

Colon Cancer Screening in Cystic Fibrosis

By Jordan Dunitz, MD and Joanne Billings MD, MPH — Adult CF Center, University of Minnesota

Everyone who is touched by cystic fibrosis (CF) – including patients, families and care teams – is encouraged by the dramatic improvement in survival that has occurred in the past few decades. Most patients now live to adulthood, and many to middle and even old age. With improved survival, it is important to anticipate new health challenges that CF patients may face with advancing age. One such concern is colon polyps and colon cancer.

From the 1960s to 1990s there were a number of individual cases of cancer reported in CF patients. In 1995, an analysis of large databases including CF patients from the US, Canada and Europe revealed an increase in cancers of the gastrointestinal (GI) tract including esophagus, pancreas and intestines. More recently there have been numerous reports of colon cancer in CF patients. The risk appears to further increase after lung transplantation. In people without CF, periodic colonoscopy is recommended starting at age 50 in order to identify and remove colon polyps. Polyps are thought to be a precursor for colon cancer, and early detection and removal of polyps appears to

reduce the risk of developing colon cancer.

There is growing evidence that colon polyps and cancer develop earlier in CF patients than the rest of the population. At the University of Minnesota, we have started routine screening colonoscopy in our CF patients starting at age 40. We recently published the results of colonoscopies performed from 2008 – 2015. We had 82 patients who underwent at least one colonoscopy. Half of these patients had at least one polyp. One quarter of the patients had three or



Individuals with CF should consider a colonoscopy by age 40

more polyps. Three patients had colon cancer. Thirty-two patients underwent repeat colonoscopies one to four years after their

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CFRI funds promising CF research nationwide

CFRI Announces \$400,000 for 2017/2018 Research Grants

By Julie Desch, MD

CFRI funds cystic fibrosis (CF) research through the Elizabeth Nash Memorial Fellowship (ENMF) and the New Horizons Research (NH) programs, as well as through Special Circumstance grants. The grant programs fund research nationwide and are vetted by scientific peer reviewers and CFRI's Research Advisory Committee (RAC). These are then ranked by the RAC and approved by CFRI's Board of Directors.

Through the New Horizons Program, CFRI funds projects by principal investigators that are original, probing and/or pioneering a new or improved approach to a therapy or cure for cystic fibrosis. The program also provides seed funding for promising new lines of basic and clinical CF research which show prospects of future funding by other sources, such as the National Institutes of Health (NIH). Funded researchers receive

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CFRI Community Summer 2017

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Letter from the Executive Director

*“Growth is never by mere chance;
it is the result of forces working together.”*

— James Cash Penney

Dear Friends,

I hope this note finds you and your loved ones well. As I shared in our last issue of CFRI Community, CFRI’s 2016 revenues surpassed all previous totals in our 42-year history, providing support to fund the brilliant work of CF researchers across the country, as well as providing services and programs to our nationwide – indeed global – CF community.

This growth was the result of many forces working together, a virtual symphony of caring individuals, businesses, foundations, and corporations who seek to improve and extend the lives of those living with cystic fibrosis.

I am delighted to share that we have a new CFRI team member to help expand this symphony. Tony Adessa, DM, has joined CFRI as our first ever Development Manager, bringing 17 years of development experience, primarily with health-related nonprofits. It is highly appropriate to use a symphonic reference; Tony is an accomplished violinist, and prior to his nonprofit development work he was Chairman of the Music Department and Associate Professor at Wesleyan College in Georgia and Holy Names College in Oakland, California. I hope that you will have the opportunity to speak with or meet Tony in the near future.

These are interesting times in the area of health care policy. Our “Many Voices ~ One Voice” advocacy and awareness campaign is very active. As the national debate continues, we will keep our constituency informed, and encourage you to raise your voice to ensure our community is protected.

Thanks to you, we are united in working to provide the CF community with vital programs and services. Cystic fibrosis remains a harsh and challenging disease. Each one of us plays a key role in the search for a cure. CFRI’s growth is not by chance – it is by virtue of our entire community working together. Thank you for being our partner on this journey.

