

# Cystic Fibrosis Center of Excellence

Volume 7, Issue 1

April 2017

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Dear friends, patients, families, and colleagues,

Welcome to the Spring 2017 issue of the Cystic Fibrosis Center of Excellence newsletter which focuses on our clinical care program at the Emory+Children's CF Care Center. Before outlining some highlights that have occurred in the last year as well as exciting new developments in the coming year, let me briefly describe our Center.

The Emory+Children's CF Care Center consists of three programs – the Adult CF program at Emory lead by Dr. Seth Walker, the Emory+Children's Pediatric program lead by Dr. Arlene Stecenko, and the Affiliate Pediatric Program at Scottish Rite lead by Dr. Kevin

Kirchner. We are one of the largest CF Care Centers in the country and the leaders of the three programs strive to be a unified center with overarching goals and ideals that spread over the three programs. We are one of over 120 care centers in the US accredited by the CF Foundation (CFF). The CFF sends experts in adult and pediatric CF care to each center at least every five years to conduct a site visit to assess that the center is fulfilling the requirements to be accredited by the CFF. Essential components of a center to attain accreditation are:

- An interdisciplinary health care team consisting of physicians and nurse practitioners, dietitians, nurses, social workers, and respiratory therapists
- A quality improvement program aimed at improving health outcomes for CF patients
- A clinical research program so that CF patients can participate in research projects so that new and effective

drugs can be made available to all CF patients

- A family/patient council that acts as advisors and advocates for the center
- An educational program for families, staff, trainees, and the community

Our Center had the last site visit in 2013 and received full accreditation.

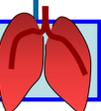
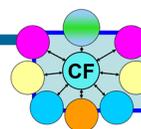
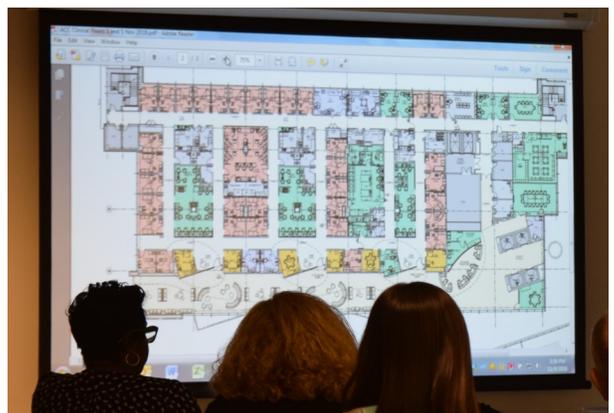
And now to the highlights. The most exciting news for the pediatric CF programs is the building of the new Children's clinic building, the Center for Advanced Pediatrics (CAP), at Tullie. Dr. Patrick Frias, the Chief Operating Officer at Children's, described our clinic area for CF children in an article in

The Atlanta Business Chronicle article from February 10, 2017 as follows: "Almost an entire floor of the facility will be dedicated to treatment and

*Almost an entire floor of the facility will be dedicated to treatment and research for breathing and airways*

research for breathing and airways, bringing together the areas of pulmonology, allergy/immunology, cystic fibrosis, and sleep." Dr. Frias goes on to say that on our same floor will be a "pediatric research center (which) will provide a convenient, dedicated location for patients to participate in clinical research trials." The building will be completed in the Summer of 2018.

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## Continued from page 1

Another highlight is that we have found the funds to create three new positions for the CF care team that we believe will markedly improve our clinical care. The first position is for a coordinator to improve mental health for patients at our three programs. This position was funded by grants from the CFF awarded to Drs. Walker, Stecenko, and Linnemann. The person recruited for this position was Shaina Blair, who was the CF social worker for the Adult program at Emory and then the pediatric program at Emory+Children's. Shaina has now returned from her maternity leave and will devote all her time to this program. The second new position is for a physical therapist and is funded by a CFF grant to Dr. Kirchner. The reasoning behind creating this position is that the Director of the pediatric center that has one of the best outcomes for lung function in children feels that believes that his physical therapist is the key to achieving these excellent lung health outcomes. Dr. Kirchner has hired a physical therapist for the Scottish Rite program to pilot a pulmonary physical therapy program there with the goal of finding sufficient funds to have these services across our entire center. Finally, Drs. Walker, Stecenko, and Kirchner have teamed together to find funds for the new position of a transition coordinator. We are in the process of recruiting this person and should be able to have her join the center in the next month or so. This person would work with the care teams from all three programs to improve the transition program from pediatric to adult care. In this issue, Brandi Middour-Oxler outlines several strategies we will use to make the transition program even better.

