



Cystic Fibrosis Center of Excellence

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

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Dear friends, patients, families, and colleagues,

We hope that you are well. As we find ourselves in the midst of the holiday season, we have much to be grateful for; high on my personal list are the many supporters of CF@LANTA and the CF-AIR research center. With that in mind, we are pleased to provide you with this update.

In this issue, we will describe several great milestones reached, brag on some of our outstanding researchers (including some doing important research outside of CF but with great relevance to that disease), and tell you about our exciting efforts to initiate a new collaboration with the CF Center and research team at Augusta University.

Milestone #1 is the long-awaited merger of the two pediatric CF programs into one, bringing the “best of both worlds” in our efforts to provide the absolute best care for our patients and families. More details about this are found on the next page.

Milestone #2 is the long-envisioned launch of a collaboration with our colleagues at the Medical College of Georgia at Augusta

University, which is the home of the one other CF Foundation-accredited CF Care Center in Georgia. This collaboration is founded in a new large programmatic grant proposal submitted this past August to the NIH, to launch the “Georgia CF Core Center,” which will focus on exercise, diet, lifestyle, GI/nutrition, and other non-pulmonary aspects of CF research in which we have invested significantly over the past few years. We are very excited to be teaming up with the Augusta group, at long last! See page 4 for more.

Finally, I am happy to report that the CF@LANTA team had outstanding representation at the North American CF Conference 2019, in Nashville, TN. We presented 57 abstracts and symposia. Several of our team members served as leaders and/or organizers of sessions related to research, education, and clinical care. We also were able to gather together both clinical team members and research team members for a joint dinner, for the first time ever (see photo). Many thanks to Dr. Kathryn Oliver for her help in arranging that fun time.



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

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



One CF!

A long-sought dream has finally come true, due to the hard work of many stakeholders: the two pediatric CF care programs within CF@LANTA, formerly known as the Emory/Egleston program and the affiliate program at Scottish Rite, have officially merged into one!

Facilitated by the physical move of the two outpatient care program sites into the fabulous new Center for Advanced Pediatrics building late in 2018, our clinical program leaders have worked very hard to identify the best parts of the two prior programs and build them into one program, where our providers and staff have been able to learn from each other in order to enable the provision of the very best in CF care for our patients. This has required a lot of work, a lot of communication, and a lot of support from Children's. We are confident that we are "better together," and that the changes we have put in place will benefit our patients and families as we strive to attain the absolute best clinical outcomes. This also makes it possible for all of the patients and families who formerly were associated with one program or the other to gain access to the overlapping but complimentary expertise of the providers and staff from the other former program. Finally, this greatly impacts our ability to enable patients and families from both former programs to be engaged in CF research.

The leadership of CF@LANTA is exceedingly grateful for all who have worked so hard to make this merger a success. We also appreciate the engagement of our patients and families as we seek a smooth transition.

The formal announcement from Children's follows:

Exciting news

Children's combines pediatric cystic fibrosis programs

Children's Healthcare of Atlanta is pleased to announce that their Egleston-based cystic fibrosis (CF) program and their Scottish Rite-based CF program have now combined into one. The new name is the Children's Healthcare of Atlanta and Emory University Pediatric Cystic Fibrosis Program. Rachel Linnemann, MD, and Kevin Kirchner, MD, will serve as Co-Directors of the program. Dr. Linnemann has also been named Director of the Children's Healthcare of Atlanta and Emory University Cystic Fibrosis Care Center, which includes both the pediatric and adult CF programs. In this role, Dr. Linnemann oversees the care of more than 700 children and adults with CF. The Children's and Emory CF Care Center is accredited by the CF Foundation and is one of the largest care centers in the country.

Frequently asked questions

Why did the pediatric programs merge?

By combining the two CF programs at Children's, we are better able to ensure the quality and consistency of care are the same for our CF patients. Additionally, the merging of the two programs will improve patient access to the CF specialized care team members and leading research studies.

Will my child's provider change?

No, your child will continue to see the same provider.

Will my child's clinic location change?

No, your child will continue to be seen at the Center for Advanced Pediatrics.

What phone number do I call to make, cancel or reschedule appointments?

