

New Frontiers In Transplantation: ECMO and the Breathing Lung

By Siri Vaeth Dunn, MSW

Jan, a 22-year-old aspiring teacher with cystic fibrosis (CF), was on the verge of death. She had experienced a pulmonary exacerbation which led to respiratory failure, and she was placed on a ventilator at her care center. Despite intubation, high carbon dioxide levels in her blood put her in a coma, and she was airlifted from out of state to the University of California San Francisco (UCSF) Medical Center. Jan desperately needed a transplant, but the odds were against her: 80% of people her age who are intubated do not survive the wait. Thankfully, due to advances in technology, surgical techniques and medical management, Jan was brought out of her coma, weaned from the vent and put on her feet, ultimately receiving a life-saving double lung transplant. The use of ECMO – extracorporeal membrane oxygenation – as a successful bridge to transplant played a key role in Jan’s survival.

At a recent CF Discovery Series, Dr. Jasleen Kukreja, MD, MPH, Surgical Director of UCSF’s top-ranked Lung Transplant Program, discussed exciting innovations in lung transplantation. As described in fascinating detail, the use of ECMO and the science-



Jasleen Kukreja, MD, MPH

fiction-like “breathing lung” technology offer hope to those who would otherwise not survive the wait to transplant.

For those with end-stage CF lung disease, lung transplantation remains the only option to extend life. Approximately 200 people with CF receive a double lung

transplant in the U.S. each year. Unfortunately, up to 20% of patients nationwide die while waiting. The shortage of viable lungs remains a significant issue. Over 80% of donor lungs are currently deemed not suitable for transplant for a variety of

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Reid D'Amico

Biomedical Engineering and Cystic Fibrosis: The Wave of the Future

By Reid D'Amico, BSE, National Science Foundation Graduate Research Fellow

I was 17 years old when I chose my career. My family and I were watching *60 Minutes*, when the words “engineering” and “medical” caught my attention. At the time, the fields of medicine and engineering were two separate entities; isolated paths for either physicians or people who build structures and machines. It was the summer before my senior year of high school, and I actively avoided thinking about college applications – and especially my potential major. As I watched the segment, however, I found myself dumbfounded. How could someone actually employ engineering to understand and cure disease? After that TV segment, I immediately began my research. As a high school student, I won awards at international science and engineering fairs because of my great love for building gadgets from scratch, but even my hydroelectric turbine and plant microbial fuel

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CFRI Community Summer 2016

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Letter from the Executive Director

Dear Friends,

In the CF world, we know that we cannot take even one breath for granted. We are fortunate to have formed a community in which we can lean on each other and help those in need take that literal and metaphorical breath. Members of our CF family have faced serious health crises and tragic losses these past months, and it is heartening to see our community band together to help and provide hope for the future. For nearly 41 years, CFRI has been honored to work in partnership with you. Together, we accomplish great things.

This year, CFRI is in a position to reach beyond our community to bring awareness of the disease – and its myriad challenges – to the general public and legislative decision makers. Working with you, we can have a stronger voice in state and federal issues that adversely impact the lives of our loved ones. We welcome your involvement in our new “Many Voices ~ One Voice” CF advocacy and awareness campaign as we tackle roadblocks to a healthier life with CF. When you receive action alert messages from us, please do respond. Together, our voices will make a powerful difference!

As we heighten public awareness of cystic fibrosis and its challenges, together our community will work to find solutions to problems, share in the challenges, and rejoice in the victories, whether big or small. As we work toward this goal, we will not lose sight of our vital programs that make a positive difference in the daily lives of our community: our 1:1 free counseling program, CF Caregivers Support group, online Mindfulness Based Stress Reduction classes, National CF Family Education Conference, Discovery Series, Retreat for Mothers of Children & Adults with CF, and the CF Summer Retreat for adults with CF. Our publications provide education, research and support information, while offering opportunities to support CFRI, including our lovely Mothers Day Tea fundraiser and annual fall Gala. We are your partners in living!