In the following pages you will read about work presented at our recent CF Tripartite Program Meeting. This is a

time for our three clinical programs to come together as a unified group to discuss how we can continue to provide our patients with the best care.

With best wishes,  
Arlene Stecenko, MD, [CF@LANTA](mailto:CF@LANTA)



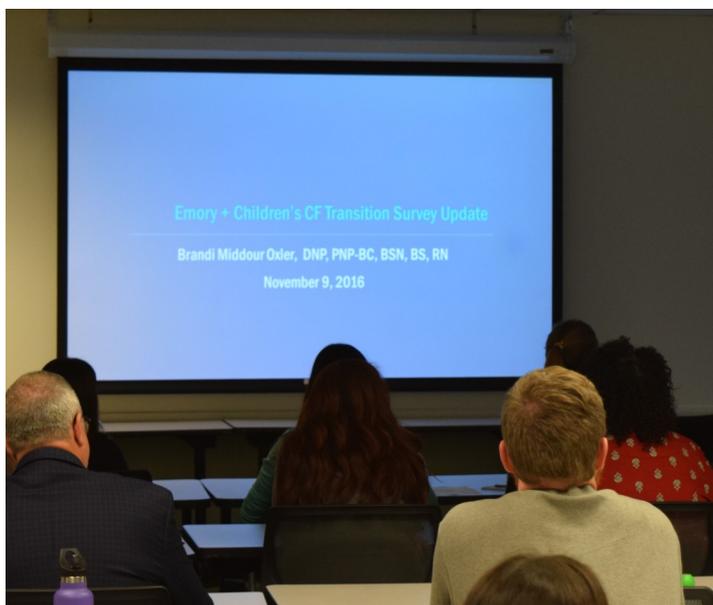
## Tripartite Meeting Recap: Transition Project/Survey Update

The CF Transition Program began at the Scottish Rite location in 2008, and later at Egleston in 2012. The purpose of this program is to educate and empower adolescents to take over their own medical care and medical decision-making as they prepare to change from pediatric to adult care. This robust, and award winning program, was one of the first CF Transition programs in the country.

In 2015 while working on my doctoral project, I joined a multidisciplinary transition team from all three care centers to illicit patient feedback and improve the transition program. Members included myself, Dr. Randy Hunt (Emory Adult CF), Barb Crews (PNP, Scottish Rite), Stephanie Pendley (PNP, Egleston), Shaina Blair (Social Worker, Egleston), and Alissa Siragusa (Child Life, Scottish Rite). Together the team wrote a survey that asked adults who had participated in the transition program how they felt about their transition timing, transition readiness, and their opinion on helpful program elements. This is one of the first surveys of CF adults who were active in a transition program and have since moved into adult care. Thanks to the hard work of the team the survey completion rate was an impressive 63%. Results revealed that most patients found it anxiety provoking to leave their pediatric providers, but the inclusion of the adult CF providers at a final capstone combined clinic attenuated this concern. Patients varied in preference for transition timing. Despite high levels of patient-perceived readiness, patients reported several knowledge deficits including insurance knowledge, knowing how to reorder medications, and how to schedule appointments.

A poster of this work was presented at the 2016 North American Cystic Fibrosis Conference and was very well received by many leaders in the CF community. The transition survey is just one of many ways that the CF Center is using to improve the transition program and increase understanding of possible best practices for pediatric to adult transition. In the future, changes to the transition program could include partnering with adolescents to choose a transition time based on individual skill mastery and personal readiness. In 2017 the transition study will begin its second phase where transition program participants will be asked to take a part in a Pre-Transition Survey at their pediatric visit before transferring to the adult CF team. Future endeavors will include investigating if participation in transition programs has effects on important CF outcomes. An update on the project was also presented at the November Tripartite meeting.