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,

Hello friends. The year is off to a fantastic start. As our cover article describes in greater detail, CFRI’s Research Advisory Committee (RAC) recently ranked proposals for funding that were submitted by cystic fibrosis (CF) researchers from across the United States and vetted by outside scientific reviewers. The RAC recommendations were presented to CFRI’s Board of Directors, which voted to approve \$400,000 in funding for three new and two ongoing research projects. Our “family” of cystic fibrosis (CF) researchers continues to grow, and it is exciting to see how many preeminent CF researchers have received CFRI funds to support their groundbreaking work throughout the years.

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Colon Cancer Screening in Cystic Fibrosis

Continued from front cover

first colonoscopy. For those patients who had polyps on their first colonoscopy, 81% had polyps on the repeat procedure. Half the patients who did not have polyps on their first colonoscopy were found to have polyps on their second colonoscopy.

Based on our findings, we recommend that all CF patients who are medically stable undergo periodic colonoscopy starting at age 40. Those patients who have three or more polyps or polyps with advanced histopathology (higher risk of cancer) should have a repeat colonoscopy in one to three years. All other patients should have a repeat colonoscopy in three to five years.

For CF patients who have undergone lung transplantation, we recommend the first colonoscopy at age 40 or five years after

transplantation, whichever comes first. We recommend that follow-up colonoscopy follows the same guidelines as CF patients who have not undergone transplantation.

While the timing of a colonoscopy is important, the technique is equally important. Prior to a colonoscopy a patient has to complete a “colon prep.” This washes all of the stool out of the colon so the doctor can get a good look at the walls of the colon. Since CF patients tend to have sticky stool, they need a more thorough prep than patients without CF.

At the University of Minnesota, we have developed a colon prep that has been quite effective but still tolerable according to our patients (see sidebar). If a colonoscopy is recommended and you have CF, please consider reviewing this prep with your doctor. Many of the polyps in CF patients

are found in the right side of the colon. It is important that the doctor performing the colonoscopy is aware of this so that your entire colon is thoroughly examined.

Our understanding of colon polyps and colon cancers in CF is still evolving. It is unclear if the

Colonoscopy Prep for Those with CF

When having a colonoscopy, it is crucial that the inside of the intestine be clean in order to allow a thorough examination of the colon for the presence of any growths and abnormalities, as well as their biopsy or removal. The cleansing process presents an extra challenge in patients with cystic fibrosis. In response, the team at the University of Minnesota has developed instructions specifically designed for individuals with CF who are undergoing colonoscopies. Please type the following URL into your browser to read and download these very useful instructions, which you may wish to share with your care provider in advance of the procedure:

www.cfri.org/pdf/colon.pdf

increase in polyps and cancer are directly related to the cystic fibrosis transmembrane conductance regulator (CFTR), a difference in the bacteria in the CF colon, or some other cause. More research will be required to better understand why CF patients appear to develop polyps and cancer earlier than those patients without CF. As our understanding improves, recommendations for screening may change.



Jordan Dunitz, MD



Joanne Billings, MD, MPH

CFRI's CF Summer Retreat: Outside Expectations July 30 – August 5, 2017

Are you an adult with CF? Do you crave connection with your peers in a safe and welcoming place? CFRI offers an annual CF Summer Retreat at Vallombrosa Retreat Center in Menlo Park, California, that provides adults with CF – as well as their spouses, friends and family members – a wide range of activities including hikes, MBSR, art, rap sessions, and educational workshops with phenomenal guest speakers. Want more? Group-bonding activities include movies, a talent show and comedy night. CFRI's CF Summer Retreat allows you to be with your “tribe.”

For many, the retreat is like coming home each year. In addition to camaraderie, the

Retreat provides strategies to improve psychosocial health, and cope with CF as it impacts one's daily life. As one participant wrote after attending last year, “I love, love, love Retreat and all it's about.”

The Retreat runs from Sunday, July 30th through Saturday, August 5th. Choose to attend whatever days fit your schedule. Please join us in 2017!

