilitated by sodium and chloride ions – the components of salt – that are reabsorbed for reuse. The protein

CFTR (Cystic Fibrosis Transmembrane Conductance Regulator), which is faulty or missing in those with CF, allows movement of these ions as part of the pumping system that creates the water flow. Those with CF have salty skin because salt is not reabsorbed, and the “sweat test” measures the excess salt.

Fortunately, the sweat gland is not subject to the infections and the many drug interactions within the human body that make measuring efficacy of new drugs in drug trials difficult. Current trial protocols measure changes in FEV (lung capacity), exacerbations, and hospital stays, all of which take time, large amounts of money – and many patients – who are often difficult to recruit.

So what does Dr. Wine's research suggest as the answer? Simply measure changes in the rate of sweat before and after the patient takes a new drug. This was discussed by Dr. Dennis Nielson of UCSF earlier at the conference as an “n-of-one” trial, meaning the patient becomes his own control. Dr. Wine measures bubbles of sweat from specific glands created under a layer of oil on the skin. He has an elaborate setup to achieve this, but a simpler evaporimeter is available that could be used clinically.



Jeff Wine, PhD

Unfortunately rates of sweat from individual glands are variable, so Dr. Wine is currently working to establish a baseline that uses the ratio of sweat generated from a CFTR-dependent cholinergic response (M-sweat) and CFTR-independent adrenergic response (C-sweat).

Dr. Wine's CFRI-funded research shows great promise as an exciting new way to run quick, efficient trials to test new CF drugs, and possibly beyond to test if a patient will be helped by an available drug.

For those interested in the technical measurements used by Dr. Wine in his lab, please watch the video of his talk available on CFRI's Youtube channel: <http://tinyurl.com/jhacgtr>

Jessica Fredrick Memorial CF Research Challenge Circle and Fund



Jessica Fredrick

CFRI's Jessica Fredrick Memorial CF Research Challenge Circle gives generously to inspire others to join the search for new CF therapies and a cure. This year, members of our circle contributed \$80,000 so as to match – dollar for dollar – donations from individuals committed to CF research. Together, these donations generated \$160,000 for CFRI's CF Research Challenge Fund, which will be used for our New Horizons and Elizabeth Nash Memorial Foundation CF research awards.

Please join this inspiring group! Become a member of the 2017 Jessica Fredrick Memorial CF Research Challenge Circle by making a minimum gift of \$2,500. You can make your gift in 2016, and your contribution will be restricted to our research program awards in 2017.

Our Circle is named in memory of Jessica Fredrick, who lost her battle with CF at the age of 21. Despite tremendous progress in CF therapies, we continue to lose our loved ones to this cruel disease, and there is still no cure. We need your help to improve and save lives.

Please give today. If you are unable to join the Circle, please consider making a year-end gift to the Research Challenge Fund, which will be designated for CF research awards. Whichever action you choose, you will inspire our CF community to do more to make the dream of a CF cure a reality.

Inflammation in CF: Finding the Balance

Continued from cover

Anti-inflammatory therapies such as prednisone and ibuprofen are effective but complicated, as they pose safety concerns for many.

Those with CF have been found to have low levels of glutathione, an abundant cellular antioxidant. In a trial of oral NAC (N-acetylcysteine - a by-product of glutathione), the lung function of those taking NAC remained stable or increased slightly, though there was no difference in biomarkers of inflammation. Results from studies of inhaled glutathione have been mixed.

Other trials exploring the impact of replenishing deficient nitric oxide levels in the CF airways using inhaled L-arginine found no change in lung function or sputum inflammation. A study of oral sildenafil in adults with mild to moderate CF lung disease found a statistically significant decrease in mean sputum elastase activity, but no improvement in lung function.

Dr. Taylor-Cousar discussed the “cautionary tale” of leukotriene B₄-receptor antagonist BIIL 284, a drug created to reduce inflammation, but was found during studies to



Jennifer Taylor-Cousar, MD

lower lung function and increase the risk of *Pseudomonas*. Said Dr. Taylor-Cousar, “the use of potent anti-inflammatories in the setting of chronic infection may increase the risk of infection-related adverse events,” adding, “decreasing inflammation without abolishing it is critical.”