~submitted by Brandi Middour-Oxler, DNP

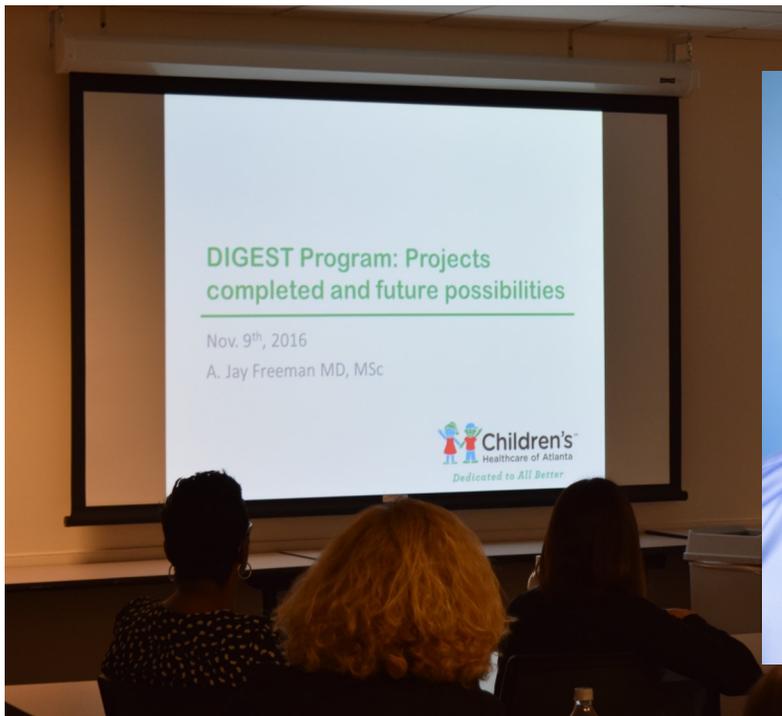


## Tripartite Meeting Recap: DIGEST Award

The DIGEST Award (Developing Innovative GastroEnterology Specialty Training) was created by the Cystic Fibrosis Foundation to expand the availability of GI experts in CF. The CFF recognizes the growing demand for physicians trained to address the unique gastroenterologic needs of CF patients and the need for a greater GI focus in the clinical research enterprise. The first iteration of the award included 15 awardees (10 pediatric and 5 adult GI providers) along with 6 core mentors. I am honored to be an inaugural DIGEST Awardee. Together, the group has embarked on a number of projects focused on improving GI-based clinical care in patients with CF and disseminating the latest updates of care to centers around the country. Efforts have ranged from creating basic guidelines to be used by GI and non-GI providers/caregivers as well as pushing forward new studies to improve our understanding of the GI manifestations of CF. I have been fortunate to be involved in a number of these projects, with a few highlighted below:

- Co-author of CFF sponsored Constipation guidelines for patients with CF
- Invited to Chair Gastroenterology and Hepatology Workshop at the 2016 NACFC Conference in Orlando
- Invited to lead Roundtable session at 2016 NACFC entitled: Working up Elevated Liver Enzymes in Patients with CF
- Led Meet the Professor Breakfast at 2016 Pediatric GI World Congress in Montreal entitled: GI issues in Cystic Fibrosis: Myths and Facts
- Invited review article in Pediatric Clinics of North America (2016): Gastrointestinal, Pancreatic and Hepatobiliary Manifestations of Cystic Fibrosis
- Member of international Cystic Fibrosis Liver Disease Consortium
- Interview with US News & World Report on Pancreatic Exocrine Insufficiency
- Local Primary Investigator for CFF sponsored GROW Study

~submitted by A. Jay Freeman, MD



## Tripartite Meeting Recap: Role of Lung Clearance Index in Monitoring of Early Cystic Fibrosis Lung Disease

Airway disease in Cystic Fibrosis begins in the small airways from a very young age, but is not easily detected by standard clinical tests. Measurement of lung function as an indicator of airways obstruction by spirometry is generally available for children older than age 6 years and by that age most children have developed significant small airway disease. As most children with Cystic Fibrosis are diagnosed through newborn screening, it is important to start monitoring for lung disease early and to identify patients that are at risk of rapid progression of their lung disease.

