

Cystic Fibrosis Center of Excellence

Emory University - Children's Healthcare of Atlanta - Georgia Tech

Volume 11, Issue 1

April 2021

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Dear friends, patients, families, and colleagues,

We hope this finds you well and staying safe as our nation climbs out of the pandemic times that have impacted us so greatly.

We are pleased to provide you today with the next CF@LANTA e-newsletter. We have a great deal to tell you!

Of course, many will be wondering how our research programs have been impacted by the COVID-19 pandemic. I'm happy to say that all of our lab teams continue to move forward in the fight to understand, control, and cure Cystic Fibrosis. Most of our labs were either partly or fully shut down during the summer of 2020, as our institutions scrambled to put in place safety precautions that remain active now. We were mostly home, analyzing data, writing papers and grants, and learning to love/hate Zoom. Fortunately, in the fall we were able to get back close to full activity. Some supplies and reagents became hard to find, or have been on back-order for months. But nothing, not even a pandemic, can hold us back from our important work in CF.

In February, we submitted a proposal to the CF Foundation to renew our "Research Development Program" (RDP) grant. This proposal brings a focus entirely on pulmonary aspects of CF, complementing the NIH P30

grant that we were awarded last September (described in the most recent e-newsletter), which has a non-pulmonary focus. We will hear soon whether that proposal is funded. I am grateful to several colleagues at Emory and Georgia Tech, whose contributions enabled the RDP proposal to be quite exciting and compelling in the end.

In this e-newsletter, we begin to introduce you to the members of the CF@LANTA Community Advisory Board. These are supporters with connections either to CF or to one of our institutions, or both, who are working to take our story out into the public. They also advise us on new directions for the Center, and how we can position ourselves to be something of which all Atlanta can be proud. On page 4, you will meet Mr. Ric Geyer, a long-time supporter and friend, whose work in Atlanta and Macon has had great impact on those communities. We also introduce you to new Emory faculty member, Dr. Dio Kavalieratos, and tell you about a really exciting initiative that ties our researchers and clinical teams together like never before: the Georgia CF Data Warehouse. Finally, I am pleased to introduce you to our new Program Manager, Mrs. Lilly Meier (see photo). Lilly has been working with us part-time for several months, and has been a fantastic addition to the team. She serves as the point of contact for our research groups, for philanthropy, and for managing Center activities.

We send you the very best wishes, and gratitude for your continued interest and support.

~Nael A. McCarty, PhD,
Director,
CF@LANTA



Georgia CF Data Warehouse

Since 2010, the Emory + Children's CF Center of Excellence has been collecting samples (such as blood, sputum, and bacteria from respiratory cultures) from its cohort of more than 700 cystic fibrosis patients. These samples are used by CF research scientists to conduct experiments aimed at uncovering basic mechanisms of CF disease and have generated large amounts of biologic data. Clinical teams also have been collecting clinical data from CF patients each time they go in for a routine clinic visit or are hospitalized. The two sets of data—research data from patient-derived samples and clinical information—when combined, have the potential to reveal invaluable longitudinal information about the progression of cystic fibrosis.

However, the data currently live separately, and are not easily combined. In order to connect them, CF@LANTA, in collaboration with Emory, Children's and Georgia Tech, has set out to design and build a high-quality cloud-based infrastructure (called the "Georgia CF Data Warehouse") that will support the integration of research data and clinical data.

Here's the catch: there is no other CF data warehouse like this, and so our team has nothing to model after. Everything is being designed and built by our team from scratch.

The foundation for the Georgia CF Data Warehouse began with the establishment of the CF Biospecimen Repository (CF-BR) in 2010 by Nael McCarty, PhD, which is now led by Arlene Stecenko, MD. The goal of the CF-BR is to collect patient-derived samples and provide them to CF scientists for CF-related research. Ninety percent of CF patients followed at the Children's + Emory CF Care Center participate in the CF-BR. Participants range in age from 3 months to 77 years and many provide multiple samples per year. Over the past five years, the CF-BR has provided more than 2,600 samples to 27 labs, primarily at Emory, Georgia Tech, and the University of Georgia. In addition to the data from those samples, the Georgia CF Data Warehouse aims to seamlessly integrate countless clinical data points, all of which will be kept safely behind an impenetrable firewall.