The CF Summer Retreat has stringent infection control protocols; all participants must

adhere to CFRI's Infection Control Policy. For more information, go to www.cfri.org. Generously sponsored by AbbVie and Gilead Sciences, with additional support from Kroger Specialty Pharmacy and Allergan.



CFRI Announces Research Grants

Continued from front cover

\$70,000 per year for a minimum of two years, based on Research Advisory Committee review and the submission of financial progress reports on their first year of research.

New Horizons projects in their second year of funding include research by Paul Quinton, PhD, and Guillermo Flores-Delgado, PHD, of the University of California San Diego: “Assessing The Role Of Secretary And Absorptive Epithelium Lining Lung Airways.” In addition, Peter Haggie, PhD, of the University of California San Francisco, will receive a second year of funding to study, “Novel Therapeutic Approaches for Cystic Fibrosis Caused by the W1282x Premature Termination Codon.”

Two principle investigators were selected out of an outstanding pool of seven applicants for the 2017 – 2019 New Horizon funding cycle. Jeff Wine, PhD, and Nam Joo, PhD, of Stanford University received funding to study, “A Novel Approach to Improve Mucociliary Clearance for CF Patients,” with the goal of finding if the synergistic mucociliary clearance and inhibiting fluid absorption have a therapeutic potential and benefit. UC San Diego’s AKM Shamsuddin, PhD, was also selected to pursue his research on the “Pharmacology of CFTR HCO₃ Secretion in

Native Small Airways in Health and Disease,” investigating how HCO₃ is managed by the epithelial cells of the small airways.

An Elizabeth Nash Memorial Fellowship award was granted for a second year to Michael Joyner, MD (Principal Investigator), and Noud van Helmond, MD, a Post-Doctoral Fellow at the Mayo Clinic in Rochester, Minnesota to continue their investigation on, “Improving Drug Delivery in Cystic Fibrosis using Exercise.” The project tests the idea that administering nebulized albuterol, a bronchodilator, during exercise improves drug delivery.

Elizabeth Nash Memorial Fellowship Awards for the 2017 – 2019 cycle were granted to Richard Boucher, MD (Principal Investigator) and Kenichi Okuda, MD, a Postdoctoral Research Associate, at the University of North Carolina at Chapel Hill. Doctors Boucher and Okuda will study, “Localization of CFTR and Secretary Mucins MUC5AC and MUC5B in Human Airway.” Their work will assess the role of the surface epithelium versus submucosal glands for the specific secretion of MUC5AC and MUC5B.

In addition to the New Horizons and Elizabeth Nash Memorial Fellowship awards, Special Circumstance grants allow CFRI to respond to important and timely projects



Julie Desch, MD

that fall outside the timelines of the ENMF and NH programs. Currently, Danieli Salinas, MD, Assistant Professor of Pediatrics and Preventive Medicine at Children’s Hospital Los Angeles and the Keck School of Medicine, is studying, “Sweat Rate Measurement for Confirmation of Cystic Fibrosis Newborn Screening.”

Tremendous progress has been made in the field of CF over recent years, and CFRI-funded research has had a pivotal impact. I look forward to the discoveries that will be made by this group of talented researchers.

News from the Board *Continued from page 2*

Our excellent education, support and advocacy programs are having a significant impact both regionally and nationally. I am proud of CFRI’s work to improve the lives of the CF community, whether it be through retreats, conferences, and counseling support, or by meeting with state and federal decision makers to advocate for governmental actions that will enhance and improve the lives of those impacted by CF.

CFRI’s fiscal management is outstanding, and we were once again honored to receive Charity Navigator’s highest 4-star rating. CFRI is your partner in living. On behalf of the Board of Directors, I thank you for making this possible through your partnership, participation and support.

Peace and good health,

A handwritten signature in blue ink, appearing to read "Bill Hult".

Bill Hult | Board President



Jessica Fredrick

All Donations Made Through This Issue of CFRI Community Matched 100% and Designated for CFRI’s Research Awards!