Continue to call 404-785-KIDS (5437)

CF Scholars Program — reboot

The CF Scholars Program is excited to relaunch in 2019. We have an excellent group of Scholars in the program this year, who began their training in August. We will give further details on each of them in an upcoming issue of the newsletter, but the eight active Scholars are named here:

Jacob Davis, BS - Georgia Tech

Rebecca Kapolka, MD - Emory

Madeline Mei, BS - Georgia Tech

Kristofer Waldetoft, MD/PhD - Georgia Tech

Malinda Wu, MD - Emory

Conan Y. Zhao, BS/BA - Georgia Tech

Debayan Dey, PhD - Emory

Kathryn Oliver, PhD - Emory

Upcoming event: Annual Dr. Daniel Caplan CF Family Science Dinner

We are very excited to continue our tradition of hosting a special evening for our CF community. CF parents, caregivers, and spouses are invited to join us as we host CF scientists and providers at this annual event. There will be brief talks after dinner that will touch on exciting new research and programs for CF. There will be time for informal chats and mingling with these scientists and your CF providers. **Parents/ Caregivers from Children's Healthcare of Atlanta and Emory Adult CF Foundation-accredited programs are invited to attend. Due to infection control risks to people with CF, since our special guest speaker has CF, no other CF patients will be able to join the meeting in person. The event will be live-streamed so that our patients can participate: <https://zoom.us/j/294261547>. If you are interested in attending, please RSVP right away to Mrs. Glenda Mason at: dcaplan.cfevent2019@gmail.com.

Thursday, December 12, 2019

Health Sciences Research Building (HSRB) on the Emory University Campus
1760 Haygood Drive, 1st Floor
Atlanta, GA 30322

Dinner 5:30-6:30 pm, Program 6:30-8:00 pm

<p>Dinner Health Science Research Building, Café Area</p>
<p>Welcome Rachel Linnemann, MD Director, Children's+Emory CF Care Center Co-Director, Children's+Emory Pediatric CF Program</p>
<p>Dr. Walter B. Fain, PhD Executive Director, Center for Advanced Communications Policy Principal Research Scientist, Georgia Institute of Technology Home Lab, Director Title: "Research Begins in the Home"</p>
<p>Dr. A. Jay Freeman, MD, MSc Associate Professor of Pediatrics Director of Digestive Health for the Emory+Children's Pediatric CF Program Director Advanced Pancreatic Care Program @ CHOA Medical Director GA Chapter of the National Pancreas Foundation Division of Pediatric Gastroenterology, Hepatology, and Nutrition Title: "New CF Exercise Research Program: Collaboration with Dr. Ryan Harris at Augusta University"</p>
<p>Dr. Jessica A. Alvarez, PhD, RD Assistant Professor of Medicine Division of Endocrinology, Diabetes & Lipids Emory University School of Medicine Title: "Healthy Eating and CF Nutrition Research"</p>
<p>Dr. Rachel Linnemann, MD and Dr. Joanna Goldberg, PhD Co-Directors of the CF Scholars Program Title: "Introduction of Class of 2021 CF Scholars"</p>
<p>Keynote Speaker: Mr. Jerry Cahill CF Advocate and Director Grants & Educational Programs BOOMER ESIASON FOUNDATION Title: "Living, Breathing and Succeeding, with Cystic Fibrosis."</p>

Building the Georgia CF Bridge

We are excited to share the news of the long-awaited research collaboration between the Atlanta CF Center and the Augusta University CF Center, and want to take this opportunity to introduce Drs. Caralee Forseen, Katie McKie, and Ryan Harris as key research leaders there.

In addition to providing exceptional care to people with CF, Dr. Harris' research program is very unique. Almost everyone knows that CF affects the lungs. Did you know that the CFTR protein is present in the blood vessels and muscle, too? Dr. Harris directs the Laboratory of Integrative Vascular and Exercise Physiology (LIVEP) at Augusta University (www.livep.net) where their research program in CF focuses on exercise – an “activity” that needs a properly functioning heart, blood vessels, and muscle. In fact, the Georgia CF Core Center collaboration described on page one of this newsletter has a key focus on exercise.

The Augusta CF research team is really interested in how CF pathology impacts the blood vessels and muscle. Over the past few years the team has been working on a small pilot study to investigate whether sildenafil, an already FDA approved drug, can improve the blood vessel function and exercise capacity in people with CF. Based on the exciting data from this study (<https://www.ncbi.nlm.nih.gov/pubmed/30168731>) and those that were recently published in *Therapeutic Advances in Chronic Disease*, a follow-up multi-center clinical trial was recently funded by the Cystic Fibrosis Foundation.

The purpose of this 3 year clinical trial (<https://clinicaltrials.gov/ct2/show/NCT04039087>) is to determine if 12 weeks of sildenafil can improve exercise capacity, heart function, and blood vessel and muscle function. To learn more about this exciting study, contact us. You can either visit the laboratory's website at www.livep.net or you can call Dr. Harris and his research team at **706.721.LIVE (5483)**.

We look forward to continuing on this exciting path together and understanding more of what we don't know as it relates to CF.