The Georgia CF Data Warehouse will work somewhat like an ice cream parlor. Those who are interested in studying the data collected from the Children's + Emory cohort will have access to a dashboard (or "menu") of what data lies in the Warehouse. For clinical data, there will be a broad

description of the people with CF who we treat - age ranges, mutations, medications, conditions, and more. For the research data, there will be rich descriptions of study results as well as the focus of each CF research lab – this function is aimed at building upon each other's successes and also fostering collaboration. From there, researchers will consult with a very small group of biostatisticians and clinicians who have access to the secure data in the Warehouse ("Warehouse Personnel.")

The Warehouse Personnel will then go in and collect the data desired by the researcher and present it as code, completely scrubbed of patient-identifying information. From there, investigators will analyze the data to improve outcomes for CF patients, increase their quality of life, detect disease in earlier stages, and explore personalized interventions.

The key to the Warehouse is the patients. Patients and their families who allow us to store their information securely in the Warehouse will pave the way for the better care of CF patients in the future. Their contributions will help treat and prevent CF-related diabetes and *Pseudomonas* infections. They will help researchers determine the healthiest CF diet and the best way to treat pulmonary exacerbations. The patients that help us fill the Warehouse with CF data will change lives.

The Warehouse is quickly moving beyond the concept phase, and is now in the hands of experienced biotechnicians, clinical informaticians, and data scientists who are building the complex programming needed to store the data. The architecture is being designed, and soon, the first pilots for the Warehouse will begin.

This project is supported by awards from the NIH and the Cystic Fibrosis Foundation, as well as a generous donation from the Hertz Family Foundation. If you are interested in supporting this project, please email Dr. Arlene Stecenko.

Georgia CF Data Warehouse Key Personnel:

Arlene Stecenko, MD, Emory. Director
 Sam Brown, PhD, Georgia Tech, Co-Director
 Yifei Wang, PhD, Georgia Tech, Data Scientist
 Lance Waller, PhD, Emory, Director of the Strategic Data Science Initiative at Emory and Consultant to the Warehouse
 Rushi Kamaleswaran, PhD, Emory, Bioinformatics Specialist and Data Scientist

For more information, please contact Dr. Nael McCarty or Dr. Arlene Stecenko.

A New Collaboration - CF Palliative Care

Dio Kavalieratos, Ph.D., joined the Emory University School of Medicine as Associate Professor and Director of Palliative Care Research in March 2020. Dr. Kavalieratos is a health services researcher, whose work focuses on how to improve outcomes for people with serious life-limiting illnesses, through the development and testing of clinical models of palliative care services. In other words, how can health care services be created and organized to promote quality of life and reduce suffering for people with serious illnesses. Palliative care is a clinical specialty that focuses on relieving the multifaceted burdens of serious illness and improving quality of life for patients and their families, at any stage of illness. Palliative care includes expert symptom management, psychosocial and spiritual support, and goals of care elicitation.

Dr. Kavalieratos co-leads the CF Foundation's Committee on Palliative Care in Cystic Fibrosis, which coordinates guideline development, research, and outreach work for the Foundation regarding serious illness. In 2020, Dr. Kavalieratos was first-author of the CFF's evidence-informed guidelines on integrating palliative care into usual CF care, including training in basic aspects of palliative care for CF team members and regular assessment of unmet palliative needs. Currently, the Committee is starting work on new guidelines to address pain management for people living with CF.

In addition to his own research program, Dr. Kavalieratos was recruited to develop a university-wide community of scholarship regarding serious illness research, as well as mentor trainees of all levels in palliative care research. Dr. Kavalieratos has expertise in qualitative and mixed methods research, systematic review and meta-analysis, complex interventions, clinical trials, and implementation science. Dr. Kavalieratos earned his PhD from the University of North Carolina at Chapel Hill, then completed a postdoctoral fellowship at the University of Pittsburgh School of Medicine, where he then joined the faculty until coming to Emory. In 2019, Dr. Kavalieratos was the first non-physician to be awarded the Early Career Investigator Award from the American Academy of

Hospice and Palliative Medicine.

With funding from the CFF, Dr. Kavalieratos's InSPIRe:CF study is the first multi-site clinical trial to compare adding specialist palliative care to regular CF clinic care. At Emory and four other CF clinics across the USA and Canada, more than 250 adults with CF and their caregivers are being enrolled to receive either usual care or usual care plus quarterly visits with a palliative care specialist to address symptom burden, side effects of treatment, psychosocial concerns, and other topics. The model was first tested in a pilot study at the University of Pittsburgh (also funded by CFF), and showed feasibility, acceptability, and potential efficacy. Emory collaborators include Randy Hunt, MD, Kimberly Curseen, MD, and Lynn Sparks, CRNP.

