

# The Emory+Children's Cystic Fibrosis Center of Excellence

## Update from the Director

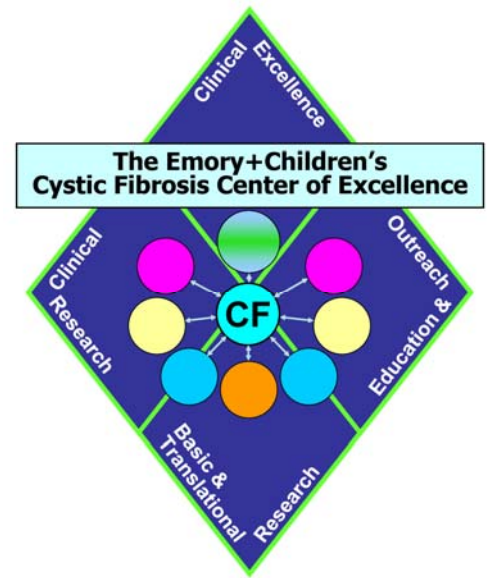
Welcome to the fourth edition of our newsletter. We appreciate your interest in learning about all of the exciting things that are going on in the CF program. There's so much to tell!



Those of you who are paying particular attention will have noticed that this newsletter is being sent on behalf of the CF Center of Excellence rather than from the Center for CF Research. Why the change, you might ask?

We are happy to report much progress in the efforts to establish the Emory+Children's Cystic Fibrosis Center of Excellence, as introduced in previous editions of the newsletter. With the trademarked nickname "**CF@LANTA**," just because this is a much shorter name, the Center of Excellence seeks to become the home of the best comprehensive CF program in the country. Readers of previous newsletters will remember seeing the logo, shown here at right, which incorporates all four parts of our mission: Clinical Excellence, Basic & Translational Research, Clinical Research, and Education & Outreach. The Basic & Translational Research component of the Center of Excellence encompasses the activities of the Center for CF Research, which opened its virtual doors in January 2010. The Center of Excellence serves as an umbrella for the activities at all three clinical sites (Emory/Egleston pediatric, Emory adult, and CHOA/Scottish Rite pediatric clinics and hospitals) and CF-related research and training taking place at Emory, Children's, Georgia Tech, and elsewhere across Atlanta and surrounding cities.

New interest on behalf of Children's Healthcare of Atlanta is helping greatly to make **CF@LANTA** a reality. This, in part, reflects the realization that the CF program is making incredible progress in growing better and stronger, and that our very positive momentum makes it likely that further investment in the CF program will lead to great things for our patients, our institutions, and our city.



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## Great Strides



As many of you know, we have a wonderful relationship with the Georgia Chapter of the CF Foundation. Our scientists, physicians, and staff strongly believe in the work of the CFF, and we partner with them to raise funds to support the important work of the Foundation.

Great Strides is the Cystic Fibrosis Foundation's largest and most successful national fundraising event. This year, we are walking in the Great Strides walk at Georgia Tech on May 18, 2013. Please help us meet our team's fundraising goal of \$40,000 by sponsoring our walkers. Your generous gift will be used efficiently and effectively, as nearly 90 cents of every dollar of revenue raised is available for investment in vital CF programs to support research, care, and education.

Making a donation is easy and secure! Just visit [http://www.cff.org/Great\\_Strides/NaelMcCarty7211](http://www.cff.org/Great_Strides/NaelMcCarty7211) and click the "Click to Donate" button on that page to make a donation that will be credited to our team. Any amount you can donate is greatly appreciated!

CF is a devastating genetic disease that affects tens of thousands of children and young adults in the United States. Research and care supported by the CFF is making a huge difference in extending the quality of life for those with CF. However, we continue to lose precious lives to CF every day. That's why your help is needed now more than ever to ensure that a cure is found sooner - rather than later. To learn more about CF and the CF Foundation, visit [www.cff.org](http://www.cff.org).