All of us at CFRI are eternally grateful for your support, as it allows us to reach out, grow, and provide programs and a voice for our caring and resilient CF community.

Warmly,



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



Sue Landgraf

News from the Board

Dear CFRI Community,

I hope this finds you well. The last quarter has been filled with activity on all fronts. Following CFRI's Strategic Plan goal, “Supporting innovative basic research that leads to an increased understanding of the disease and enables novel therapeutic approaches,” we revised our research award programs and increased funding amounts and timeframes for the Elizabeth Nash Memorial Fellowship and New Horizons Campaign. Our “family” of cystic fibrosis (CF) researchers, which includes some of the most renowned researchers in the field, continues to grow. CFRI's Board of Directors approved \$440,000 in research



Bill Hult, President

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cfri | Summer 2016

Many Voices ~ One Voice: CF Advocacy and Awareness Campaign

By Siri Vaeth Dunn, MSW

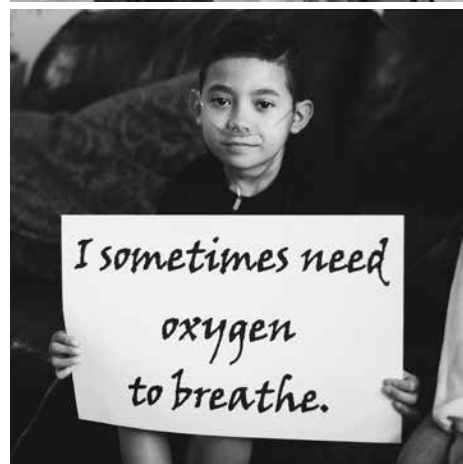
Imagine after watching your child suffer the effects of cystic fibrosis (CF) – the most common fatal genetic disease in North America for which there is still no cure – you learn that the FDA has approved medication that could save your child’s life. Now imagine your child is denied access to this medicine by your state’s insurance program. What would you do?

Unfortunately, this situation is increasingly common, as states and insurance companies wrestle with the cost of medications and therapies that are a matter of life or death for many people with CF. As an orphan disease – one that impacts less than 200,000 people in the U.S. – cystic fibrosis often falls through the cracks when it comes to policy decisions and research funding. In response, CFRI is proud to launch a new cystic fibrosis advocacy and awareness campaign, “Many Voices ~ One Voice,” which will bring issues that are vital to the CF community to the attention of the general public, as well as to elected officials who make decisions which directly impact access to medical care and medications.

As part of this campaign, our community members and supporters receive updates and action alerts from CFRI on policy issues where our input is critical. Participants can easily send letters online directly to their elected officials at both the state and national level. In addition, CFRI organized successful letter-writing campaigns which led to the designation of May as Cystic Fibrosis Awareness Month in multiple states. Moving forward, we need you to add your voice!

Living with cystic fibrosis can be painful, time consuming, debilitating, expensive, and heart breaking. Those who have the power to expand access to medications and quality care need to hear from those of us who are living with and impacted by this cruel disease. Our many voices – united as one voice – will have a powerful impact. Please join us!

To participate in the Many Voices ~ One Voice Campaign, please visit our website and click on the Advocacy link.



Biomedical Engineering and Cystic Fibrosis

Continued from cover

cells paled in comparison to the awe manifested in those few short minutes. That same summer night, I decided that I was going to pursue medical research, or more specifically, was going to be a biomedical engineer. My hardwiring for math and science was not only the foundation of this great revelation; it was also personal, for at age 11, I was diagnosed with cystic fibrosis (CF).

I graduated from Duke University in 2015, where I studied Biomedical Engineering with a focus in Tissue, Cellular, and Molecular Engineering. I then started my PhD in Biomedical Engineering at Vanderbilt University. My drive comes from my experience with my disease. As a CF patient, I can’t help but let my thoughts interact with the daunting disease that leaves me contemplating how fragile life can be. However, despite its harm, cystic fibrosis is where I plan to harness my power. As I

venture deeper into my PhD, I will be able to apply my personal experiences with cystic fibrosis to the field of pulmonary medicine.