Prepared in collaboration with:

Dio Kavalieratos, PhD
Associate Professor
Department of Family and Preventive Medicine
d.kavalieratos@emory.edu



Ric Geyer—Social Impact

We are pleased to introduce you to one of the long-standing members of our CF@LANTA Community Advisory Board, Mr. Ric Geyer of Macon, Georgia. Ric is a CF father and a beloved member of our community, known for his dedication to finding ways to improve our cities in ways that benefit many. Ric and his son, Ricky, also were integral to the “HackforCF” hackathon that we led in 2013.

After receiving his MBA from the Wharton School, Ric spent the next 25 years immersed in two different worlds: professionally, that included 10 years at Ford, another 10 years at Deloitte Consulting, and then another 5 years working in Mayor’s offices in Detroit and Atlanta. But his other world was in volunteering and the arts. Ric was introduced to volunteering by an infamous Detroit bar-owner, “Honest” John Thompson, who called him early one morning to deliver a load of turkeys to churches, orphanages and homes in the area who needed food. “That was eye-opening for me. I went into some pretty bad spots and found nothing but smiles and positive responses in every situation.” That got him hooked on volunteering.

Eventually, he decided to see if he could make a difference on his own. So, he bought a vacant building in a blighted neighborhood on Detroit’s near-west side with the intent to create a wood and a metal shop and find some artists and neighborhood folks who needed work. One thing led to another, and four years later Ric’s 4731 Grand River Arts Incubator was named “Arts Building of the Year” and he was named “Arts Entrepreneur of the Year” by the Detroit Free Press. As Ric says, “We learned that not only can these projects have a dramatic impact on the people you hire or the artists that you assist, but also on the neighborhood itself and the people who live there”.

After a move to Georgia, Ric purchased “787Windsor”, six derelict industrial buildings in the historic Mechanicsville neighborhood in Southwest Atlanta. Ric’s goal in Mechanicsville was “Development without Displacement” to provide hope and opportunity. Three years later, 787 was named “Best Event Venue in the City” by Creative Loafing Magazine.

Ric recently moved to Macon to purchase a vacant industrial property he found located at 206 Lower Elm in Macon’s Railroad District. Over the last 18 months, Ric and a diverse group of volunteers and local residents have covered the exterior with world class street art and have spent hundreds of hours repairing and updating the inside of the buildings to create a home for Triangle Arts Macon. The result? In addition to being awarded the Historic Macon Foundation’s “Preservation Award for Revitalization”, they have created a truly unique environment - an amazing space dedicated to the arts that treasures creativity, freedom and diversity.

Ric is currently expanding his vision for Triangle Arts Macon to include outside demonstrations and art installations. “These installations can be great advertising for companies that want to be seen as good citizens in the communities in which they serve”. An example is the outdoor art exhibit and auction funded by the Sembler Development Company going up next month near one of their construction sites in Macon. Not only will they be able to increase traffic for their tenants, they will also be acknowledged for their support of local artists. “It’s like advertising with a human twist – and – because its outdoors, it’s a safe and responsible way to enjoy artistic expression during what we hope is the tail end of the pandemic”.

Ric left his “professional” career for good several years ago and has not looked back. He is always looking for his next social impact/arts project, so if you have any ideas or connections to share, please contact him at 404-919-5980. CF@LANTA is blessed to be able to work with outstanding people like Ric. To learn more, visit www.triangleartsmacon.com.



Highlights

Leann Rittenbaum Ott Fellow for 2020 Named

Leann Rittenbaum Ott was a beloved member of our local CF community. This award was established in her honor, in order to recognize CF@LANTA trainees who are making excellent progress in the fight to treat, manage, and cure CF.

Dr. Kathryn Oliver has been named the Leann Rittenbaum Ott Fellow for 2020, based on the abstract "Utilizing yeast phenomics to discover gene interaction networks that influence biogenesis of CFTR nonsense alleles" authored by Dr. Oliver with her mentors Dr. Eric Sorscher and Dr. John Hartman (UAB). Keep up the great work, Dr. Oliver!