The Lung Clearance Index is a newer method for the measurement of ventilation inhomogeneity that can result from progressive obstruction of the small airways in early stages of the disease. This test requires less effort than spirometry and can be performed for a wider age spectrum of patients, ranging from infants and young children to adults with CF. Its normal values do not change significantly with age, and it can be useful to track changes in the small airways over time. Studies have validated the use of LCI in the settings of acute pulmonary exacerbations and with development of bronchiectasis on imaging. Further studies are needed to better define the minimum clinically important change in LCI and how it can be used effectively in clinical and treatment decision making for patients with CF, and we look forward to performing some of these studies in our Program

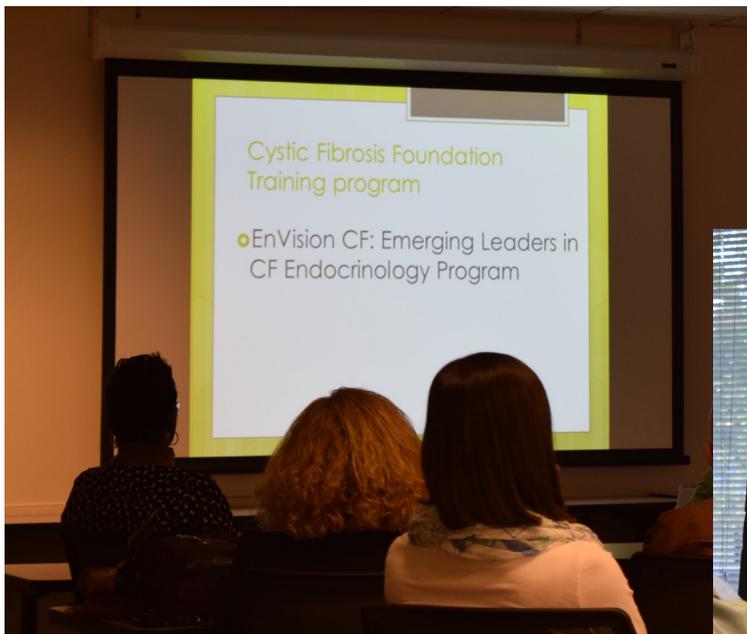
~Submitted by Lokesh Guglani, MD



## Tripartite Meeting Recap: EnVision Emerging Leaders

Cystic fibrosis-related diabetes (CFRD) is one of the most common comorbidities in patients with cystic fibrosis. Unfortunately, those who have a diagnosis of CFRD have increased morbidity and mortality. They may see deterioration in nutritional status and higher rates of respiratory exacerbations requiring hospitalization. Many see a decline in pulmonary function when high blood sugars are uncontrolled. In an effort to address the growing endocrinologic needs of the CF community, the Cystic Fibrosis Foundation (CFF) announced their support of a training program that would expand the availability of CF-endocrinology experts throughout the country. The goal of CFF is to develop the next generation of leaders in pediatric and adult CF endocrinology. The program recruited eligible physicians in internal medicine and pediatrics with subspecialty certification in endocrinology. Sixteen EnVision Emerging Leaders were selected, 8 pediatric endocrinologists, 8 adult endocrinologists. Dr. Tanicia Daley, a pediatric endocrinologist at Children's Healthcare of Atlanta, was selected as a recipient of the CF Envision Training award. This opportunity will increase CF endocrinology resources available to our CF population. In addition to increasing time spent with CF patients, Dr. Daley will also investigate how nutritional and pulmonary clinical status is affected in toddler and school age children who have pre-diabetes compared to those without, and how the elimination of simple sugars may improve glucose tolerance.

