We hope that this newsletter finds everyone well! This newsletter was created as a way to improve communication with our patients. It includes updates on new staff and changes in CF clinic, information on new research studies, and health information pertinent to you. This is being done as part of our Quality Improvement initiative here at the UNC Cystic Fibrosis Center. You may be wondering who exactly “we” are, what this initiative is, and how it might affect you.

“We” are the Adult CF Quality Improvement team, which is comprised of CF clinic physicians and nurses, your social worker and dietician, hospital-based caregivers, research coordinators, and very importantly, CF patients. This team has grown since its inception in 2004, and our QI efforts continue to expand. Our goal is to evaluate all aspects of CF patient care at UNC in order to pinpoint areas on which we can improve in order to optimize your health and your care experience.

Most recently, our team has set out to change the way we take care of pulmonary exacerbations. Importantly, having an exacerbation is not only unpleasant to go through, but if it happens too often can cause significant and permanent worsening of your lung disease. Therefore, one of our goals is to better detect the onset of pulmonary exacerbations, so that we can initiate treatment sooner and lessen the severity and/or duration of these episodes. We also want to change how care is delivered in the hospital, when that is required to treat the exacerbation. During the upcoming months in CF clinic, your CF caregivers will give you more information on the changes we would like to make.

Since we are aiming to improve your health care, the most important input is YOURS! If there are aspects of your CF care experience with UNC which you feel need improvement or if there are topics you would like to see addressed in this newsletter, please let us know. You may e-mail these comments to pulmonary@med.unc.edu. Please also send us an email if you would like to be involved in the QI team, or would like to receive future correspondence with us about your CF Clinic and our combined efforts to improve it. Please know that your email won’t be shared with anyone else, and will only be used to facilitate your care and to seek your input on our QI projects.

Best Wishes,
The Adult CF QI Team

Seasonal Tips — Flu Season
The flu season is upon us. It is important that patients with CF receive a flu vaccine each year. Our goal is to have all patients seen in the Adult CF clinic receive their flu vaccination by December 31.

The Adult CF clinic has flu shots in stock. However, we also encourage you to contact your local primary care provider, health department and pharmacy to inquire about flu shot availability near you. The Adult CF group will be happy to provide you with a letter verifying your need to receive a flu shot. Patients with CF should not receive the nasal flu vaccine preparation. We ask that you contact Kathy Hohneker, our nurse-coordinator, when you receive your flu shot. Contact her at (919) 966-7049 or by email at khohneker@med.unc.edu.

During flu season, please remember these infection control guidelines:
- Avoid contact with people who are sick with flu or viral illness. Droplets from cough and sneezing spread the influenza virus.
- Wash hands frequently with soap and water, or with alcohol-based hand sanitizers.

Contact us immediately (919-966-4131 for the pulmonary fellow on-call) if you experience fever greater than 100.5°, chills, dry cough, body aches, fatigue and/or headache. Medications are available to help alleviate flu symptoms, but they must be started within 48 hours of the onset of symptoms.

Please contact us at (919) 966-7049 if you have any questions. These websites may be helpful:
http://www.cdc.gov/flu/keyfacts.htm
http://www/nfhd.org/influenza

The flu season is upon us. It is important that patients with CF receive a flu vaccine each year. Our goal is to have all patients seen in the Adult CF clinic receive their flu vaccination by December 31.

The Adult CF clinic has flu shots in stock. However, we also encourage you to contact your local primary care provider, health department and pharmacy to inquire about flu shot availability near you. The Adult CF group will be happy to provide you with a letter verifying your need to receive a flu shot. Patients with CF should not receive the nasal flu vaccine preparation. We ask that you contact Kathy Hohneker, our nurse-coordinator, when you receive your flu shot. Contact her at (919) 966-7049 or by email at khohneker@med.unc.edu.

During flu season, please remember these infection control guidelines:
- Avoid contact with people who are sick with flu or viral illness. Droplets from cough and sneezing spread the influenza virus.
- Wash hands frequently with soap and water, or with alcohol-based hand sanitizers.

Contact us immediately (919-966-4131 for the pulmonary fellow on-call) if you experience fever greater than 100.5°, chills, dry cough, body aches, fatigue and/or headache. Medications are available to help alleviate flu symptoms, but they must be started within 48 hours of the onset of symptoms.

Please contact us at (919) 966-7049 if you have any questions. These websites may be helpful:
http://www.cdc.gov/flu/keyfacts.htm
http://www/nfhd.org/influenza
Hello, I would like to introduce myself to you. My name is Jennifer Hendrix and I am your new CF social worker. I have been working at UNC Hospitals as an adult social worker for 2 years and have recently accepted the position as a CF social worker. Before coming to UNC, I joined the UNC Healthcare team as a social worker in the adult CF clinics. I became interested in CF while doing my post-backup clinical placement. I specialize in adult and post-transplant care.