We are actively raising funds in support of our research awards, which propel innovative cystic fibrosis investigations. Your gift to CFRI – made through this newsletter – will be matched dollar-for-dollar by members of the Jessica Fredrick Memorial Research Challenge Circle and designated for CFRI’s New Horizons and Elizabeth Nash Memorial Fellowship research awards. Please support the search for new therapies and a cure!

In Honor of

February 1, 2017 — April 30, 2017



The Adelman Family
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Nicholas P. Barnes
Makinnon and Marin Baugh
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Rebecca Boyer
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Kori Tolbert
Chris Vallee
Clare Jean Webster
Kareese and Henry
Wilson
Amanda Wood



In Memory of

February 1, 2017 — April 30, 2017

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Gianna Altano
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Beth Arvidson
Victor Baglio
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Louis A. Trigueiro
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Tom Walton
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Maurice Wernli
Hayley Wester

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

CFRI's Moonlight Masquerade

A Gala to Support CF Research, Education, Support & Advocacy Programs

Save the date! CFRI's Moonlight Masquerade will be held Saturday, October 28, 2017 from 6:00 pm to 11:00 pm at the beautiful and historic Hillsborough Racquet Club in Hillsborough, California. Enjoy gourmet delicacies, fine wines and fabulous entertainment while celebrating progress in the field of CF research and therapies. Honor our 2017 CF Champion, Dr. Rick Moss of Stanford, who has had a major impact in the field of CF. Bid in our exciting auction, and end the night on the dance floor. All proceeds are directed to CFRI's research, education, advocacy, and support programs to improve the lives of those with CF.

Cost: \$165 per person / \$300 per couple. Sponsorship packages are available. For more information go to www.cfri.org, or call 650.665.7576.

Generously sponsored to date by Vertex Pharmaceuticals, AbbVie, Chiesi USA, and Novartis Pharmaceuticals.



CFRI and Me: Partners for Life Some Easy Ways to Deepen Your Relationship

- **COME to a CFRI FUNDRAISING EVENT, or hold your own!** Check out our listings at cfri.org, or think out of the box, and we'll help you make it happen 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** offers benefits that can include increased income, substantial tax savings, the 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 talessa@cfri.org.

Save the Dates!

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

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Third Tuesday of Every Month

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Parents/Caregivers of Children

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Parents/Partners/Spouses of Adults

Participate in person or by phone:

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

July 28 – July 30, 2017

Pullman San Francisco Bay

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See back cover for speakers and sponsors

CFRI Summer Retreat

July 30 – August 5, 2017

Vallombrosa Retreat Center

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Siri Vaeth Dunn, MSW at

svdunn@cfri.org

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

CFRI Announces New Organizational Structure



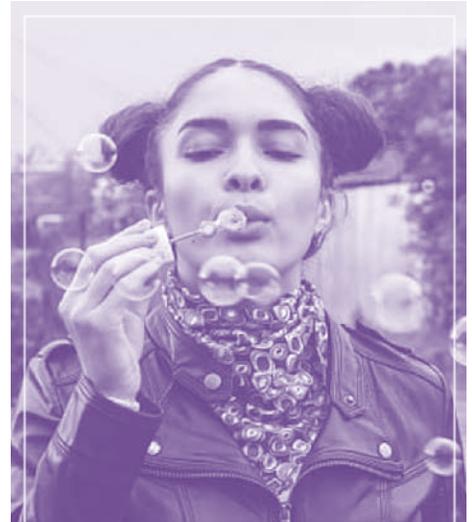
CFRI was formed in 1975 by a small group of parents whose children had cystic fibrosis. At that time, the organization's Bylaws mandated that CFRI be structured as a membership organization. While this structure worked well initially, as CFRI's budget and programs expanded significantly the requirement to have a voting membership increasingly created administrative complications.

In February 2017, the voting members of CFRI submitted ballots to dissolve the membership classes and adopt a self-perpetuating board structure. CFRI no longer has formal

members, but all former members are kept abreast of CFRI programming via CFRI emails, the *CFRI Community Newsletter*, Annual Report, and other communications. CFRI's Board meetings are open, and any person or group may bring questions or concerns directly to the Board in person as well as through communication with the staff, Executive Director or Board members.