Patients most likely to benefit from anti-inflammatories are those with mild lung disease but safety must first be established. Unfortunately, anti-inflammatory therapies often take years to demonstrate effect, yet Phase 2 clinical trials usually last only two to three months. While it is too soon to know with Orkambi, the treatment of CF G551D patients with ivacaftor (Kalydeco) resulted in decreased inflammatory markers. A Phase 2 study with adult CF patients to evaluate CTX-4430 – believed to “tune down the inflammatory response without immunosuppression” – is now enrolling, as is a study of Ultrapure JBT-101 (RESUNAB™), a synthetic endocannabinoid-mimetic that has received Orphan Drug and Fast Track status for CF in the US.

As summarized by Dr. Taylor-Cousar, “Immunity in CF is characterized by too much inflammation, and the insufficient resolution of inflammation.” Despite the promise of CFTR modulators in decreasing the damaging immune response, the development of safe and effective anti-inflammatory therapies is vital. Current trials may “chart the future of anti-inflammatories in CF,” and participation is critical for this pivotal research.

CFRI Funded Research: Past Progress and Future Promise — Part 1

Continued from cover

The earliest CFRI-funded researchers made some of the most significant discoveries in the field of CF. In 1977, CFRI awarded its first grant of \$18,000 to Paul Quinton, PhD, to study “isolated sweat glands in CF.” Dr. Quinton’s contributions to the field are extraordinary. In 1983, six years prior to the discovery of the CF gene, he made the pivotal discovery that the fundamental problem in CF is one of chloride impermeability.

The 1980’s were a time of exciting discoveries for CFRI-funded researchers. Jonathan Widdicombe, PhD, provided the earliest evidence of the CF chloride defect in airway cells and conducted pioneering studies of airway cell cultures and fluid movement in CF airway cells. In 1986, Jeffrey Wine, PhD created his sweat bubble assay, discovered the “heterozygote effect,” and demonstrated for the first time that carriers of CF showed a remarkable effect of their single mutation. This method would later be utilized to measure CFTR function. Dr.

Wine’s discovery that “a little CFTR goes a long way,” has tremendous significance in this era of CFTR-modulators. Thanks to Dr. Wine, we know that minimal CFTR function may be enough to significantly improve the disease expression of a person with CF.



Dr. Wine’s sweat bubble assay

CFRI-funded researcher Alan Verkman, PhD, developed a cell-based assay in 1987 to detect CFTR functionality. He went on to develop a cellular assay to measure chloride transport using a fluorescent probe. This research was instrumental to the high throughput-screening assay used by Vertex to discover ivacaftor.

Also altering the field was an important finding by CFRI-funded researchers Beate Illek, PhD, Horst Fischer, PhD, William Reenstra, PhD, and Terry Machen, PhD, who discovered that CFTR channels could be activated by a tyrosine kinase inhibitor, genistein. This discovery eventually led to the understanding that a “potentiator” could make the CFTR protein coded for by a specific mutation (G551D) function, thereby providing proof of concept for the entire field of CFTR modulation.

In addition to these extraordinary discoveries, CFRI-funded researchers have also addressed the creation of CF cell lines (Gruenert); explored the processing and

Continued on page 5

CFRI continues to fund projects that focus on basic, clinical, and translational CF research. CFRI's Research Advisory Committee is currently in the process of reviewing Letters of Intent submitted by CF researchers nationwide who are seeking funding for 2017/2018. This review is the first step in determining the candidates to be invited to submit full proposals. The new funding cycle will begin in June, 2017 and I look forward to sharing an update in the near future.

I thank you for your steadfast support of those impacted by cystic fibrosis and hope you will join me in helping CFRI to reach even greater heights in 2017. Together, we can accomplish great things.

