



North American Cystic Fibrosis Conference (NACFC)

Nearly 4,000 cystic fibrosis researchers and health care professionals gathered in Orlando, Fla., Oct. 11 – 13 for the 26th NACFC, sponsored by the Cystic Fibrosis Foundation. Your UNC CF team was well represented by all disciplines, including physicians, researchers, nurses, respiratory therapists, social workers, and dietitians. In addition to providing dozens of presentations to CF colleagues from around the world, this meeting provides us with new information on care and drug development, and allows the exchange of new ideas about ways to improve the health and quality of life for people with CF. The seeds planted at this meeting are already sprouting into new research and care projects designed to constantly improve the lives and health of CF patients at UNC. Although there are too many “highlights” to review here, you can share in our excitement by viewing some major presentations at the meeting on:

- Correcting the basic CFTR defect (Drs. Steve Rowe and William Skach)
- Advances in GI aspects of CF (Dr. Drucy Borowitz)
- Improving adherence to CF therapies (Dr. Kristin Riekert)

Links to each of these presentations can be found on the CFF.org website:
[<http://www.cff.org/research/NACFC/>]

Clinical Research Corner

Here are a few clinical trials currently enrolling at UNC.

eICE (Early Intervention in CF Exacerbations)

This study is being conducted to see if regularly monitoring lung function and symptom changes at home helps us detect and treat exacerbations better and, as a result, help to maintain lung function. Patients will be randomly put into a “usual care” or “home monitoring” group, each with different requirements for study visits at UNC. Among other criteria, patients must be at least 14 years old and have an FEV₁ greater than 25% of normal.

Grifols

Alpha-1 HC is the investigational drug being tested in this clinical trial. Research has shown that administering inhaled alpha-1 HC can reduce inflammation in lung tissues, which allows them to better fight infection. This is the first trial of this

in CF patients. The study requires six visits at UNC and, among other criteria, patients must be at least 18 years old and have an FEV₁ between 40-90% of normal.

Claudia Salazar is the contact for eICE and Grifols: (919) 966-9198 or claudia_salazar@med.unc.edu.

VX11-661-101

This clinical trial tests the drugs VX-661 and VX-770 (Kayldeco) administered together. Along with determining safety and tolerability, the study is designed to find out if the drugs may help improve lung function and reduce symptoms. Among other criteria, patients must have two copies of the delF508 mutation (the common mutation), an FEV₁ between 40-90% of normal, and be able to complete 9 visits at UNC, including some overnight stays.

Nadia Bendahmane Shive is the contact for VX11-661-101: nadiab@med.unc.edu or (919) 966-9198.

All text regarding these research studies has been approved by the UNC Biomedical IRB.



Breathing Easy on 6-Bedtower

A combination of circumstances and the desire to improve the care of CF patients has led to important changes during hospitalizations. As you know, the use of treatments that improve mucus clearance is important to maintain lung health and recover from pulmonary exacerbations. Coordinating aerosol treatments and airway clearance techniques can be a challenge during hospitalizations when care team members from different disciplines are required. Further, the sheer burden of aerosol treatments and equipment (nebulizer) care in hospitalized CF patients is huge. We believe that optimizing the delivery of these treatments will benefit everyone admitted with a CF exacerbation.

We hope you will be pleased to learn respiratory therapists now staff 6-Bedtower around the clock! Jenn Dane, an RT with significant experience now serves as our Adult CF Specialist (both inpatient and in clinic), and oversees a team of RT’s devoted to respiratory care on 6BT. These caregivers will review your respiratory care plan with you (including all inhaled treatments and the airway clearance plan), deliver aerosol treatments, ensure respiratory equipment is properly cleaned and cared for, and will implement airway clearance techniques at the proper place amongst your other respiratory treatments.

Manual chest PT (chest clapping) has been the primary method of airway clearance at UNC for many years. Some patients prefer this method, while many others do not. Unfortunately, research studies haven’t provided clear guidance on “what works best”, and an individualized approach is usually required. Nationally, trends are away from manual chest PT (CPT), and some recent studies show equal benefit with certain airway clearance. At UNC, it has often been difficult to meet our demand for CF airway clearance using only manual CPT, and changes in the healthcare system have made this an even greater challenge. In response, we are utilizing the addition of enhanced RT expertise and have significantly expanded the number and types of airway clearance devices available to hospitalized patients. We are excited to introduce you to some airway clearance devices that may be new to you (MetaNeb®; Acapella Duet®; PARI PEP™; and The Vest®), and are confident that we will continue to provide excellent airway clearance therapy during your hospitalization. Of note, patients recently admitted to the hospital have had an opportunity to work with our new RT team, try some new devices, and have typically found them to be very helpful.

Working together and trying several different techniques to find what works best for YOU is certainly the best approach, and this is what we will continue to strive to do!

