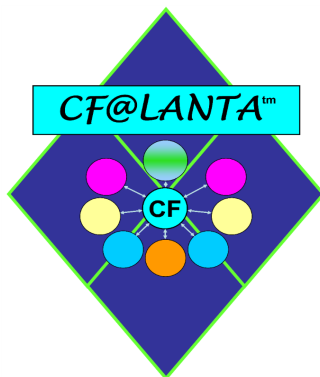
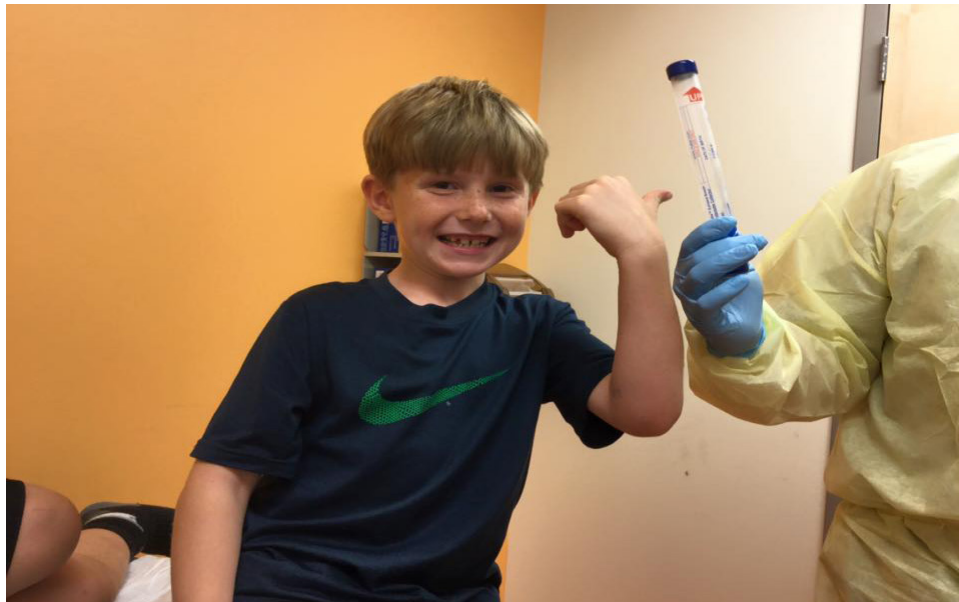


Cystic Fibrosis

Impact Report



Children'sSM
Healthcare of Atlanta

With the help of many stakeholders our two pediatric cystic fibrosis (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.



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.

Even amidst COVID-19, our important CF work continues. Our researchers are working hard to ask and answer important questions related to the pathogenesis of CF in all of its forms. We **continue to study both the pulmonary and nonpulmonary complications of CF**, such as those that attack the endocrine and gastrointestinal systems. We continue to train the next cadre of CF researchers and clinician scientists, including the innovative CF Scholars Program. CF@LANTA continues to provide outstanding clinical care for our patients, even while having to adapt to the new realities imposed upon us by COVID-19. This includes the establishment of enhanced programs in Quality Improvement.





The Children's+Emory CF Care Center has hired a Process Improvement Specialist, Sydney Schiff, that is dedicated to helping **improve quality and efficiency** for both our pediatric program at Children's and adult program at Emory. As an industrial engineer with a six-sigma green belt, Sydney is leading quality improvement (QI) initiatives with the help of both care teams in hopes of **streamlining care** across the entire center. She is working on discipline-specific projects by partnering with our dietitians, genetic counselor, social workers, respiratory therapists, etc., as well as leading center-wide initiatives. Some of these initiatives include helping to create an improved scheduling process for labs and oral glucose tolerance tests, mapping out a treatment protocol for non-tuberculous mycobacterium, developing a lung health treatment guideline, creating a G-tube algorithm, and improving overall clinic efficiency. She is also managing our Patient and Family Experience of Care surveys to track trends and patient-reported feedback to assist in improvement efforts. Both the pediatric program and adult program have been accepted into the CF Learning Network. We are joining this network of top CF centers across the nation to help **test and implement best practices to improve clinical outcomes and experience** of care for all people with CF. This network is driven by quality improvement and partnering with the CF community to improve care and patient experience.

To better partner with our CF community, we now have several Patient and Family Partners joining our QI team for both the pediatric and adult teams. We are quickly realizing how invaluable it is to have their input and participation in this network. Sydney is also serving as the Quality Improvement Leader for both programs and acts as a liaison between the network and center. As a part of this network, both programs are working on a specific CFLN quality improvement project. Both programs have chosen to **focus on increasing the number of clinic visits** that are collaboratively planned with patients and families. The goal of this project is to **empower our patients and families to help drive the agenda during visits to ensure what is important to them is discussed during clinic**. This network also gives us access to many clinical outcome metrics and reports while exploring two new measures – FEV1 Indicated Exacerbation Signal and Health Related Quality of Life.



Sydney Schiff

CF@LANTA, our comprehensive Cystic Fibrosis program, is happy to announce that the NIH has funded our P30 grant proposal to establish the “Georgia Cystic Fibrosis Research and Translation Core Center” (the Georgia CF Core Center) at Emory University, Children’s Healthcare of Atlanta, Augusta University, and the Georgia Institute of Technology. This grant will **leverage activities at these institutions to solve critical problems associated with CF**, focusing on non-pulmonary aspects of CF disease including CF-related diabetes, and the impact of CF on nutritional status, GI function, and liver disease. Unique to our center will be the **study of the relationship between these co-morbidities and lifestyle/behavioral choices** such as diet, exercise, and sleep.



This project also includes 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 only other CF Foundation-accredited CF Care Center in Georgia. Combined, the Atlanta and Augusta programs provide **care for over 900** people with CF. The 61 investigators participating in this proposal reported **\$45.4 million active total funding** as of August 2019, much of which is for CF-related projects.



The Georgia CF Core Center includes **three research Cores** as follows: (1) Diabetes, GI, & Nutrition Core; (2) Lifestyles & Behaviors Core; and (3) Clinical Research and Informatics Core. These research Cores will provide a variety of services to enable investigators to engage in CF research. The Clinical Research and Informatics Core will host the “Georgia CF Data Warehouse,” which will tie together clinical data from our 900 patients, our collection of biological samples from those patients, and laboratory data from our investigators studying those samples. This unique resource will provide to investigators across our participating institutions excellent opportunities to **engage in translational CF research**, as we seek to **identify new therapeutic targets** and **advance our understanding** of current CF therapeutic and lifestyle approaches, ultimately leading to a more comprehensive understanding of CF disease.

In closing, we say none of these advances would be possible without the **generous support of donors like you**. We would like to invite you to join us for a virtual CF@LANTA Update, scheduled for **October 14, 2020**. Please register for this free event by visiting www.cfatl.org, under the EVENTS tab at the top of the page.