



# Cystic Fibrosis Center of Excellence

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

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Dear friends, patients, families, and colleagues,

As we welcome summertime, we are pleased to provide you with this update on behalf of CF@LANTA. We hope that you are well.

In this issue, we introduce you to Dr. Rachel Linnemann, who is the new Director of the Children's Healthcare of Atlanta and Emory University Cystic Fibrosis Care Center (the Children's and Emory CF Care Center, for short). Dr. Linnemann was selected after an extensive national search undertaken by the search firm Witt-Keiffer with the support of Children's. We want to thank Mark Lotz, Executive Recruiting Director at Children's, and his team for their outstanding work.

Dr. Linnemann comes to this position with excellent training and an outstanding record of accomplishment during her time as one of our program leaders. Her commitment to our patients and families is extraordinary. Her vision for our clinical program is to improve the health and lives of the ~700 people living with CF receiving care at our Center by: (a) being a clinical center of excellence, producing top clinical outcomes nationally; (b) leveraging the strength of our large program to integrate with and enhance research, education, and outreach; and (c) build and enhance our program's national reputation for preeminence in CF. Dr. Linnemann's appointment as Care Center Director was approved by the CF Foundation on June 21, 2019. We are ecstatic to have Dr. Linnemann in this crucial leadership role, and look forward to working with her to achieve great things.

We also introduce the work of three of our outstanding junior faculty who are helping to lead our growth in non-pulmonary aspects of CF research: Drs. Freeman, Alvarez, and Daley. We are excited by this newly

enhanced focus in research to solve problems that our patients and families want us to solve.

Finally, we want to express our thanks to Mr. Scot Rittenbaum, who until very recently was the Executive Director of the Georgia Chapter of the CF Foundation. Scot and his wife Karen are moving to Charleston, to be near their daughter and family. An outstanding partner and friend, loved by all, he has been a big part of the CF@LANTA journey for its whole existence. We will deeply miss seeing his smiling face at CFF events, will miss his soft guidance, and will miss his big hugs. We wish him and Karen all the very best.

~Nael A. McCarty, PhD, [CF@LANTA](#)



Scot Rittenbaum at the 2019 CFF Wine and Roses Event



## Research Profile: A. Jay Freeman, MD—Improving GI, Nutrition and Liver Health in Patients with CF

I started my Pediatric Gastroenterology (GI), Nutrition and Hepatology fellowship at Emory University and Children's Healthcare of Atlanta (CHOA) in 2011. I knew very early in my career that I wanted to focus on improving the care of patients with CF who experienced GI and liver manifestations of the disease. I began my career in CF research with a project that combined the expertise in Dr. Nael McCarty's CF physiology lab with that of my mentors, Dr. Saul Karpen's biliary physiology lab. We studied the impact of an intratracheal induced pneumonia on bile acid transporters in a CF mouse model. While the study provided a greater understanding of CF pathophysiology, I knew that my career lay more in clinical research. I was hired as an assistant professor in the Department of Pediatrics at Emory and CHOA after fellowship which allowed me to complete a Master's of Science in Clinical Research (MSCR). Since then I have focused my research and clinical efforts on better understanding the impact that GI and hepatic symptoms have on pulmonary and global outcomes in patients with CF.

As I completed fellowship and started as an attending I was selected as one of the initial 15 CF Foundation DIGEST (Developing Innovative Gastroenterology Specialty Training) Program awardees. This program allowed me to become involved in establishing treatment guidelines for a number of GI and hepatic conditions early in my career. Over the last 5 years I have helped establish care guidelines and best practices for constipation, pancreatitis, liver transplant and newborn GI care. I

remain active in clinical research as well, serving as the local PI for the PUSH, MRE and ELASTIC studies which look to determine predictors for the development of CF liver disease, as well as the GROW study which explored the impact of oral glutathione on growth in CF. Currently I serve as the national PI on the GALAXY study which is using electronic patient reported outcome measures to better understand the variation and natural history of GI symptoms among patients with CF. From the initial GALAXY data, we will look to develop interventional trials to address the most common GI symptoms in CF.

Away from the hospital and clinic I enjoy spending time with my wife and our three boys as we make our rounds to the local parks, tennis courts, baseball and soccer fields.

~submitted by A. Jay Freeman, MD



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## CF Scholars Program

The CF Scholars Program is excited to relaunch in 2019. The goal of the CF Scholars Program is to recruit, educate, and mentor pre-doctoral and postdoctoral researchers and clinicians to become the next generation of academicians in cystic fibrosis research. By the completion of this program, participants should have gained an increased understanding of CF and how to perform team science, enhanced their communication skills, and become patient and scientific advocates. The program includes in-depth and frequent interactions between CF clinicians and CF scientists so the trainee will be educated on the important role each plays in the lives of the CF patient and their family. The CF Scholars Program is headed by directors Joanna Goldberg, PhD, Nael McCarty, PhD, and Rachel Linnemann, MD. To learn more about who are CF Scholars and the activities of the program, please check out <http://www.pedsresearch.org/research/centers/cf-air/cf-center-of-excellence/education-outreach/cf-scholars-program/>. New applications were due in mid-June, check the website for the announcement of the new CF Scholars for 2019.