IN THIS ISSUE:	
New Staff	2
Outpatient Clinic	3
Contact Phone Numbers	3
CF Conference	4
Clinical Research	4



Lauren Parrish, RN
CF Clinic Nurse
(919) 966-7049
MParrish@unch.unc.edu

I am the new Registered Dietitian working with the adult Cystic Fibrosis clinic at UNC. I have 7 years of experience in the field of nutrition and have a special interest in caring for patients' long-term nutrition needs. Prior to joining the CF team at UNC, I worked at hospitals in Charlotte, NC and Memphis, TN, where I was introduced to caring for pulmonary patients, which sparked an interest in the role of nutrition in CF care. I obtained my undergraduate degree in nutrition at Mississippi State University and completed an internship in nutrition at The University of Alabama Birmingham. I developed an interest in food and nutrition at an early age while helping my mom and grandmother prepare meals. I continue to enjoy meal planning and cooking and can be creative when making recipe suggestions to fit food preferences and nutritional needs!



Courtney Busby, RD, LDN
CF Dietician
(919) 966-1294
cbusby@unch.unc.edu



Jenn Dane, RRT
Respiratory Clinical Specialist

My name is Jennifer, but I do answer to Jenn! I am the new Adult CF Clinical Specialist for Respiratory. While I may be new to this role I am not new to Respiratory Therapy. I received my training in Burlington, VT and graduated from Champlain College with an Associates Degree in Science for Respiratory Therapy. I worked at Fletcher Allen Health Care in Burlington for 5 years, traveled for a year, and have been here at UNC Hospital for the last 6 years working in Critical Care and ECMO (a specialized procedure for very sick children), and now in CF. Currently I am working on my Bachelors in Health Care Administration.

A little bit about me: I grew up in Vermont on a farm. We raised Morgan Horses, beef cows, and I raised 2 Jersey's for my 4-H project. After 37 years in Vermont, I moved to North Carolina for warmer weather! I have two cats, Mac and Kate, and my interests are playing in my flower beds, watching NASCAR, going to the beach, watching a good movie, and traveling.

Continued on page 3



What's one important thing you can do to help maintain your lung function? Come see us...often! Data has shown that patients do better when they are seen in clinic regularly (at least once every three months). These regular clinic visits help us detect subtle changes in lung function that you might not feel, but may still require treatment. If undetected, small changes can lead to more significant loss of lung function over time--requiring hospitalization, home IV antibiotics and/or other intensive measures to try to recapture lost pulmonary function.

In order to make clinic follow-up easier, we will try to schedule your next appointment before you leave clinic. If your doctor gives you antibiotics at your appointment to treat an exacerbation, we'll arrange to see you sooner---within 2 weeks of completing your antibiotics. Seeing you at the end of your therapy helps us make sure you have recovered completely from your exacerbation, your lung function has improved, and no further treatment is needed.

If finances are impacting your ability to come see us, please let us know! There may be assistance available to help with transportation and other costs. Please contact Jennifer Pagel (919-966-7873), Kathy Hohneker or Lauren Parrish (both at 919-966-7049) to discuss. We look forward to seeing you soon!

Continued from page 2



Laura Beth Rupcich, PA-C
CF Inpatient Physician Assistant

I started working as a physician assistant (PA) with UNC's Hospital Medicine Department in December 2011. I provide care for inpatients. With the CF Team's help, CF patients can now be admitted to my service, Med H, when they have an exacerbation. If you are admitted to Med H, you will see me Mon-Fri. I enjoy being the consistent face you see while in the hospital and work to provide good communication between you and the CF Team!

Before becoming a PA, I was a CF research and clinical assistant from 2008-2009. During that time, I learned what a great CF Team UNC has! I am originally from Charlotte, NC and I went to UNC for my Biology undergraduate degree and to Wake Forest University for my Master's degree to become a PA. I got married in April 2012, and in my free time, I like to cook, take my dog for walks, and spend time with friends and family.

Contact Phone Numbers



In addition to the numbers given on page 2, here are some helpful points of contact for your care.

Scheduling Appointments **919-966-6838**
Pulmonary Clinic

Nurse Coordinators: **919-966-7049**
Kathy Hohneker, RN & Lauren Parrish, RN
Call for refills, if feeling sick, and other non-urgent questions. (M-F 8am-5pm)

Social Worker: **919-966-7873**
Jenn Pagel, LCSW (M-F 8am-5pm)

Hospital Operator: **919-966-4131**
For urgent needs and when needing medical attention outside of nursing hours, call to have your physician or the on-call Fellow paged.

Admitting: **919-966-2051**
For scheduled admission, call Admitting mid-morning on the day of your admission to notify them of your contact phone number for when bed is available.

Medical Records: **919-966-2336**