

CF FAMILY NEWSLETTER

Fall 2024



A Distinguished Career: Farewell Dr. Retsch-Bogart!

Dr. George Retsch-Bogart recently retired after a long and brilliant career with the UNC Pediatric Pulmonology Division. In this article, we will attempt to summarize some highlights of his many accomplishments and contributions to our field.

George graduated from the University of Cincinnati College of Medicine in 1978. After residency training in pediatrics at the University of Minnesota, he remained there from 1981-1986 as a staff pediatrician and Clinical Instructor. He came to UNC for fellowship training in pediatric pulmonology in 1986-89. He then joined the UNC faculty, rising through the ranks to tenured Professor in 2012, and remained a respected faculty member until his retirement in 2024.

Here at UNC, George held numerous important leadership roles during his faculty career. He served as Medical Director for the pediatric bronchoscopy laboratory and for the Children's Airway Center. He was the Pediatric Pulmonology Division Chief from 2011-2015. He served as the NC TraCS Participant and Clinical Interactions Resource (PCIR) Director, and Medical Director of the CTRC. Finally, he served as Associate Director for the UNC CF Clinical Care Center for many years.

In terms of service to the state of North Carolina, George led the successful effort to institute newborn screening for CF in our state. This was a complex and difficult process which has clearly benefited the children of North Carolina significantly. Unlike in past years, almost all children with CF are now identified at birth, which enables us to begin working right away with fami-

lies to put preventive care in place, improving long term outcomes of children with this condition. After successful initiation, George continued as an active, key advisor to this important state program.

From early in his career, George has been an active and successful researcher, and he quickly became a national leader in clinical trials involving children with cystic fibrosis (CF). He maintained funding from a large number of grants from the CFF, NIH, and the pharmaceutical industry, and gave numerous invited talks at the national CF Therapeutics Development Network (TDN) meetings and North American CF Conference. His work to help bring the CFTR modulator drugs to FDA approval and application in children is a towering achievement which has dramatically improved the lives of thousands of children and families living with CF (more on this below).



Despite his multiple leadership roles in clinical trials and translational research, George also continued to see CF patients in clinic, where he has been a beloved longtime physician for many of these patients. He also covered our pediatric pulmonology inpatient and consultation service and did many bronchoscopies for our procedure service. He was always one of the most highly rated teachers in the Pediatric Pulmonology division, for both residents and fellows. In recognition of his excellence as a physician, George has received awards, including the Richard C. Talamo Distinguished Clinical Achievement Award from the Cystic Fibrosis Foundation, *(continued on page 2)*

A Distinguished Career: Farewell Dr. Retsch- Bogart! *(continued from page 1)*

the James Emonson Faculty Honour from the NC Children's Hospital, and Best Doctors in America.

In particular, George played a critical role in expanding the CF Therapeutic Development Network (TDN) to enable the successes of the last 2 decades in finding new treatments for CF, including the highly effective CFTR modulators Kalydeco® and Trikafta®. His role was two-fold: he enabled TDN centers to conduct the research and refined the study designs proposed by sponsors to foster success. George was appointed to be the faculty advisor to the TDN Coordinating Center in 2007 and oversaw the expansion of the network



from 18 research centers to, eventually, over 90. He identified and facilitated needed training. He benchmarked best practices at multiple research sites and built a quality

improvement/mentoring program to facilitate the highest quality clinical research at many TDN research centers. He often was called upon to have the hard conversations with centers that were having issues; because of his humble, servant leadership style he could have those conversations in ways that led to success. In addition to enabling TDN research centers to effectively conduct the studies, he also was the chair of the Clinical Research Executive Committee (CREC) of the TDN. The CREC sets the strategic vision for the TDN and establishes the research priorities for the network. A key activity of the CREC is to critically review the study protocols that are proposed for conduct in the TDN. In George's role as chair, he summarized the discussions and concerns related to these reviews to provide to sponsors, and again, was often the person who had conversations with them about the likelihood of success of their study. What stood out about George when engaging with sponsors, was his integrity; if he felt that a study could not succeed or had

not been designed in a way that was optimal for people with CF, he would not compromise. The TDN will miss George, but as we could expect from him, he took the last year to prepare other leaders to take on his many roles, leaving the TDN prepared for the challenges ahead.