Hi there! I am your CF dietitian, Sarah Jones. Introducing: Sarah Jones

Need Help During the Holidays? Members of the CF/Pulmonary Research and Treatment Center have collected donations to help patients from our clinic who are having a difficult time affording essential items such as food, utilities, clothing and gasoline during the holiday season. Small, one-time donations may be available to assist patients with specific needs. Please contact Jennifer Hendrix (JHendrix@uncselunc.edu, 919-966-7837) by December 15 if you would like to request assistance from this fund.

Introducing: Sarah Jones

Hi there! I am your CF dietitian specializing in adult and post-transplant care. I am excited to start working with you and at UNC Hospitals as a CF dietitian. I completed my undergraduate degree in Nutrition at the University of Wyoming and my Master’s in Nutrition at UNC and first became interested in CF while doing my final work in the pediatric and adult CF clinics. I joined the UNC Healthcare team shortly thereafter and have spent the last three years of my working life, where I have met many of you.

My goal is to help you manage nutrition-related aspects of your CF. We often focus on your weight, which is extremely important, but there is much more: bone health, diabetes management, GI issues, enzyme use, antioxidants, vitamins, and anything else that is important to you.

Please feel free to give me feedback and/or share your ideas. I consider you all my best teachers. I am always ready to learn more and find new ways to do things. I look forward to meeting you!

Sincerely,
Sarah Jones, MPH, RD (919) 966-1294 sjones7@uncselunc.edu

Get Involved: Current Clinical Research at UNC

The most important ways to improve the lives of people with CF are to learn more about the disease and develop new therapies to treat it. Around the country and the world, physicians and researchers are doing just that! However, none of these efforts would be successful without CF patients’ help. Your participation in clinical studies is one very effective way to help the fight against CF. If you’d like to learn more, please contact nadiab@med.unc.edu or Kathy Hohneker (khohnekr@med.unc.edu, 919-966-7049) if you would like to request assistance from this fund.

Mucus Clearance During Acute Exacerbations of Cystic Fibrosis (GRC 24S) Current Clinical Research at UNC

This study is designed to understand why CF patients develop pulmonary exacerbations, by testing the idea that the lungs’ ability to clear mucus deteriorates after a trip to the hospital (like a virus infection), which then leads to an exacerbation. Patients who are at least 18 years old, have an FEV1 of at least 30%, and who have required IV antibiotics at least twice within the last year are eligible. The study involves 8 visits to UNC.

Evaluating Regulators of Mucus Hydration Changes in Adult Lung Diseases (IRB 07-1778) Current Clinical Research at UNC

This study examines how the CF lung produces such a thick mucus, and how this changes across the course of disease from childhood to adulthood. Adult patients with CF who have an FEV1 between 30 and 60% of predicted are eligible. The study can be completed in one visit.

A Double Blind, Cross-Over Study Comparing Aerosolized Lubinactant and Vehicle on Mucus Clearance in Adult CF Patients (GRC 3710) Current Clinical Research at UNC

Lubinactant (surfactant) is a compound that has detergent properties that reduce mucus stickiness in the lungs. The compound has been used in other forms to treat respiratory distress in infants, and this study will test its effectiveness as a CF therapy in aerosolized form. Patients who are at least 14 years old and have an FEV1 of at least 40% are eligible. The study involves 8 visits to UNC.


In October, the North American CF Conference was attended by 3,800 researchers and caregivers who are committed to curing this disease and providing healthy lives for our patients. This year, results from 3 clinical trials with drugs that target the underlying problem in CF were presented. This is a tremendous advance, and makes us optimistic that we will fundamentally change the course of disease in the near future.

VX-770 (Vertex Pharmaceuticals): This drug is a pill designed to make certain mutant CF proteins function more normally. Because it is a pill, it has the potential to correct many aspects of CF, and not just the lung disease. The drug was taken by CF patients with a specific CFTR mutation (called “G551D”) for 2-4 weeks. Patients taking the drug showed dramatic reductions in sweat chloride values, improved FEV1 and CFTR function in the cells that line the nose, and a trend toward improved lung function tests. This drug is expected to be initiated within the year. If you would like to learn more, go to http://www.youtube.com/watch?v=KpTnKpsFRSE to see Drs. Bob Beale and Frank Accurso talk about this exciting study.

Denufosol (Inspire Pharmaceuticals): Denufosol is an inhaled medication that is aimed at restoring normal salt and water transport in CF lungs. A large study involving 352 patients showed improvement in patients with mild lung disease (FEV1 > 75%) inhaling the drug or a placebo 3 times a day for 6 months. Importantly, lung function was found to be significantly improved during this time. All patients were then allowed to use Denufosol for an additional six months. During this longer term, lung function continued to show even greater improvements. Another large trial is underway to see if this trend is continuing. This study will be repeated prior to seeking FDA approval.

PCT-124 (PCT Pharmaceuticals): PCT-124 is another oral drug that is targeted toward the CFTR “stop mutations”, which lead to an incomplete CFTR protein. About 10% of CF patients in the US have these mutations. In Israel, a 3-month long study showed evidence of normal CFTR protein production and improved functional cells that line the nose. Patients also were noted to have less cough, and these results are encouraging.

The company plans a rigorous, long-term study to more definitively test their product in the coming year. Stay tuned!