As someone with CF, it is hard to research the disease that inspired my passion years ago. It is beyond the mental battle of CF; it’s the unfortunate reality that studying CF may expose me to pathogens that could leave my lungs in danger of severe infection. To counter this, I have chosen to study another lung disease: pulmonary hypertension.

Pulmonary hypertension is a progressive and fatal illness of the blood vessels in the lung. The constant remodeling of the small arteries elevates the pressure in the lungs, increasing the workload on the right heart until it eventually fails. This field of research allows me to directly manipulate cells and tissues without the worry of getting sick. As an engineer, I write codes and programs that can sort and manipulate large amounts of data. I can unearth complex correlations and associations that can be used to develop the next generation

of medications and diagnostic protocols to better treat patients. My background also gives me the opportunity to incorporate mechanical testing of biological tissue to further understand how molecular targets interact with the cytoskeleton to repair or remodel defects at the cellular level. This skill set will continue to evolve until I can one day research cystic fibrosis as a professor of a lab, and mentor students who can handle CF tissues. Together, we can safely work towards a cure for cystic fibrosis.

Engineering is changing how we approach treatments for those with diseases like cystic fibrosis. With potential to incorporate math, coding, and complex system analysis, engineering illuminates a new hope to those with conditions that are currently beyond repair. Until recently, therapies used for CF aimed to manage the condition through an arsenal of medications. However, with the growing presence of engineering in medical research, we will gain new insight into the avenues that can cure diseases like cystic fibrosis.

New Frontiers In Transplantation

Continued from cover

reasons, including poor organ function and donor medical history. Tragically, viable lungs are often unusable due to geographic distances, as organs cannot be kept long on ice. This shortage leads to a long wait, during which many CF patients face a health decline requiring intubation, often making them ineligible for transplant.

As described by Dr. Kukreja, the longer a person stays on a ventilator “in a stuporous



state,” the worse the outcomes. The goal for Jan – and other patients in her situation – was “to have a walking, talking, exercising patient,” awake, aware, and off the vent. ECMO, a modified heart-lung machine that pumps and oxygenates a patient’s blood, thereby allowing the heart and lungs to rest, played a key role in achieving this goal.

UCSF was one of the first to use ECMO and is a leader in successful outcomes. According to Dr. Kukreja, between 2003 to early 2016, 509 lung transplants were performed at UCSF, of which 37 patients started on ECMO and 32 were successfully bridged to transplant. Of CF patients at UCSF who utilized ECMO – i.e. were in grave condition – 93% survived one year, and 83% were alive after three years. These rates,

noted Dr. Kukreja, are better than those for non-ventilatory supported patients in the rest of the country.

Patients cannot remain on ECMO indefinitely; the longest a UCSF patient has been on the device is 39 days. While age is “a moving target,” contraindications include multi-system failure, bleeding disorders, bloodstream infections, and low platelet levels. Patients with single system failure are good candidates. As ECMO is increasingly seen as a life-saving bridge to transplant, more hospitals are incorporating the technology into their centers.

The hope for every patient listed for transplant is that donor lungs will arrive quickly. Because the number of suitable organs “cannot keep pace with need,” researchers and clinicians hope to utilize breathing lung technology to expand the pool of viable lungs.

Currently, donor lungs are chilled, packed in ice and transported to the transplant center.

Noted Dr. Kukreja, “We hope when we bring organs back that they will work as they did in the body, but we have no way to assess this. We just keep our fingers crossed.” Breathing lung technology, first developed in 2007 by Swedish physician Stig Steen MD, PhD, changes this. Using the Organ Care System (OCS), lungs are maintained at body temperature and kept alive by infusing them with warm blood and oxygenating them via ventilator. This technology allows doctors to treat poorly functioning lungs with antibiotics, perform a bronchoscopy, and monitor peak inspiratory pressure, pulmonary vascular resistance, and peak flow ratio, “so that we know exactly what type of organ we are putting into a patient, and

how the lung is functioning.” Importantly, “breathing lungs” can be kept alive for 17 hours, providing more time to assess their condition as well as to transport them across larger geographical distances.