In summary, we in the UNC Pediatric Pulmonology Division, CF care teams and researchers around the world, and people living with CF salute Dr. George Retsch-Bogart. His leadership, integrity and outstanding example to us all are missed every day. We wish him a happy and healthy retirement!

Article contributions by Jill Van Dalfsen, Director of Network and Clinical Trial Operations at CFF TDN Coordinating Center, Patricia Burks, RN, MA, CCRC, Clinical Trial Affairs Sr. Director at CFF, Terry Noah, MD, Jacob A. Lohr Distinguished Professor of Pediatrics, UNC Pediatric Pulmonology, and Marianna Henry, MD, MPH, Assoc. Professor of Pediatrics, UNC Pediatric Pulmonology.



Changing Faces at UNC's Pediatric CF Center!

Be on the lookout for these new faces when you comes to clinic!



First, the CF Care Team bids a heartfelt goodbye to Robert "Drew" Gardner. Dr. Gardner recently completed his pediatric pulmonology fellowship, where he was a CF Foundation clinical fellow and had several research interests including primary ciliary dyskinesia. While we (and his CF families) will miss him, he has not gone too far, taking a position at Levine Children's Hospital in Charlotte, NC. He will continue to see children with CF in Charlotte as well as serving as the Associate Director of their Pediatric CF Care Program.



The CF Care Team welcomes Sydney Hendricks, our new first year pediatric pulmonology fellow. Dr. Hendricks is a native of eastern North Carolina who did her undergraduate and medical school training at East Carolina University. Some of you may have met Dr. Hendricks, as she has been a general pediatric resident at UNC for the past three years. Dr. Hendricks has not yet decided her fellowship scholarship focus, but she has passions for advocacy and education, and she was recently awarded a CF Foundation clinical fellowship. We look forward to working with Dr. Hendricks as she learns about CF and other pulmonary conditions during fellowship.



The CF Care Team is also pleased to announce that Dr. Jane Gross will be joining the faculty at UNC this Fall. Dr. Gross is coming from National Jewish Health, where she been involved in numerous clinical trials and served as Associate Director of their Cystic Fibrosis Therapeutics Development Center. Her primary research interest is in how respiratory infections such as non-tuberculous mycobacteria (NTM) spread from person to person, particularly in healthcare settings. Through her studies, she has developed a toolkit to identify and stop healthcare-associated outbreaks within CF Care Centers. We are very excited that Dr. Gross has chosen to bring her CF clinical and research expertise to Chapel Hill!

The Virtual North American Cystic Fibrosis Conference: September 26-28

nacfc 2024

Join us virtually for the North American CF Conference on September 26-28! You can have access to several of the sessions live by registering for free here: <https://www.nacfconference.org/virtual-nacfc>

There will also be several sessions available on the CF Foundation's YouTube channel two weeks after the conference concludes. The channel can be found here: <https://www.youtube.com/user/CysticFibrosisUSA>



CF Nutrition: School Lunches

It's back to school time for a lot of children and that makes us Nutritionists think about school lunch. Your child may eat food that the school provides, food that you pack from home, or a combination of these. Do you enjoy packing lunches or feel it's a chore? Do you talk with your child about choices they can make at school for lunch? Are you looking for new menu ideas to pack for lunch? Check out the tips below from some other great Registered Dietitians/Nutritionists. You may be able to use these ideas just as they are, or you may need to adjust them to have more calories or more sodium based on your child's nutrition needs.

How to Get Kids to Pack a Good School Lunch, April 30, 2021, By Jill Castle, MS, RDN <https://thenourishedchild.com/lunch-box-packing-tips/>

How to Get Kids to Eat Healthy at School, March 5, 2021, By Jill Castle, MS, RDN <https://thenourishedchild.com/school-food/>

Teenager Not Eating Lunch at School? (Here's Why + Tips), November 16, 2023, By Jill Castle, MS, RDN <https://thenourishedchild.com/trouble-my-teens-school-lunch/>

6 Tips for Packing Healthy Lunches for Kids from a Registered Dietitian, by Alex Turnbull, RD Jul 18, 2024 <https://myfamilynutritionist.com/healthy-lunches-for-kids/>

10 Picky Eater Lunch Box Ideas from A Registered Dietitian, by Alex Turnbull, RD Jul 18, 2024 <https://myfamilynutritionist.com/picky-eater-lunch-box-ideas/>

Submitted by Kimberly Stephenson, RD & Kelly Baumberger, RD

504 Plans & CF

If your child attends public school, they are eligible for a 504 plan.