## Faculty Profile: Tania Daley, MD

Dr. Tania Daley joined Emory faculty in 2012 as an Assistant Professor of Pediatrics after completing her fellowship training in pediatric endocrinology at Children's Healthcare of Atlanta, Emory University School of Medicine. Throughout her fellowship training and early career, Dr. Daley demonstrated a strong interest in diabetes. Shortly after joining Emory's faculty, Dr. Daley sought to fill the gap around transitional care for type 1 diabetes. Through focus groups, she discovered the strengths and deficits of the diabetes program and with that knowledge, she developed the first multidisciplinary clinic for type 1 diabetics transitioning to adult care in Georgia. Each year the program expands and is generally well received by patients and their families. Many families state that the transition program played a vital role in allowing for a successful transition process.

In addition to transitional care for diabetes, Dr. Daley has a strong interest in cystic fibrosis related endocrinopathies. She serves as the primary pediatric endocrinologist for her CF center. In August of 2016, she was our inaugural recipient of the CF Foundation "EnVision CF: Emerging Leaders in CF Endocrinology" award. The CF foundation recognized the need to increase the presence of endocrinologists who have expertise in the management of cystic fibrosis. Through the EnVision program, Dr. Daley has the opportunity to work in partnership with national and international experts in the field of CF endocrinology. She was section co-chair for Endocrine and Diabetes at the 31st Annual North American Cystic Fibrosis Conference (NACFC) and will speak at the upcoming 33rd NACFC on the topic of vitamin D deficiency in CF. Dr. Daley's research interest focuses on beta cell dysfunction in CF and the impact of simple sugars on glucose homeostasis in CF.

In 2017, Dr. Daley served as the first faculty advisor for the division of pediatric endocrinology to the Emory Global Health Residency Scholars Program through Emory University School of Medicine. Through a year-long curriculum, participants receive didactics pertaining to a variety of healthcare issues in Ethiopia. The pediatric endocrinology team headed by Dr. Daley travels to the capital of Ethiopia, Addis Ababa, and collaborates with physicians and physicians in

training at Black Lion Hospital, the main teaching hospital. Based on 2017 data from the International Diabetes Federation, Ethiopia has the highest prevalence of diabetes on the continent of Africa, with several cases of type 1 diabetes. In 2017 and 2019, Dr. Daley mentored two pediatric endocrinology fellows in the program. Their efforts allowed for collaboration between the Emory team and the Ethiopia team in order to improve the healthcare infrastructure around all aspects of pediatric endocrinology with special attention to pediatric diabetes.

In the Atlanta area, Dr. Daley volunteers her time to Camp Kudzu, a local camp for children with type 1 diabetes. As an endocrinologist, she oversees the care of type 1 diabetics who spend a week away from home, many for the first time. Throughout the year, she serves on the Board of Directors for Camp Kudzu.

~submitted by Tania Daley, MD



## Faculty Profile: Rachel Linnemann, MD — new care center director

Dr. Rachel Linnemann was appointed as the Director of the Children's Healthcare of Atlanta and Emory University Cystic Fibrosis Care Center in April 2019 after a national search. The Children's and Emory CF Care Center is one of the largest care centers in the country. Dr. Linnemann will oversee the healthcare of the over 700 CF patients followed at the center who range from a few days of age to almost 80 years old. Dr. Linnemann's charge as the new Director will be to bring the health outcomes of the patients followed at the center into the top ten nationwide. She is fortunate to be able to build on an outstanding foundation created by the past director, Dr. Arlene Stecenko.

Dr. Linnemann grew up in Arlington, Virginia. She completed her undergraduate degree at Brown University. She then taught elementary school for two years before attending medical school at Yale University. She completed her postgraduate training in pediatrics at Massachusetts General Hospital in Boston. Dr. Linnemann also completed her pediatric pulmonary fellowship at Massachusetts General Hospital and received a certificate in comparative clinical effectiveness through the Harvard School of Public Health to enhance her understanding of clinical research and biostatistics. In Boston, she discovered her passion for caring for people with CF, and CF became her primary clinical and research interest.