Peace and good health,



Bill Hult | Board President



CFRI Funded Research *Continued from page 4*

degradation of CFTR (Kopito); the role of inflammation and *Pseudomonas* (Machen, Ruch); the use of CT imaging to detect early lung disease (Robinson); ABPA and CF fungal infections (Moss); biofilms and nitrite sensitivity (Hassett); the CF lung microbiome (Quinn); and new 3D culture techniques to assess CFTR function (Boecking). These and many other significant contributions have significantly advanced our understanding of cystic fibrosis.

CFRI provides its funding nationwide via three granting structures: the Elizabeth Nash Memorial Fellowship (ENMF), the New Horizons Campaign, and Special Circumstance grants. Every proposal is thoroughly vetted by experts in the field in conjunction with CFRI's Research Advisory Committee. These three research programs receive their funding from foundations and individuals like you. With your generous assistance, CFRI can continue to support our CF research and clinical community to improve therapies and find a cure.

In Memory of

September 1, 2016 — October 31, 2016

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If you want your donation to honor or remember someone special, please include the person's name and address with your donation.

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

Please mail your contributions to:

CFRI 1731 Embarcadero Road, Suite 210, Palo Alto, CA 94303

What's New in 2017? ★★★★★★

CFRI is committed to expanding access to its services. In light of cross infection concerns, geographic distance, and the diverse needs of our nationwide CF community, CFRI will launch a new program in 2017, "CF Community Voices," a series of podcasts that will offer a range of information and insights from those impacted by CF. CF clinical research developments, cultural events, mental health, relationships and more will be explored. Stay tuned for more information!

CFRI will celebrate its 30th annual National Cystic Fibrosis Family Education Conference in July 2017. Our theme is *Soaring to New Heights*, and for the first time we will live stream the entire education track of the conference with free access to all individuals with CF. We are thrilled to include our national – indeed international – community in this informative and exciting event.

Our CF Quality of Life programs are transforming lives, and we seek to expand our

current offerings of Mindfulness Based Stress Reduction classes, CF Caregiver Support Groups and financial support for Individual Counseling services. Please stay tuned, as we will post dates and information as we have it.

Our weekly eNewsletter is a convenient way to stay in touch with CFRI's many program offerings and opportunities. If you are not on our email list, please join by calling 650.665.7576 or emailing cfri@cfri.org.

Thank You for Your Year-End Support: Together We Will Continue Our Progress in 2017!

As the end of the year draws near, we hope you will consider CFRI when considering your year-end gifts to those charitable organizations that are important to you. We are fortunate to have a dedicated and caring community that believes in the work of CFRI and supports our mission to fund research, provide educational and personal support, and to spread awareness of cystic fibrosis.

Your end-of-year gift is greatly appreciated and central to the work we do. This year you might think of giving through:

- The enclosed **CFRI Community** remit envelope
- A donation of stocks or other marketable securities
- An online donation at www.cfri.org
- Your company's Workplace Giving program
- A vehicle donation
- CFRI's Special Gifts letter that was mailed to you in November
- Participation as a Jessica Fredrick Memorial Research Challenge Circle or Fund Donor
- The creation of your own fundraiser through our Reaching New Heights Campaign

Whatever you are able to give is greatly appreciated. Depending on the type of gift, you may receive additional tax deductions. It is always prudent to review your charitable gifting with a financial advisor. Thank you for your support this year and for your continued commitment to CFRI's mission in 2017!

CFRI's Counseling Support Is Transforming Lives!

By Siri Vaeth Dunn, MSW

CFRI offers its CF Quality of Life Program in recognition of the challenges faced by those impacted by CF – including the isolation that accompanies this disease. Through this program, CFRI has provided funding for five sessions of individual therapy with a licensed counselor for those with CF as well as their parents, siblings, spouses, and partners. By mid-October, nearly 40 people had participated from 10 states. Two-thirds of program participants are individuals with CF, and one-third are parents. Universally, those receiving services would have otherwise been unable to afford therapy.