Our composite team, **CF@LANTA**, represents investigators and caregivers within the umbrella of the Emory+Children's CF Center of Excellence. We have been represented at each of the Great Strides walks over the past several years (come join us for the walk!), and have helped in accomplishing the record-breaking total of funds raised, all with support from people like you. We hope that we can count on your support again this year.

Together, we can make a difference in the lives of those with CF. Thank you for supporting the mission of the CF Foundation and Great Strides!

## From the Director, continued...

For example, recent analysis of outcomes across the country indicate that no single Center ranks in the top ten for outcomes for both pulmonary and nutritional measures in both their pediatric and adult patient groups. Why not? Why shouldn't the Atlanta program accomplish that goal? Is there any reason why Atlanta should not be the home of the best CF program in the country?

How will we do this? We will be the Center that puts a cap on this disease by leveraging resources that exist only in Atlanta, including the constellation of excellent institutions listed above, to explore new approaches to control and prevent disease progression in our patients. We will gather the interest of community members with ties to Emory, Children's, and/or Georgia Tech, or who care about the growth of biomedical industries in Atlanta, and partner with them to support our efforts. Most importantly, we will keep laser focus on the health of our patients and families. Our expanded mission statement:

By providing top-quality clinical care for our CF patients, supporting the education of our patients/families and the next cadre of CF investigators and caregivers, and engaging in cutting-edge, patient-centered research that will transform our approach to CF, we will turn this deadly disease into a manageable condition.

We look forward to telling you more as **CF@LANTA** comes more fully online, and greatly appreciate your continued interest.

Look for the new **CF@LANTA** website, coming soon. This will be a one-stop-shop for patients and families, caregivers, trainees, and members of the research team, and will host information relevant to all four components of the Center of Excellence. The site is currently under construction, with help from some of our patients and families.

## Clinical Team Changes & New Recruits

The Emory+Children's CF Center of Excellence is presently undergoing some change in staffing, with the retirement of **Dr. Peter Scott** from the Scottish Rite team and the move to Virginia by **Dr. Michael Schechter** from the Emory/Egleston team. We wish both Dr. Scott and Dr. Schechter the very best in these new phases of their lives, and greatly appreciate their years of commitment to our CF program.

Dr. Schechter was recruited in 2006 to become the CF Care Center Director because of his expertise in improving health outcomes in CF. He also had extensive experience caring for children with CF and had a wealth of clinical knowledge, not only about CF but also many other respiratory diseases. In addition, Dr. Schechter was well known at the CF Foundation, nationally, and internationally for his work in CF which significantly increased the visibility of our Care Center amongst the CF community. During his tenure at Emory+Children's, Dr. Schechter made several important contributions. For example, he built a very strong pediatric CF interdisciplinary clinical care team and taught them the tools for quality improvement. Together, he and his team developed several clinical care pathways in order to improve health outcomes in the pediatric CF patients in our clinic. Perhaps his most important contribution was to start the program for CF children admitted to Egleston called "Breathe In/Blast Off". This program provides an individual treatment plan for each CF child admitted to hospital turning a hospitalization for the child and their family into a positive, educational, and supportive experience. Finally, Dr. Schechter built an outstanding CF clinical research team so that participation in clinical research became an integral part of the CF clinic, thus ensuring that we do our part to bring new CF treatments to the clinic as soon as possible. We greatly appreciate Dr. Schechter's contributions to the CF Center over the 6+ years that he was part of the team. Dr. Schechter can be contacted at: [mschechter@vcu.edu](mailto:mschechter@vcu.edu).

We are happy that **Dr. Kevin Kirchner** has taken over the leadership of our Affiliate Program at Scottish Rite. Dr. Kirchner has been an important member of the team at Scottish Rite for 17.5 years, having joined the Georgia Pediatric Pulmonology Associates when he first moved to Atlanta. Abby Knapp had this to say about Dr. Kirchner: *"I've been Dr. Kirchner's patient since I was 7 weeks old. I'm very proud of him and his new position. He is always very kind and attentive. He always looks out for what's best for you. I know he'll do very well in this new position."* We note that **Dr. Josh Freeman** also shifted very recently from the Emory program to the program at Scottish Rite.