~Submitted by Tanicia Daley, MD, MPH



## Profile: Stephanie Pendley, RN, CPNP



Stephanie Pendley, RN, CPNP

I have been working at the Emory/Egleston campus for 16 years. I joined the **CF@LANTA** in 2006 after working as a nurse at Egleston and developing a love for pulmonary patients. I attended Emory University for my undergrad degree in Nursing and pursued my Master's degree at GA State. Working with the patients and team at the CF Center has been my dream job. I have learned so much about resilience and overcoming obstacles in working with our

patients and families. The team approach to CF has allowed me to learn from colleagues and other disciplines. Until working at the CF Center, I did not have the opportunity to work in research, but I have appreciated the opportunities to work on studies and learn about new and upcoming projects within the CF community. I serve as the Clinic Coordinator at the CF Center and serve as a leader on our CF QI Committee. I am also the lead Advanced Practice Provider for the PACS division. I am a local, born and raised in the suburbs of Atlanta. In my spare time, I love travelling, being a movie buff, shoe shopping, and cheering on the GA Bulldogs!

~submitted by Stephanie Pendley, RN, CPNP

## Faculty Profile: Kevin Kirchner, MD



Kevin Kirchner, MD

Dr. Kevin Kirchner has been the **CF@LANTA** Affiliate Center Director at Scottish Rite since the fall of 2012. He attended the Southern Illinois University School of Medicine, completed his Pediatric Residency at the University of Iowa, and Pediatric Pulmonary Fellowship at the University of Rochester in Rochester, NY, in 1990. He then worked as a Pediatric Pulmonologist at the University of Colorado/Children's Hospital of Denver until 1995 when he relocated to Atlanta. While in Denver, he directed the initial studies of Pulmozyme and investigated its potential effectiveness in children under 5 years of age with CF. Since relocating to Atlanta he has remained active in caring for patients with CF, and along with the other physicians in his practice has seen the Scottish Rite CF clinic grow from around 30 patients in the early 90's to over 180 patients in 2017. The Scottish Rite affiliate program has worked hard through the years to provide excellent clinical care to CF patients while adhering to the established guidelines of the CF Foundation,

spearheaded by the fantastic efforts of Dr. Peter Scott, our prior director, who retired in 2015. Building upon his initiatives, we have striven to maintain quality improvement, while strengthening our relationships with our core center, the Emory Pediatric CF Center at Egleston. Together in 2013, we were invited participants in the "ONE CF" initiative sponsored by the CF Foundation, a two year process that promoted further synergy between all three campuses and focused on the QI and process improvement of CF care across all ages. Since that initial effort, we have collectively initiated efforts to expand research offerings for clinical studies on the Scottish Rite campus that in 2017 have resulted in the Scottish Rite campus becoming a member of the Therapeutics Development Network of the CF Foundation. This will enable our campus to expand our offerings and support to research studies in CF on-site, while continuing to develop all the efforts across the CF programs in the Atlanta/ Georgia region.

On a personal note, Dr. Kirchner has been married for 30 years to Angela Weiss, and is the father of 3 children: Ian 23 yo, Erin 21 yo, and Liam 18 yo. He enjoys spending time with his wife, taking long walks in the evenings with "Max and Milo"-energetic 1 yo Morkie and Maltese, and playing golf on weekends.

~submitted by Kevin Kirchner, MD

## Faculty Profile: Rachel Linnemann, MD



Rachel Linnemann, MD

Dr. Daniel Caplan, known as the “grandfather of CF” in Atlanta, retired at the end of February after providing care for 48 years to people with CF. He was much loved by generations of people with CF and their families, who, on hearing

the news, sent in abundant personal messages expressing their gratitude for his lifetime of dedication to CF. With Dr. Caplan’s retirement, Dr. Rachel Linnemann has taken on his previous position as Associate Director of the Emory Pediatric CF Program. Dr. Linnemann will work closely in this role with Dr. Arlene Stecenko, Director of the Emory Pediatric CF program, and Stephanie Pendley, Program Coordinator.

Dr. Linnemann joined the Emory faculty in 2015. She grew up in Arlington, VA and studied human biology at Brown University. She then taught elementary school for 2 years before attending medical school at Yale University. She completed her residency in pediatrics and fellowship in pediatric pulmonology at Massachusetts General Hospital in Boston, MA. In Boston, she discovered her passion for caring for people with CF. CF

became her primary clinical and research interest, and she helped secure a 3 year grant from the CF Foundation to study palliative care in CF.