The results have been extremely positive. In order to evaluate the program, all partici-

pants commit to completing evaluations which assess depression and anxiety prior to beginning therapy and at the end of the final session. Prior to beginning therapy, 75% of program participants experienced several days of "feeling down, depressed or hopeless." By the end of the final session, 31% of respondents noted this. Over 30% of participants felt that they experienced feeling easily annoyed or irritable every day prior to therapy, while post surveys found that only 6% felt this way. Finally, prior to counseling, 25% of respondents had several days during which they experienced the feeling that they would be better off dead, or hurting themselves (75% said not at all). After therapy, only 6% felt this way, with 94% responding "not at all."



The response to CFRI's counseling support indicates a growing recognition of the importance of mental health services for the CF community. The dramatic impact of this program upon the lives of those directly impacted by CF speaks to the importance of expanding this needed program.

Merriment in the Redwoods ~ An Enchanting Success for CFRI

Merriment in the Redwoods ~ An Enchanting Adventure at Nestltdown was all that and more! Guests enjoyed the breathtaking beauty of Nestltdown, along with gourmet food, wine tasting and music. CFRI expresses warm appreciation to Barbara and Mark Beck, who generously donated the use of Nestltdown for the gala, which raised nearly \$100,000 for CFRI's research, education and psychosocial support programs. In addition to the festivities, we were inspired by the stories of those impacted by the disease, and we honored Dr. Julie Desch with CFRI's 2016 CF Champion Award – in recognition of her many contributions to cystic fibrosis research and the CF community.



Thanks to the generosity of our sponsors, in-kind donors, attendees, and hardworking Gala Committee members, Merriment in the Redwoods ~ An Enchanting Adventure at Nestltdown was a phenomenal success!

Generously sponsored by NBC Bay Area, Vertex Pharmaceuticals, AbbVie, Chiesi USA, Gilead Sciences, and Joel & Francine Bion, with additional support from Novartis Pharmaceuticals, Genentech, John & Bridget Barnes, and Mike & Dea Roanhaus.

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Save the Dates

CF Caregivers Support Group

Third Tuesday of Every Month
5:00 pm – 6:00 pm PST
Parents of Children
6:00 pm – 7:00 pm PST
Parents of Adults
Call in from across the country!
Or attend in person:
730 Welch Road
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Tess Dunn – T3TRA CFRI Benefit Concert

December 28, 2016
Moe's Alley Santa Cruz
AND Live Streamed!
For information:
booking@tessdunn.com

Online MBSR Classes

For those with CF & Caregivers
Stay tuned for 2017 dates!

Embrace – Retreat for Mothers Of Children/Adults with CF

May 5 – May 7, 2017
Vallombrosa Retreat Center
Menlo Park, CA
Registration opens in January 2017
Sponsored by
Vertex Pharmaceuticals,
Gilead Sciences and AbbVie

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

July 28 – July 30, 2017
Sofitel San Francisco Bay
Redwood City, CA
Sponsored by AbbVie

CFRI Summer Retreat

July 30 – August 5, 2017
Vallombrosa Retreat Center
Menlo Park, CA
Sponsored by AbbVie

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CFRI Mission

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

CFRI Vision

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

Visit our website at:

www.cfri.org

for more information about us
and about cystic fibrosis.

Call toll free: 1.855.cfri.now

Reaching New Heights Supporting CF Solutions

Have fun, raise CF awareness and change lives: Host a fundraiser in your community!

The ideas are endless; CFRI will help you to succeed:

- Car Wash
- Neighborhood Yard Sale
- Musical or Theatre Performance
- Walk-a-thon/Cross Fit/Jog-a-thon
- Pet Fashion Show
- Whimsical Tea Party
- Cocktails for a Cure
- Golf Tournament
- Gift Wrap Table
- Holiday Arts & Crafts Boutique
- Silent Auction



CFRI seeks individuals, families, church, school, and work communities to design & host your own unique fundraisers.

Designate your fundraiser for CF Research Awards and all proceeds will be matched 100%!

Contact Mary Convento at CFRI to discuss ideas and how CFRI can support you!

650.665.7559 / mconvento@cfri.org

Let's Reach New Heights & Find Solutions for Those with CF!

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