Currently the breathing lung is only available as an investigational device for clinical trials. The INSPIRE trial, which compared breathing lungs versus “standard of care” (i.e. packed in ice) lungs was completed last year. Dr. Kukreja, who participated in the study, noted that all lungs used in the INSPIRE trial were viable, “good” lungs. Data is currently being analyzed and the results, to be published soon, “should be very exciting.” A single-center non-randomized trial at Toronto General Hospital comparing outcomes for recipients of “marginal” lungs treated with breathing lung technology, with those who received standard of care viable lungs found that the marginal lungs performed better than the viable lungs, and there was no difference in survival rates.

Currently, there are several prospective trials both in and outside of the U.S. looking at breathing lung technology. The largest study, the international EXPAND trial, is looking at outcomes for marginal lungs that would otherwise be turned down, to see if they improve by use of the breathing lung device. If verified, the results would expand the number of available organs, thereby saving the lives of those who would otherwise not survive the wait for transplant.

Transplantation offers those with end-stage CF a second chance at life. With advances in transplantation technology, it is hoped that more people – like Jan – will have the opportunity to breathe freely with the gift of new lungs.

To watch Dr. Kukreja’s presentation, go to www.youtube.com/watch?v=-GHQW0ERxZ4

News from the Board

Continued from page 2

funding for 2016-2017 to support innovative researchers at four institutions, including the Mayo Clinic.

Our excellent education and support programs are expanding to further meet the needs of our community. We are also focusing on another Strategic Plan goal, “Heighten public awareness of cystic

fibrosis and its challenges.” Working with you and decision makers across the nation, CFRI will increase awareness of CF and advocate for legislative/governmental actions that will enhance and improve the lives of those diagnosed this challenging disease.

As the enclosed Annual Report shows, our financial health is superb, and we continue to increase our revenue yearly to meet the

needs of our community. On behalf of the Board of Directors, I thank you for making this possible through your partnership, participation and support.

Peace and good health,

Bill Hult | Board President

In Honor of

January 1, 2016 — April 30, 2016



Adam Aliotti	Jennifer Cannon, NP-C	Sean Gallagher	Courtney Hollis	Paul Mohabir, MD	Kandra Smith
The Altanos	Lauren Colonna	Mark Gerow Family	Michelle Jones	Tristan O'Neill	Ethan Spain
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Colby Babcock	Lauren Cooper	Bradly Guaydacan	Beckett Kelly	Carol Powers, RRT, CPFT	Jake Swanson
Haleigh Baker	Cameron Cornell	Sonya Haggett	Eleanor Kolchin	Robyn Primack	The Retreat Committee
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Jack Boyd	Wilson Family	Joshua Holdaway	Stacy Melle	Jackson Senra	Jeff Wine, PhD
Rebecca Boyer	Victoria Flamenco	Vicki and Richard	Linda Meyer	Rachel Silver	Denise Wold
Brian Burks	Emily Fredrick	Holgate	Hannah Mitchell	Anna Simos	Amanda Wood