Meanwhile, we are well on our way for recruitment of several physicians and physician-scientists to the Emory pediatric site, not just to replace Dr. Schechter but also as part of our plan to grow the clinical program. In this first phase of recruitment, we are at various stages of interviews and negotiations with four physicians/physician-scientists, who will bring great strengths to the program. One of the latter is a candidate for Care Center Director. Until we identify a new Care Center Director, **Dr. Stecenko** has taken on the responsibility of this role as she has served as CF Center Director at the University of Florida and at Emory/Egleston before recruiting Dr. Schechter.

With added resources from both Children's and Emory, the Atlanta team will continue to recruit top clinical staff, as well as excellent researchers, to join our efforts as we become the best CF program in the country.

**Seth Walker, MD** Among the significant changes in physician/physician-scientist staff, we are fortunate to have recruited Dr. Seth Walker as Director of the Emory Adult CF Program. Dr. Walker was recruited to Emory following the loss of Dr. Lindy Wolfenden to cancer, and joined us in June 2011. Dr. Walker is introduced in the following section.



Dr. Walker has now been the director of the Emory Adult CF Clinic for the past two years. A native of West Virginia, he graduated from a combined internal medicine-pediatrics residency at Virginia Commonwealth University in Richmond, VA. He then completed a fellowship in adult pulmonary and critical care medicine at the University of Rochester in New York. Not wanting to give up on his pediatric training, he performed research in pediatric lung function testing as a fellow. Dr. Walker briefly returned to his hometown to work at West Virginia University before coming to Emory in 2011. We are fortunate to have Dr. Walker's leadership in the Center of Excellence, and he and his colleagues have successfully grown the Adult Program both in size and quality since his arrival.

*Continued on the next page...*

## Clinical Team Changes & New Recruits cont'd

**Dr. Seth Walker continued**—A clinician at heart, he has increased the number of CF clinics a week and with good reason, as the clinic has increased from about 160 patients to more than 230. Along with the adult care team, he has focused on continual quality improvement, always believing that all aspects of the clinic's activities can be better. Dr. Walker has continued the adult program's involvement in the CF Foundation's Therapeutic Development Network. Additionally, he is looking to increase the number of clinical studies started by doctors here in the clinic. He is interested in comparative effectiveness trials, which determine differences between similar treatments and help to establish best practices.

When not at work (or bringing work home), Dr. Walker enjoys visiting Atlanta's many parks, museums, and restaurants with his wife and son. He occasionally likes to pretend he is still in shape and plays basketball and cycles. He plans to ride in the CF Cycle for Life this November and hopes to finish the 30 mile course without the need of medical attention himself.

## Research Team Changes & New Recruits



*Assem Ziady, PhD*

Last summer, after the distribution of our most recent newsletter, **Dr. Assem Ziady** was named as Associate Director for Basic and Translational Research for the Center of Excellence. Dr. Ziady is Associate Professor of Pediatrics, and joined our Center in September 2011 as one of our first investigator recruits. Coming to us from the CF program at Case Western Reserve University, Dr. Ziady brings a rich experience in how a successful CF research center operates. He is helping to guide the establishment of the infrastructure supporting the research of all members in our team. Dr. Ziady also will take a lead role in pursuing the establishment of the Atlanta Systems Biology of CF Collaborative, taking advantage of the strengths in systems biology that exist at Emory and Georgia Tech, in an

effort to successfully apply these approaches to solve the mystery of CF. We are very fortunate to have Dr. Ziady working with us in this new additional role.

**Joanna B. Goldberg, Ph.D.** We are happy to introduce our most recent recruit to the Center of Excellence and the Center for CF Research, Dr. Joanna Goldberg, Professor of Pediatrics. Dr. Goldberg brought her research and teaching program to Atlanta only four months ago, and yet she is already making great contributions to the Center's work. Dr. Goldberg and her team are described in the following section.