CFRI's Bylaws and organizational policies provide a clear system of checks and balances to govern the actions of the Board of Directors and Executive Director regarding the daily operations of CFRI. With this new structure, the Board of Directors' procedure for establishing the organization's budget is streamlined. Most importantly, this change increases the Board of Directors' flexibility to react expeditiously to challenges and opportunities when needed for the benefit of the organization, stakeholders and constituents.

The CFRI community is united in our goal to extend and enhance the lives of those living with cystic fibrosis. CFRI remains your steadfast partner in living.



**New Podcasts
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Hot Tubs and CF – A Note of Caution

By Siri Vaeth Dunn, MSW

For many people, hot tubs represent a healthful way to relax and unwind. But for individuals with medical issues – including those with cystic fibrosis (CF) – soaking in a hot tub can be a risk to one's health. The conditions found in hot tubs – warm temperatures, complex piping systems, aerosolized jets, and high-density usage can contribute to the growth of potentially hazardous pathogens.

The temperatures found in hot tubs are ideal for bacterial growth – most notably *Pseudomonas aeruginosa* and *mycobacteria*. Because of complex piping systems, it is difficult to clean hot tubs effectively. While the use of chlorine is believed by many to curb bacteria, the high water temperature and its aeration through jets have been found to lower the effectiveness of chlorine-based disinfectants. Numerous studies have consistently found *Pseudomonas*

in hot tubs, including isolates that were multidrug-resistant. One study found that *P. aeruginosa* contamination is common even where chlorine concentrations are well above recommended levels, because low-nutrient environments enhanced free chlorine resistance, thereby allowing



P. aeruginosa to thrive. The high-pressure jets found in most hot tubs create a mist of aerosolized particles that can contain easily inhaled bacteria.

Hot tubs do not contain much water in relation to the number of people who use them. If people do not shower prior to entering the tub, they bring their own bacteria and body products into the water, and disinfectants are further diluted.

Does this mean that those with CF should refrain from all hot tubs? This is a question to discuss with your care provider. For those who do enjoy a soak, the regular and aggressive monitoring and cleaning of water is key. High chlorine levels alone have been proven to be ineffective in preventing *P. aeruginosa* growth. The Centers for Disease Control has a list of precautions and recommendations on its website, including the recommendation that pH levels, as well as free chlorine or bromine levels be checked twice daily. Hot tub users are encouraged to use test strips to check the water prior to use.



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

July 28 – July 30, 2017 — Pullman San Francisco Bay, Redwood City, CA

Our 30th annual conference promises to be our most exciting thus far, offering outstanding speakers, and the opportunity to connect with your CF community from across the country through receptions, support groups and workshops. **Join us!**

Speakers: John Clancy, MD (CF Pipeline); Luke Hoffman, MD, PhD (CF Pathogens); John Mark, MD (Adjunctive Therapies); Ray Poole, MBA (CF Cornerman); Carol Power, RT (Respiratory Therapy Options); Paul Quinton, PhD (CF Research Breakthroughs); Kristin Riekert, PhD (CF and Adherence); Karen Von Berg, DPT (CF and Physical Therapy); Isa Stenzel Byrnes, LCSW, MPH (Identity and Belonging)

CFRI-Funded Researchers: Andrey Malkovskiy, PhD (Stanford); Peter Haggie, PhD (UC San Francisco); Guillermo Flores-Delgado (UC San Diego); Paul Beringer, PharmD (University of Southern Cal.); Daniel Salinas, MD (USC/Children's Hospital Los Angeles); Noud van Helmond, MD (Mayo Clinic). **For those attending ONLY the Research Track, please go to our website for details on pricing.**

Continuing Education Units (CEU) Available! Provider approved by the California Board of Registered Nursing, Provider Number CEP12165 for 11.25 CE contact hours. For more information, email Carole Nakamura at cnakamura@stanfordhealthcare.org.

Early Bird Registration: for the full conference (on or before 6/28/17) – **\$185 per person**

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

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

To ensure good health for all, please use proper hygiene practices. All participants/guests with CF must adhere to CFRI's Infection Control Policy.

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

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

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