In Memory of

January 1, 2016 — April 30, 2016



Kimberley Adelman	Mary-Jane Burroni	Erby George III	Timothy Laufenberg	Danny and Kevin	Joseph Sinnaeve
Marcus Adelman	David Cardana	Mary Lee Hagen	Dawn Longero	O'Brien	Jonathan Skinner
Jack Aiello	Sonya Chartrand	Robert Haggett	Annie Lundahl	James O'Brien	Tammy Smerber
Gianna Altano	Melvin Clary	Kathleen Halsey	Krista Malone	Ed O'Reilly	David Stuckert
David Armknecht	Cassandra Cochran	David Hardy	Lucy Marsh	Michele Olson	Laurie Stuckert
Jodi Armknecht	Marty Detrick	Henry Helmers	Nahara Mau	Jennifer Ortman	The Thibault Children
Victor Baglio	Anthony Diprofo	Gay Henderson	Jamie Smolin	Laura Osterloh	Dr. Tongue
Ann Baldwin	Jason Dolan	Charlene Hensley	McDonald	Lisa Pearne	Jake Trezza
Ronald Baldwin	Kerri Efrd	Nicholas Hollis	Alison Minshall Nagy	Erin Phillips	Louis Trigueiro
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Irvin Beltrame	Maria Izabel Fajardo	Melody Johnson	Loretta Morris	Kaylee Reed	Tom Walton
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Amy Bienenstock	Jessica Fredrick	Kitty Kious	Ross Mosier	Tim Schenck	Tara Weir
Gene Boswell	Laura Gale	Lori Kipp	Anne Marie Murphy	Heidi Schroeder	Cynthia Witman
Marion Bourque	Aaron Gallagher	Wanda Langley	Elizabeth Nash	John Sentman	Gayle Woelffer

Tributes

Our "In Honor of" and "In Memory 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



Jessica Fredrick Memorial 2016 CF Research Challenge Circle and Fund: On the Hunt for a Cure

Cystic fibrosis (CF) is the most common fatal genetic disease in the United States. While new therapies are enhancing the lives of many, the harsh reality is that CF has no cure, and continues to claim the lives of those who battle this debilitating disease. Without funding for innovative CF research, the cure will continue to elude us, and members of our community will still suffer.

With the leadership of our Jessica Fredrick Memorial CF Research Challenge Circle, and the generosity of those who contribute to the Jessica Fredrick Memorial CF Research Challenge Fund, CFRI will expand its research funding.

We need your help. Please donate to the Jessica Fredrick Memorial 2016 CF Research Challenge Fund. Unless otherwise notified, all gifts received through this newsletter will be matched by the Circle and used to fund the New Horizons, Elizabeth Nash Memorial Fellowship and Special Circumstance CF researchers.

Donate today, and join us as we hunt for a cure.

To contribute to the Jessica Fredrick Memorial 2016 CF Research Challenge Fund, supporting our CF researchers, please call 650.665.7559, or email cfri@cfri.

Julie Judge's Enduring Legacy

CFRI mourns the recent passing of Julie Judge, mother of Peter and Kathy, who lost their lives to cystic fibrosis (CF). Julie honored her children by creating the "CF Quality of Life Program, a Living Legacy of Peter and Kathy Judge," now overseen by CFRI, which helps to fund counseling and other support services that enhance the

quality of life of those with CF. Julie Judge and her family lived with the many challenges presented by CF, and it speaks to her strength of character and compassion that she founded a program that addressed the need for psycho-social support for the CF community. We will remain forever grateful for her foresight and dedication.



B E C O M E A C F R I P A R T N E R I N L I V I N G

- **ATTEND A CFRI FUNDRAISING EVENT OR HOLD YOUR OWN!** Whatever your interest, we have an event for you! In addition to our Nestltdown event, we have concerts, golf tournaments, and other opportunities. Or come up with an idea and we will support you.
- **TRIBUTES IN HONOR OF AND IN MEMORY OF** Any gift to CFRI can be made in honor or in memory of a loved one. Your loved one's name will appear in our newsletter; if requested, an acknowledgement will be sent to the person you designate.
- **GIFTS OF STOCK TO CFRI** Giving a gift of appreciated stock to CFRI is easy and rewarding. You do not pay capital gains tax on stock that has appreciated over the years, and you will receive an income tax charitable deduction for the fair market value of the stock on the date of the gift.
- **CHARITABLE PLANNED GIVING** Planned giving offers benefits for donors that often include increased income and substantial tax savings, while providing the opportunity to meet your philanthropic goals and provide 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.