Dr. Linnemann joined the faculty of the Emory University Department of Pediatrics in 2015 where she quickly established a reputation for excellence through her work as the CF Quality Improvement Officer. She secured grant funding to hire a mental health coordinator to direct mental health screening and provide mental health services for both the pediatric and adult CF programs. Dr. Linnemann also developed a quality project on adolescent lung function that has led to improved outcomes over the past several years.

From a research standpoint, Dr. Linnemann currently serves as site PI for seven clinical trials and is Co-Director of the CF Foundation-funded Emory Therapeutic Development Center, part of the national CF Clinical Trials network. She has also been a co-investigator on funded research projects related to CF palliative care and quality of life. She is currently a co-investigator on Dr. Balazs Rada's federally funded grant related to neutrophil extracellular trap markers and CF lung disease progression.

From an education perspective, Dr. Linnemann mentors pediatric pulmonary fellows on research and quality improvement projects. She is also co-director of the CF Scholars Program, a program that aims to recruit and mentor trainees to become the next generation of academicians in CF research. When not at work, Dr. Linnemann spends time with her husband, 4 year old son, and dog. She loves the beach, long walks, and superhero movies.

~submitted by Rachel Linnemann, MD



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## Recent CF-AIR Publications

Recent publications by CF-AIR members can be viewed online here:

<http://www.pedsresearch.org/uploads/blog/doc/2019-06CF-AIRNewsletterPubs.pdf>

## Grant Highlight: ORBIT-CF Study

We are happy to announce that the ORBIT-CF Study is underway! ORBIT-CF stands for Outcomes Related to Body Composition in Teens and Adults with Cystic Fibrosis. The overall goal of this study is to learn more about how nutrition, muscle, and body fat influence clinical outcomes in CF such as risk for diabetes and lung function. This study is funded by the Cystic Fibrosis Foundation and is being conducted at both Emory and the University of Alabama at Birmingham, with collaboration from Children's Hospital of Philadelphia. Dr. Jessica Alvarez, PhD, RD is leading the study with our own Emory CF Physicians Drs. Arlene Stecenko, MD, and William (Randy) Hunt, MD. The Lead Research Coordinator is Elizabeth Ivie, MS, RD.

For this study, we are recruiting teenagers and young adults with CF, ages 16-30 years. The major research aims of the study are: 1) to determine if individuals with CF are at higher risk for accumulating fat in the abdominal (belly) area, 2) to determine if the quality of the diet contributes to abdominal fat accumulation, and 3) to determine if this fat is associated with diabetes risk and worse lung function in individuals with CF. Study volunteers will be seen at the Emory University Hospital Clinical Research Unit. We will use state-of-the-art body imaging tools, including magnetic resonance imaging (MRI) and dual energy X-ray absorptiometry (DEXA), to measure muscle and body fat. Study procedures will also include an oral glucose tolerance test to assess diabetes risk,

indirect calorimetry to determine how many calories one burns at rest, and detailed dietary assessment. In a sub-set of study volunteers, these measurements will be assessed annually for two years.

This study was developed to address two of the top priority research areas of encouragement identified by the CF community, which are nutrition/diet and CF-related diabetes. It is also a follow-up study based on findings from our previous BEAM-CF Study. In the BEAM-CF Study, adults with CF seemed to have higher abdominal fat compared to non-CF controls even though body mass index did not differ between the groups, and this was associated with higher blood glucose levels. Adults with CF also reported eating a higher amount of added sugars from their diets and this was associated with higher abdominal body fat. These findings were recently published in the *Journal of CF*. Importantly, the findings highlighted the need to look carefully at both body composition and diet quality in individuals with CF.

It is our hope that the new information collected in the ORBIT-CF Study will help us make decisions about better nutrition monitoring and interventions to maintain optimal health and longevity for individuals with CF.

~submitted by Jessica A. Alvarez, PhD, RD and Elizabeth Ivie, MS, RD



## 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 2nd and 4th Wednesday at 4 pm in ECC 302. Chalk talk style talks for faculty and trainees
- [CF-AIR Workshop](#): A weekly Wednesday meeting for research-in-progress and journal club presentations. Typically meet at 4:00 pm in ECC 302, and IBB 1316 1st & 3rd Wednesdays (videoconference on 1st & 3rd Wednesdays)
- [CF Scholars Meetings](#): A monthly program for CF Scholars, Friday afternoons, see website schedule.

Sign up for the [CF-AIR Weekly Digest](#) to hear about all events of interest to researchers, just email [namccar@emory.edu](mailto:namccar@emory.edu)

#### Clinics:

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

Emory Adult CF Clinic  
Emory Clinic, Building A  
1365 Clifton Road NE  
Suite A3209  
Atlanta, GA 30322  
404-778-7929

#### Website:

[www.pedsresearch.org/research/centers/cf-air](http://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/](http://www.pedsresearch.org/research/centers/cf-air/donors-visitors/)

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