*Dr. Goldberg's lab from left to right: Dina Moustafa, PhD, Josh Owings, PhD, John Varga, PhD, Joanna Goldberg, PhD*

Dr. Goldberg received her BA in Biology from Boston University and PhD in Microbiology and Immunology from University of California (UC), Berkeley. Following postdoctoral training at UC Berkeley, she took her first faculty position in Boston at the Channing Laboratory, Brigham & Women's Hospital, Harvard Medical School. In 1996, she was recruited as an Associate Professor to the Department of Microbiology at the University of Virginia and moved up the ranks to Full Professor.

Dr. Goldberg's research focuses on the strategies used by bacteria to cause diseases in humans; in particular, respiratory infections in patients with CF. Her laboratory investigates the synthesis and regulation of surface polysaccharides and other potential adhesions and virulence factors from *Pseudomonas aeruginosa* and members of the *Burkholderia cepacia* complex, both of which are key pathogens in CF. The general approach is to perform bioinformatic and

genomic analysis of these bacteria and to construct and characterize specific bacterial mutants. These constructed mutants are then monitored for relevant phenotypic and genotypic characteristics and changes in the virulence and physiology using *in vivo* and *in vitro* models of infection. The long-term goal of this work is to devise rational methods to disrupt virulence and promote clearance of infecting bacteria.

Dr. Goldberg joined the Center and the Department of Pediatrics at Emory University School of Medicine as a Full Professor in January 2013. Since arriving at Emory she has begun to expand her research interests to include studies of the microbiome of CF, changes in the metabolic profile of respiratory pathogens associated with acute exacerbations in CF, and determining why respiratory infections are more severe and frequent in individuals with CF-related diabetes.

The research in her laboratory is supported by grants from the CF Foundation and the NIH.

## Milestones in Program Growth

### November 13, 2012: Presentation at Joint Board Meeting

This past November marked the fourth joint meeting of Emory's Woodruff Health Sciences Center Board and the Children's Healthcare of Atlanta Board. For the first time, the agenda included presentations on specific programs; we are honored to have been invited to present the current state and the plans for the Emory+Children's CF Center of Excellence. Drs. McCarty and Stecenko were able to describe how we are leveraging the long-standing commitment from Emory and Children's in CF Care, and the recent establishment of the Center for CF Research, which together have positioned us perfectly to grow the CF Center of Excellence to be the comprehensive CF center known as best in Clinical Care, Education, and Research. We described our recent accomplishments, and plans for the near future, and introduced this assembly of amazing attendees to the strong group that comprises our team. Comments received following our presentation were very strong and supportive.

### November 26, 2012: Visit to CF Foundation Headquarters in Bethesda, MD

In recognition of the massive amount of change our program has undergone in the past ten years, the leaders of the Center of Excellence asked the top officers at the CF Foundation if they would host a visit from us. Our plan was to treat this as an inverse site visit, of sorts, so that we could tell them about all that we had accomplished recently while also seeking to strengthen our relationship. The following members of [CF@LANTA](#) converged on Bethesda on November 25: Nael McCarty, PhD; Arlene Stecenko, MD; Seth Walker, MD; Assem Ziady, PhD; and Joanna Goldberg, PhD. After spending the evening preparing for our visit, Drs. Ziady, Goldberg, and McCarty stopped by the NIH the next morning to speak with Dr. Susan Banks-Schlagel, Senior Scientific Advisor, Airways Biology and Disease Branch at the National Heart, Lung and Blood Institute. All five of us then met at the CFF offices, where we were able to spend the majority of the day with the following leaders of the CFF: Dr. Robert Beall, President and CEO; Dr. Preston Campbell, Executive Vice President; Dr. Bruce Marshall, Vice President for Medical Affairs; Dr. Chris Penland, Senior Director for Research; and Dr. Elizabeth Joseloff, Director for Integrative Biology. Each member of the visiting team contributed to part of the presentation, and we had two break-out sessions for part of the day: one focusing on research and the other on clinical care. We left Bethesda feeling that we had accomplished our goals, and that we were entering a new era of cooperation with the Foundation and joint focus on solving the problem of CF.