Merriment in the Redwoods An Enchanting Adventure at Nestldown



Sunday, September 11, 2:30 pm – 7:00 pm

Join us at Nestldown, a hidden gem above Los Gatos, California, for delightful entertainment, gourmet food, extraordinary wines and libations, and an exciting auction. Discover the whimsical Enchanted Cottage, Medieval Garden, amusing topiaries, and secret benches amongst the redwoods. Be inspired by a moving tale of life with CF, while honoring the 2016 CF Champion award recipient. For those wanting to play, Bocce ball awaits, as does life-sized chess, giant jenga and a playful train.

All proceeds raised at this magical event will support CF research award programs. Tickets are \$200 per person. Exciting sponsorship opportunities are available. For more information, please contact Siri Vaeth Dunn (svdunn@cfri.org), or call 650.665.7576.

CF Summer Retreat “Blockbuster: Live in 3D!” Please Join Us! August 16 - 21, 2016

Bubble ball soccer, U-Jam, support sessions, educational presentations, camaraderie, good food, healing, and laughter: find all this and more at the CF Summer Retreat, held at Vallombrosa Retreat Center in Menlo Park, California. The retreat provides a safe environment that enhances positive coping skills, social support, and education for people who share common experiences with CF. 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 also 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 1.855.237.4669



Save the Dates

CFRI’s 29th National Cystic Fibrosis Family Education Conference

July 29 – July 31, 2016
Sofitel San Francisco Bay
Redwood City, CA
Register Now!

CF Benefit Golf Tournament at Pasatiempo

August 1, 2016
Pasatiempo Golf Club
Santa Cruz, CA
Contact CFRI for details

CFRI Summer Retreat

August 16 – August 21, 2016
Vallombrosa Retreat Center
Menlo Park, CA
Register Now!

Sponsored by Gilead Sciences

Merriment in the Redwoods An Enchanting Adventure at Nestldown

September 11, 2016
Los Gatos, CA
Buy your tickets now!

*Sponsored by
Vertex Pharmaceuticals,
AbbVie and Chiesi USA*

CF Caregivers Support Group

Fourth Tuesday of Every Month
7:00 pm – 9:00 pm PST
*Call in from across the country! Or
come to CFRI’s office, Palo Alto, CA*
*Sponsored by
Vertex Pharmaceuticals*

Online MBSR Class

For those with CF & Caregivers
Summer 2016 Dates to be Announced
Register now!
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Vertex Pharmaceuticals*

CF Discovery Series

Sept. 13, 2016, Oct. 11, 2016
and Nov. 8, 2016
6:00 pm – 7:00 pm PST
CFRI Office, Palo Alto, CA
Livestreamed to the nation!
*Sponsored by
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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

CFRI's 29th National Cystic Fibrosis Family Education Conference

Riding the CF Wave

July 29 – July 31, 2016

Sofitel San Francisco Bay • Redwood City, CA

Our annual conference brings together experts in the field of cystic fibrosis (CF) to provide the latest updates in research and care to our diverse CF community.

Speakers Include:

Ginny Dieruf • Jordan Dunitz, MD
Raksha Jain, MD • Dennis Nielson, MD, PhD
Matt Porteus, MD, PhD • Jeffrey Wine, PhD
Alexandra Quittner, PhD • Emily Schaller
Jennifer Taylor-Cousar, MD

Early Bird Registration (on or before 6/28/16)
– \$185 per person

Regular Registration (6/29/16 and after)
– \$215 per person

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

Research Track Only Registration
– \$125 for Saturday & Sunday, including lunches
– \$75 for one day, including lunch



Research Track Speakers Include:

Carolyn Boecking, MD • Andrey Malkovskiy, PhD
Danieli Barino Salinas, MD • Yan Wei Lim, PhD
AKM Shamsuddin, PhD • Michael Tracy, MD

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 specifics.

For more information, visit www.cfri.org or call 1.855.cfri.now

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

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