What is a 504 plan? A 504 plan is a legal document for students with physical/medical needs that protects their rights and health while at school. A 504 plan is different from an Individualized Education Plan (IEP). The 504 plan allows for certain accommodations for your child. Some accommodations may be to have and take enzymes (or other medications) in school, access to extra snacks and drinks through out the day, unrestricted access to the bathroom, or allowances made in the event of illness or hospitalization. The specific accommodations needed or recommended will depend on each child's specific needs while at school.

How do I get a 504 plan? There are a few steps to take in order to get a 504 plan implemented for your child. Because the 504 is a legal document, there has to be a meeting between parents (and children 14+ years old) and school personnel to discuss the needed accommodations and document them.

1. Contact the school to request a 504 meeting.
2. You will receive a written notice of the date of the meeting (at least 10 days in advance)
3. Attend the meeting and the plan will be discussed. You will need to either bring a letter from your CF team to the meeting or send it in before.

Do we really need one? Your CF team does recommend it, but the decision is completely yours!

What if my child attends a private school? Private schools are not required by law to provide accommodations, however in the majority of cases, they will work with families to make a plan that best meets the needs of each child.

Questions? Reach out to your CF Social Worker to talk about your child's needs.

Submitted by Amy Sangvai, MSW, LCSW & Ellen Penta, LCSW

RESEARCH

Many CF studies are ongoing at UNC! More information on clinical trials being done here at UNC and around the country can be found on the Clinical Trials page at www.cff.org or by searching www.clinicaltrials.gov. You can also contact one of your hard-working Pediatric CF Research Coordinators directly:

Grace Morningstar at grace_morningstar@med.unc.edu.



Volunteers Needed!

Our research team needs preschool-age children (3-5 years old) who will help us practice and earn certification with a non-invasive procedure called multiple breath washout (MBW). This can be done before or after a clinic visit.

MBW is a test that shows researchers how well lungs clear gases found in the air and whether there are areas of the lungs where air is trapped (by mucus, for example). Your child would breathe normally during the test, while watching a movie and wearing a facemask. The task requires your child to breathe 100% oxygen while connected to a special machine that measures how fast your child clears certain gases in the air each time they breathe in and out. This process is repeated a minimum of 3 times and typically takes no more than 5 minutes per attempt.

If interested, please contact Julie Goudy at 984-974-2364.

Understanding Oral Diseases in CF to Develop Tailored Preventative Dental Interventions

Previous studies have shown that young children with CF have less caries compared to their peers without CF. However, in teenagers and young adults with CF caries is more frequent than in people without CF. In this study we evaluate the frequency of caries and periodontitis in people with CF ages 12-30 years. We also collect information on aspects that can explain the higher frequency of such problems in CF. Such risk factors may be different composition and flow of saliva, different bacteria in the mouth/saliva and the higher frequency and different foods consumed by many individuals with CF.

Study details if interested:

Three annual visits combined with a CF clinic visit

Free dental exam in 1st and 3rd year

Collection of saliva and sputum

Questionnaires at time of the study visits

For more information, contact Sundass Khan at sundass_khan@med.unc.edu.





Flu shot season is here! If your child gets a flu shot at an outside clinic, please let us know!



Join in on CF Parent Education Nights!

Don't miss an opportunity to join upcoming virtual workshops to help you navigate life as a parent of a child with Cystic Fibrosis! You can find out more, watch previous workshops, and sign up here:

www.cfparenteducation.com

Help Us Make the Newsletter Better!



If you would like to submit an article or have an idea for the next CF Family Newsletter, please contact Kelly Moormann at kelly.moormann@unc.edu.

Contact Us

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Visit us on the web at:
www.uncchildrens.org/uncmc/unc-childrens/care-treatment/pulmonary-care/cf

UNC MyChart: <https://myuncchart.org>

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