The following day, we received a message of thanks from the Foundation, which came along with an offer of some limited financial support to help our Center continue on its exciting trajectory of growth, until the next opportunity to compete for CFF Center Grant funding. The members of the visiting team are very grateful for the advice and support we received, and continue to receive, from our partners at the CFF.

### March 15, 2013: Visit of the CFF GA Chapter

The CF Center of Excellence benefits from an excellent relationship with the GA Chapter of the CF Foundation. For example, Dr. McCarty meets regularly with Mr. Scot Rittenbaum, Executive Director, and Mrs. Molly Taggart, Associate Executive Director. The [CF@LANTA](#) team has contributed to the amazing successes in fundraising for the CFF represented by the record-breaking sums gathered through the "Great Strides Walk-a-Thons" in Atlanta for 2011 and 2012. (See Page 2 for a note about Great Strides 2013.) Members of our team have gone to the Chapter office to provide some continuing education for staff members on the pathophysiology of CF and new research developments. Several of our team members are making new connections with the Chapter staff, so that we can continue to work together toward our common goal.

*Continued on the next page...*

## Milestones in Program Growth cont'd

### March 15, 2013: Visit of the CFF GA Chapter



Most recently, **CF@LANTA** hosted a visit from the GA Chapter staff. We took our guests for a tour of the labs in the Emory-Children's Center building, had them meet the three new CF investigators that we have recruited to Atlanta thus far (Drs. Tirouvanziam, Ziady, and Goldberg) as well as some of the Atlanta-based investigators that we have recruited into CF (Drs. Hansen and Koval), and then got to know each other over a nice catered lunch. We talked about new happenings in the CF world (including the new infection control guidelines released just the day before) and about ways that we might be able to collaborate on some exciting ideas our team has for joint activities. We appreciate

having this opportunity to get to know our local partners better, and look forward to expanding and strengthening our relationship.

## Other News

### CF Nutrition and Social Work Consortium

March was an exciting month for all of the Atlanta Care Centers as we hosted the 7<sup>th</sup> Annual CF Nutrition and Social Work Consortium in downtown Decatur, March 21-23, 2013. The dietitians and social workers from the Emory Adult and Pediatric Programs along with the Scottish Rite Pediatric Program worked diligently over the past year to organize this exciting meeting in our city. Additionally, team members from Georgia Regents Health System worked alongside their Atlanta colleagues during the conference.

Dietitians and Social Workers from care centers around the US came to Atlanta to build networks between CF professionals and to be further educated around nutrition and psychosocial needs specific to the CF pediatric and adult populations. The Consortium had its' highest attendance ever, including 110 Dietitians and Social Workers representing 75 different CF centers from across the country.

Several Atlanta care center staff members, physicians and researchers shared their expertise with conference participants through presentations. This included a "Nuts and Bolts" overview of CF care, from Dr. Seth Walker; Dr. Vin Tangpricha spoke about "Vitamin D: Immunity and Bone Health"; and Dr. Nael McCarty taught the attendees all about "CF Research: From Molecules to Mankind". The weekend concluded with a panel discussion on transition with several patients and parents from the Emory Adult program sharing their experiences on moving from pediatric to adult care. This important conference proved to be a great opportunity for education and networking. We appreciate the work that our team members put into this, including the leadership by: Jessica Enders, RDLD, Clinical Dietician in the Emory Adult CF program; Shaina Blair, LCSW, Social Worker III in the Emory Adult CF program; and Liz Revilla, RDLD, Clinical Dietician in the Emory Pediatric CF program.

### **New main phone number for the Emory Adult CF clinic**

In order to better serve our patients we have developed a phone line that is just for the Emory Adult CF program and can connect you to any of our staff members.

**The new main line is 404-778-7929.**

The main menu from this number will provide you with the following options that will direct you to each individual's extension.