Prepared in collaboration with:

Dr. Ryan A Harris, PhD, CEP, FACS
 Director, Laboratory of Integrative Vascular and Exercise Physiology
 Augusta University, Augusta, GA



Award-winning Trainee, Mr. Vincent Giacalone

We are proud to announce that Vincent Giacalone was recognized at the 2019 North American CF Conference as one of two winners in the Junior Investigator Award for best abstracts. Vincent is a PhD student in the Immunology and Molecular Pathogenesis doctoral program at Emory, and is gaining excellent training under the tutelage of Dr. Rabindra Tirouvanziam, Associate Professor of Pediatrics and key team member in the CF-AIR research center.

The title of Vincent's abstract was: ***“Induced Sputum as an Alternative to Bronchoalveolar Lavage for Evaluation of Airway Inflammation in Young Children with Cystic Fibrosis.”***

2019 Junior Investigator
Best Abstracts



Basic Science
Melanie Spero, PhD
Caltech



Clinical Research
Vincent Giacalone, BSc, PhD Candidate
Emory University

#NACFC 

Research Highlights

Professor Claudia Morris, MD
Division of Emergency Medicine
Department of Pediatrics
Emory University School of Medicine
Member of CF-AIR

Dr. Morris, an outstanding physician-scientist that we helped recruit to Atlanta, is well known for her work in nutritional research that targets inflammation and oxidative stress. She has studied the arginine-nitric oxide pathway in both sickle cell disease (SCD) and asthma, and holds three Investigational New Drug (IND) applications for nutritional interventions for the treatment of SCD and thalassemia. Dr. Morris has led the efforts to have Emory/Children's join the prestigious nationwide pediatric emergency research network (PECARN). We are happy to announce that this was accomplished this fall. Please see the news release: http://news.emory.edu/stories/2019/09/pecarn_emory_childrens/index.html (please copy link into browser)

Professor Anne Fitzpatrick, PhD, RN
Division of Pulmonology, Allergy/Immunology, CF, and Sleep
Department of Pediatrics
Emory University School of Medicine
Member of CF-AIR

Dr. Fitzpatrick is a pioneer in the field of personalized treatment for pediatric asthma, with more than 90 publications in the field, and has served as principal investigator in numerous federally funded studies. Her research has established that pediatric asthma is more heterogeneous than previously thought, leading to varied responses to one-size-fits-all treatment approaches. She advocates for pediatric asthma patients and for "personalized" or "precision" medicine, a new model of diagnosis and treatment, through her roles in national and international organizations. Consistent with that approach, we are happy to share a press release from the National Heart Lung and Blood Institute (part of the National Institutes of Health) about Dr. Fitzpatrick's study published in the *New England Journal of Medicine*, a highly prestigious journal. The study shows that African-American asthma patients respond differently to commonly used asthma

treatments, compared to Caucasian asthma patients. All visits at our site were conducted at Children's. Please see the news release: <https://www.nih.gov/news-events/news-releases/study-assesses-asthma-treatment-options-african-american-children-adults> (please copy link into browser)

Professor Rabindra Tirouvanziam, PhD
Division of Pulmonology, Allergy/Immunology, CF, and Sleep
Department of Pediatrics
Emory University School of Medicine
Member of CF-AIR

We are happy to report the publication of a new study based upon a collaboration between researchers at Georgia Tech (lab of Prof. Krish Roy), the University of Alabama at Birmingham (UAB, lab of Prof. Amit Gaggar), and Emory/Children's (lab of Prof. Rabindra Tirouvanziam). This study tested a novel hypothesis for how the activity of the highly pathogenic neutrophils in the CF airway might actually be used to enable the delivery of a silver bullet medication that will regulate the activity of those same pathogenic neutrophils, *in situ*, in the lung.

This a great example of transformative work performed by our CF@LANTA trainees and we are doubly proud because this research was facilitated in its earliest stages by a pilot research grant from the CF-AIR research center.

Please find open access to the paper and an introductory video here: <https://insight.jci.org/articles/view/131468> (please copy link into browser)

In its full form, this work was supported by the following grants to the Tirouvanziam (T), Roy (R), and Gaggar (G) labs:

- Children's CF-AIR Center pilot grant (T, G, R)
- The Robert A. Milton Chair funds (R)
- The Georgia Tech Foundation (R)
- NSF DMR 1417137 (R)
- NIH/NIGMS-T32GM008433 (R)
- NIH-R01-HLI02371 (G)
- NIH-R01-HLI26603 (T)
- NSF DGE-1650044 (R)
- CF@LANTA RDP grant from the CF Foundation (MCCART15R0)

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 and occasionally at Georgia Tech. 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 (Emory), and IBB 1316 (Georgia Tech), 1st & 3rd Wednesdays (videoconference available 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

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