Since arriving at Emory, she has become very involved in the cystic fibrosis team. She provides clinical care for pediatric patients and is the CF Quality Improvement Officer for the Division of Pediatric Pulmonology. A major effort centered around obtaining a grant from the CF Foundation to hire a mental health coordinator to coordinate mental health screening and provide mental health services for the pediatric and adult programs at the Emory+Children’s CF Center.

From a research standpoint, Dr. Linnemann is an investigator in Emory’s Therapeutics Development Network (TDN) research group. She serves as site PI and co-investigator for several of our TDN CF clinical trials. She continues to be involved in CF palliative care/quality of life research with colleagues in Boston and is part of a CF Foundation working group on palliative care. She also has an interest in factors contributing to rapid rate of lung function decline in the adolescent years and is beginning several projects in this area.

When not at work, Dr. Linnemann spends time with her husband, 2 year old son, and dog. She loves the beach, long walks, and superhero movies.

~submitted by Rachel Linnemann, MD

## Recent CF-AIR Publications

- Balekian DS, Linnemann RW, Hasegawa K, Thadhani R, Camargo CA Jr. Cohort Study of Severe Bronchiolitis during Infancy and Risk of Asthma by Age 5 Years. *J Allergy Clin Immunol Pract.* 2017 Jan - Feb;5(1):92-96. doi:10.1016/j.jaip.2016.07.004. PubMed PMID: 27523277.
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*If you have a publication you would like in the next newsletter, email Karen Kennedy, [kmurra5@emory.edu](mailto:kmurra5@emory.edu).*

### Recent CF-AIR visitors

- **Kambez Benam, DPhil**, February
- **Alfin Vicencio, MD**, February

## Events for Researchers

These events will be taking a break for the summer months, check the websites below for the upcoming schedule.

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

- **CF-AIR Faculty and Trainees Research (CF-TR):**  
On the first Tuesday of the month, faculty chalk talks on either the overall work in their lab, or on a grant proposal planned for submission soon. On the third Tuesday of the month trainee chalk talks discussing planned manuscripts or fellowship proposals. Meet at noon in ECC 302
- **CF-AIR Workshop:**  
A weekly Wednesday meeting for research-in-progress and journal club presentations. Meet at 4:30 pm in ECC 302
- **CF Scholars Meetings:**  
A monthly program for CF Scholars, Friday afternoons, see website schedule

More information and current schedules can be found on

[www.pedsresearch.org/research/centers/cf-air/seminars-workshops/](http://www.pedsresearch.org/research/centers/cf-air/seminars-workshops/)  
and

[www.pedsresearch.org/research/centers/cf-air/cf-center-of-excellence/education-outreach/cf-scholars-program/](http://www.pedsresearch.org/research/centers/cf-air/cf-center-of-excellence/education-outreach/cf-scholars-program/)

### Clinics:

Children's Healthcare of Atlanta  
CF Care Center:  
Children's at North Druid Hills  
1605 Chantilly Drive NE  
Atlanta, GA 30324  
404-785-2000

Children's at Scottish Rite  
Cystic Fibrosis Affiliate Program  
5455 Meridian Mark Road, Suite 200  
Atlanta GA 30342  
404-785-2898

Emory Adult CF Clinic: 404-778-7929

### Website:

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

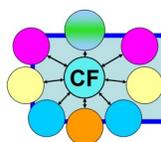
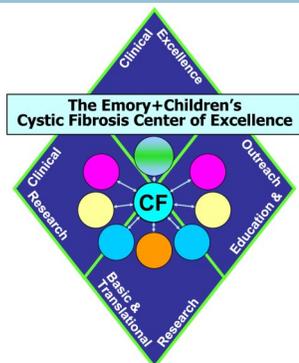
If you are interested in supporting our research and outreach programs please visit:

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

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**Center for Cystic Fibrosis  
and Airways Disease Research**  
Advancing Wellness in Patients Through Research