After normal business hours the line will take you to the Emory Operator to get in touch with the on call physician if needed or a message can be left for any of the staff.

We hope this new number and phone tree will make getting in touch with the team easier and more efficient.

## Recent Accomplishments

Please see the following link for a video produced by the Emory News Center regarding our CF Research Program: [http://news.emory.edu/stories/2013/05/video\\_cystic\\_fibrosis\\_research/index.html](http://news.emory.edu/stories/2013/05/video_cystic_fibrosis_research/index.html)

- ◆ Dr. McCarty was named Chair of the organizing committee for “The Enigmatic Chloride Ion: Transport, Regulation, and Roles in Physiology”, the International Meeting of the Society of General Physiologists, Woods Hole, MA, 2013.
- ◆ Dr. Ziady was made senior editor of a book on “Real-time imaging of gene expression.”
- ◆ Dr. Koval is Chair and Co-organizer of the upcoming 2013 International Gap Junction Conference this July in Charleston, SC.
- ◆ Dr. McCarty took over as Director of the Molecules-to-Mankind PhD program at Emory, September 2012.
- ◆ Dr. Ziady won the award for the Best Scientific Publication for Clinical and Translational Science in the Emory Department of Pediatrics, for his paper entitled: “Interaction with CREB binding protein modulates the activities of Nrf2 and NF- $\kappa$ B in cystic fibrosis airway epithelial cells”.
- ◆ Dr. Koval was named to the Editorial Boards of *PLoS ONE* and *Tissue Barriers* in September, 2012
- ◆ Dr. Ziady was Invited to Spain for the European CF Basic Science meeting in March 2013 for talk on “Nrf2 dysfunction in CF.”
- ◆ Dr. Ziady will serve as co-chair of “Chemical and Molecular Conjugates” session at the American Society of Gene and Cell Therapy meeting in May 2013.

## Oral Presentations at the 2012 North American CF Conference

- ◆ Dr. Randy Hunt (Adult pulmonary fellow in the McCarty and Hansen labs): “Elevated Airway & Systemic Glucose Impedes Lung Bacterial Clearance in a Murine” at the 2012 North American CF Conference
- ◆ Dr. Ziady: “Nrf2 Dysfunction in CF & Approaches to Activation” at the 2012 North American CF Conference
- ◆ Dr. Koval Chaired a Featured Topic oral platform session at Experimental Biology 2013 in Boston: “Cell Stress and Lung Disease”
- ◆ Dr. Stecenko: “Why Hyperglycemia Is Bad - Link Between Glucose, Oxidative Stress & Inflammation” at the 2012 North American CF Conference
- ◆ Dr. Schechter: “Macroevironmental Influences on Early Lung Disease” at the 2012 North American CF Conference
- ◆ Dr. Liz Revilla, Research Dietician: “High Dose Vitamin D for Prevention & Repletion of Vitamin D Deficiency in a Pediatric CF Population: Results of a Quality Improvement Project” at the 2012 North American CF Conference
- ◆ Dr. Schechter: “Comparing Effectiveness & Comparing Costs of CF Therapies” at the 2012 North American CF Conference
- ◆ Marcela Preininger (Tirouvanziam lab): “Pure, FACS-Sorted, Live Neutrophils From CF Airways Display Marked Changes in Their Transcriptional Profile, Consistent with Reprogramming” at the 2012 North American CF Conference
- ◆ Dr. Stecenko: “Coronary Artery Disease in Cystic Fibrosis - Is it More Common Than We Think?” at the 2012 North American CF Conference
- ◆ Dr. Schechter: “Relationship of Socioeconomic Status & Environmental Tobacco Smoke Exposure with Disease Outcomes in the EPIC Observational Cohort” at the 2012 North American CF Conference
- ◆ Dr. Stecenko: “Redox Imbalance in the Development of CFRD” at the 2012 North American CF Conference

## New Extramural Grants

- ◆ Dr. Ziady was awarded a subcontract on a new NIH-funded study of early CF lung disease.
- ◆ Dr. Ziady was awarded a new CF Foundation grant: “Validation of novel markers of disease severity in CF subjects.”
- ◆ Dr. McCarty, Hansen, and Koval were awarded a new CF Foundation grant: “Mechanistic Studies Linking Mutations in CFTR to Airway Glucose in CFRD.”