LEAPP Fellowship Awarded

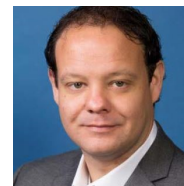
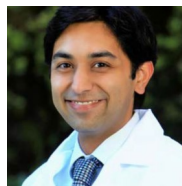
Michelle McKinnon, one of our Pediatric CF Advanced Practice Providers, was awarded the new 2-year "Leadership and Education Advanced Practice Provider CF Fellowship Program" (LEAPP) fellowship from the Cystic Fibrosis Foundation after a competitive application process. The LEAPP Fellowship involves CF specialized APP training, QI, and multi-site APP collaboration. Congratulations to Michelle!

New Grant Awards—Congratulations!

- New NIH Grant to **Dr. Steve Diggle**, Georgia Tech. Project title: "Understanding *in vivo* antibiotic resistance in diverse *Pseudomonas aeruginosa* populations."
- New NSF grant to **Dr. Peter Yunker**, Georgia Tech, with Co-PIs **Dr. Brian Hammer** and **Dr. Steve Diggle**. Project title: "Material consequences of distinct interbacterial modes of aggression in bacterial biofilms."
- New NIH Grant to **Dr. Joshua Chandler**, Emory. Project title: "Neutrophil Hyperexocytosis And Hypochlorous Acid Exposure in Early Cystic Fibrosis Lung Disease."
- New Cystic Fibrosis Foundation Grant to **Dr. Nael McCarty**, Emory. "Mechanisms Underlying the Lung Pathophysiology of CF-related Diabetes."
- New Cystic Fibrosis Foundation grant to **Dr. Michael Noto**, Emory. "Bacterial cardiolipin as a modulator of lung inflammation."
- New Cystic Fibrosis Foundation Grant to **Dr. Pratyusha Mandal**, Emory. Project Title: "Role of Programmed Cell Death Signaling in CF Lung Pathology."
- New Cystic Fibrosis Foundation Fellowship Award to **Dr. Alexandre Cammarata-Mouchtouris**, Emory. Project title: "Epigenetic regulation of CF lung inflammation."
- New CFF Grant to **Dr. Nael McCarty** and **Dr. Rabindra Tirouvanziam**, Emory. Project Title: "Pathophysiology of CFRD - innate immunity in the airway."

Award Winning Faculty

Two CF-AIR members received recognition at the 2020 Pediatric Institute Faculty & Staff Awards on Nov 12, 2020. **Dr. Jay Freeman** won the "Clinical Innovations in Clinical Program Development Award" for his Advanced Pancreatic Care Program. **Dr. Ajay Kasi** was awarded "Teacher of the Year – Subspecialty Pediatrics." Congratulations!



L: Dr. Ajay Kasi

R: Dr. Jay Freeman

Recent Publications in High-Impact Journals

Griese M, Costa S, Linnemann RW, Mall MA, McKone EF, Polineni D, Quon BS, Ringshausen FC, Taylor-Cousar JL, Withers NJ, Moskowitz SM, Daines CL. **Safety and Efficacy of Elexacaftor/Tezacaftor/Ivacaftor for ≥ 24 Weeks in People With CF and ≥ 1 F508del Allele: Interim Results of an Open-Label Phase Three Clinical Trial.** Am J Respir Crit Care Med. 2020 Sep 24. doi: 10.1164/rccm.202008-3176LE. Epub ahead of print. PMID: 32969708.

Events for Researchers

Each month there are several opportunities for CF-AIR researchers to get together to discuss their work.

Full CF-AIR Calendar of Events

- [CF-AIR Faculty and Trainees Research Joint Lab Meeting \(CF-TR\)](#):
Meets on the 1st and 3rd Wednesday at 3:00 pm, virtual only for now. Chalk talk style talks for faculty and trainees.
- [CF-AIR Workshop](#):
Meets on the 1st and 3rd Wednesday at 4:00 pm, virtual only for now. Research-in-progress and journal club presentations .
- [CF Scholars Meetings](#):
A monthly program for CF Scholars, Friday afternoons; see website schedule.

Interested in more information? Send an email to Dr. McCarty (namccar@emory.edu) or to our new Program Manager, Lilly Meier (lilly.meier@emory.edu)

Clinics:

Pediatric Clinics at the CAP
1400 Tullie Road NE
Atlanta, GA 30329
404-785-KIDS

Emory Adult CF Clinic
1605 Chantilly Dr. NE
Atlanta, GA 30324
404-778-7929

Website:

www.pedsresearch.org/research/centers/cf-air

If you are interested in supporting our research and outreach programs please visit: www.pedsresearch.org/research/centers/cf-air/donors-visitors/

Contact:

Nael McCarty, PhD
Program Director
namccar@emory.edu