## New Extramural Grants continued

- ◆ Dr. Stecenko was awarded a new CF Foundation grant: "Redox Imbalance and the Development of CF Diabetes."

## New Publications

- ◆ The Ziady group published two peer-reviewed papers on the mechanism of Nrf2 dysfunction in CF epithelia and TB stimulation of T cells
- ◆ The Tirouvanziam group has just had a major paper accepted for publication: Laval et al., "Metabolic adaptation of neutrophils in cystic fibrosis airways involves distinct shifts in nutrient transporter expression," *Journal of Immunology*, 2013, in press
- ◆ Dr. McCarty and his lab team, including Drs. Cui and Zughaier, published three papers on the evolution and function of CFTR, the protein defective in CF, and one paper on host-pathogen interactions in the CF lung.
- ◆ Dr. Koval had a review article published in the 2013 edition of *Annual Reviews of Physiology*: "Claudin Heterogeneity and Control of Lung Tight Junctions".

## New Patents and Disclosures

- ◆ Dr. Ziady was awarded a provisional patent regarding manipulating inflammatory signaling in CF.
- ◆ Dr. McCarty was awarded US patent number 8,106,013 for a peptide toxin that interacts with the CFTR protein.
- ◆ Dr. McCarty was awarded US patent number 8,324,158 for a peptide toxin that interacts with ClC-2 chloride channel proteins.

## Current Funded Pilot Studies

***The Center for CF Research, with funding from Children's Healthcare of Atlanta, was able to support the following two pilot projects for 2012-2013:***

**Title of Project:**

*Development of a CFRD Mouse Model*

Amount of Award: \$50,000

Principal Investigator: Jason Hansen, PhD, Dept. of Pediatrics, Emory

**Title of Project:**

*Phage-Nanoparticles to Reduce Cystic Fibrosis-Associated Infections*

Amount of Award: \$50,000

Principal Investigator: Andres Garcia, PhD, Dept. of Mechanical Engineering, Georgia Tech

Co-Investigators:

Nael McCarty, PhD, Dept. of Pediatrics, Emory

Susu Zughaier, PhD, Dept. of Pediatrics, Emory

Rodney Donlan, PhD., Clinical and Environmental Microbiology Branch, CDC

We thank the members of our External Advisory Board for serving as reviewers of these proposals.

## What is the CF Biospecimen Registry?

This is a biorepository of samples from cystic fibrosis patients including sputum, throat swabs, nasal scrapes, blood, exhaled breath condensate, bacterial isolates, and bronchoalveolar lavage fluid with the intent to find biomarkers predictive of acute pulmonary exacerbations. Since August 2010 we have collected samples from the clinics and hospitals at Emory and Egleston, and we are now officially beginning to include Scottish Rite as a new location for subject enrollment. Please email [cfbioregistry@gmail.com](mailto:cfbioregistry@gmail.com) for additional information.



## Visitors



**A.P. Naren, PhD**, University of Tennessee-Memphis, traveled to Atlanta to

give a seminar on “Macromolecular complexes of CFTR in Cystic Fibrosis, CFTR-related disorders” on November 1, 2012



**Jon Koff MD**, Yale University, joined the team for a workshop

on “Viral induced EGFR signaling suppresses interferons; a novel epithelial pathway relevant to CF.” on November 28, 2012



**Robert Tarran, PhD**, University of North Carolina joined the team in Atlanta for a seminar on “ASL

Volume Homeostasis and CF Lung Disease Pathogenesis” on December 4, 2012



**Terry Robinson, MD**, Stanford University Medical Center traveled to Atlanta to give a seminar on

“Aggressive Early Intervention—A Paradigm Shift in CF Care” on January 23, 2013



**JP Clancy, MD**, University of Cincinnati, traveled to Atlanta to give a seminar on “TGF-beta and Ion Transporter

Regulation: A Means to Modify the CF Phenotype” on February 12, 2013



**Jennifer Bomberger, PhD**, University of Pittsburgh, joined the team in Atlanta to

give a seminar on “Pseudomonas Aeruginosa-Respiratory Virus Interactions in the Cystic Fibrosis Lung” on February 28, 2013



**Carolyn Cannon, MD, PhD**, University of Texas Southwestern Medical Center traveled to Atlanta to give a seminar on

“Aerosolized Nanoparticle Therapeutics for Cystic Fibrosis Pulmonary Infections” on March 13, 2013



**Jane Taylor, MD, FAAP**, University of Missouri—Kansas City School of Medicine joined the team in Atlanta to give a seminar on

“Impact of Intercurrent Respiratory Infections on Lung Health in Infants Born <29 Weeks with BPD” on March 19, 2013

## Special Thanks to...

### **Children's and Mr. Doug Hertz for Quasi-Endowment in his Name**

Following a historical practice, Children's Healthcare of Atlanta's Board of Directors recently designated a portion of the Children's endowment to support an area of interest important to Mr. Doug Hertz. All past chairmen of the System Board and Foundation Board have been honored on their departure with this designation of funds to an area of interest. For more than 20 years, Mr. Hertz has served as a Trustee and most recently as both Chairman of the Foundation Board and Chairman of the System Board. In honor of his long-standing volunteer leadership, Children's has designated two million dollars of the current endowment in support of the Children's Cystic Fibrosis Program. Funds generated by this designated quasi-endowment will be used to support the current program and its growth over time. We are honored to be the recipient of these designated funds and look forward to continuing the great legacy Mr. Hertz has at this institution to better the care and research available to our CF patients and families well into the future.

### **Mr. and Mrs. Billy and Olivia Blanchard**

Billy and Olivia Blanchard have a long-standing relationship with Children's Healthcare of Atlanta. As a patient family, volunteers and supporters, Mr. and Mrs. Blanchard have experienced all facets of the work being done at Children's and continue to show their appreciation for this institution through contributions of both their time and their finances. Mr. and Mrs. Blanchard have supported various areas of need in the Children's system and although they are not personally affected by Cystic Fibrosis, they were moved to hear about the work underway in the Children's Center for Cystic Fibrosis Research. After hearing about the ideas and projects being pursued by Dr. Nael McCarty and his team, Billy and Olivia made a financial contribution of \$25,000 in support of the research being pursued. We are extremely grateful for this wonderful contribution and look forward to a continued partnership with Mr. and Mrs. Blanchard as we battle this disease for our patients and families.

## Highlighting one of our Patients



Olivia is the 16 year old daughter of Marileigh and Bill Taylor. She is a patient at the Scottish Rite clinic, where Dr. Julie Sedor is her pulmonologist. Olivia attends Eagles Landing Christian Academy, in the 10th grade. Her favorite activities are soccer and competitive swimming. As part of the Transition Program, Olivia wrote the following poem. We thought our readers might like to see it.

Thanks Olivia, for sharing this with us.

### Cracks

*I love this soul  
for what it is and what it's not.  
I love the body that holds it too.  
And although it's not perfect---  
It is.  
Because you need cracks to shine and see through.*

*All in all I'd say I'm lucky.  
That my body isn't watertight  
or I wouldn't be able to touch peoples lives.....  
nor they touch mine  
And we'd lose our sight (on what matters, at least)*

*We can't be watertight vessels  
And expect to love or to live  
Because only when we we're broken  
Are we able to see that gift God gives.  
No two cracks are exactly the same.  
And just because someone's isn't as evident  
doesn't mean they don't feel pain.*

*But I think that's the whole point-  
It does no good to dwell on our own  
but seek to comfort someone else  
so they know that no one's alone.*

By: Olivia Taylor, 2013