Patient Assistance Resources

Affording the medications you need to maintain your health may be difficult. Below is a list of resources, including assistance for certain medications for those that meet the eligibility requirements. Please contact the social worker (Jennifer Hendrix-919-966-7873) if you have questions or if you need help completing an application.

CYSTIC FIBROSIS FOUNDATION: www.cff.org. This program offers copay assistance for Tobramycin and Pulmozyme. Apply online or call 888-315-4154.

CF PHARMACY: The CF Pharmacy is part of the national CF Foundation. They ship medications directly to patients' homes. The website lists all their products and prices. Currently, the CF Pharmacy does not accept NC Medicaid. www.cfservicespharmacy.com or 800-541-4959.

PATIENT ACCESS NETWORK FOUNDATION: This foundation provides assistance for TOBI and Pulmozyme. To apply call 866-316-7263 or online at www.patientaccessnetwork.org/HowApply.html.

PHARMAECUTICAL SPECIALITIES, INC.: This pharmacy specializes in inhaled antibiotics for CF and offers a few different programs, including free Source CF vitamins with a particular inhaled antibiotic. For more information, please visit www.psipharmacy.com or call 800-818-6486.

AXCAN PHARMA, INC.: Offers assistance programs when purchasing Ultrase enzymes. Patients receiving Medicare, Medicaid, and/or Tricare are excluded from these assistance programs. For information, contact 800-472-2634 or visit www.axcan.com.

SOLVAY PHARMACEUTICALS, INC.: Offers assistance programs for qualifying patients. For further information visit www.solvaypharmaceuticals-us.com/products/SolvayCares or contact 800-256-8918.

DIGESTIVE CARE, INC.: Offers an assistance program to obtain Pancreacarb when not covered by insurance. Please contact the social worker if you think you might be eligible for this program.

NOVARTIS PHARMACEUTICALS INC.: Provides assistance to those patients having financial difficulty obtaining TOBI. Contact 877-862-4423 or visit www.pharma.us.novartis.com.

GENETECH PHARMACEUTICALS INC.: Links patients with assistance programs to help with copays for Pulmozyme. Call 800-690-3023 or visit www.genetechaccesssolutions.com.

PATIENT SERVICES INCOPORATED: Provides assistance for obtaining TOBI for eligible patients. For info or an application, call 800-366-7741 or email uneedpsi@uneedpsi.org.

BOOMER ESIASON FOUNDATION: Provides scholarship information for CF patients interested in pursuing undergraduate and graduate degrees. Visit http://esiason.org for more information.

CF LEGAL INFORMATION HOTLINE: A toll-free hotline provides free info about the laws that protect the rights of individuals with cystic fibrosis. Patients and families can receive information in many areas including: Health insurance, social security disability, Medicare/Medicaid, or employment issues. Contact 800-622-0385 or CFLegal@cfserv.com.

CYSTIC FIBROSIS LIFESTYLE FOUNDATION: $500 recreational grant for a one-year time period. To apply, go to: www.CFLF.org.

WEBSITES: www.needymeds.org, www.freemedicinefoundation.com, and www.pparx.org all identify patient assistance programs for various medications.

TAXES: The IRS allows you to count medical expenses that exceed 7.5% of your adjusted gross income on your itemized tax deductions. You can visit www.irs.gov/taxtopics/tc502.html for additional information regarding medial expenses and tax deductions, or speak with your tax preparer for additional information.

***2009 Federal Poverty Guidelines*:** www.dhhs.state.nh.us/DHHS/PIO/LIBRARY/Policy-Guideline/federal-poverty-guidelines.htm.

UNC CYSTIC FIBROSIS CENTER

Spring 2009

Quality Improvement at UNC

In January 2009, we were awarded grant from the Cystic Fibrosis Foundation to enhance the quality of the care we provide our CF patients at UNC. With these funds, we have launched a quality improvement program that targets care both inside and outside of the hospital. We are focusing on early detection and treatment of exacerbations. Our goal is to reduce the number of IV antibiotic courses and unnecessary loss of lung function over time.

Outpatient Improvements

When you are out of the hospital and at home, it is very important to pick up on the early signs of getting sick. The sooner you realize you are sick, the sooner you get started on antibiotics, and the sooner you feel better without losing a lot of lung function. This is the basis of our outpatient quality improvement program. If you choose to participate in this program, you will monitor your weight, symptoms, and lung function on a weekly basis. If you notice a change, you should call the CF team right away. When you are sick, you can use these tools on a daily basis to make sure you are getting better with your treatments. As part of this program, you will receive a small, electronic spirometer to measure your lung function at home. In addition, you will receive a notebook to help you and your CF doctor track this information over time. We will ask you to bring your notebook and spirometer with you each time you come to CF clinic and the hospital. This program should help you realize the early signs of getting sick so you can notify the CF team as soon as possible. If you are interested in participating in this program, notify Kathy Hohneker or your CF doctor.

Inpatient Improvements

If you need to be admitted to the hospital, we want to give you the best care available. The two main therapies you will receive in the hospital are IV antibiotics and airway clearance. One of the most effective ways to clear mucus from your lungs is to coordinate your inhaled therapies with chest physiotherapy (PT). We are working as a team to make this happen 2-3 times a day while you're in the hospital. As part of our new system, the physical therapy (PT) staff notifies the nurse about 20 minutes before they plan to do chest PT so that the nurse can start your nebulized medicines (albuterol, hypertonic saline, pulmozyme) with the goal of finishing them just prior to chest PT. Exercise is also an important part of airway clearance and getting better, and it is our goal that the PT staff will help you exercise at least 5 times a week while you're hospitalized.

Additionally, we want to be able to track your progress. We will be placing a chart in your hospital room to record when you receive your nebulized treatments and chest PT, as well as exercise sessions. There will also be space on the chart to record and monitor changes in your symptoms (cough, sputum production, appetite, etc), weight, and PFTs while hospitalized. If you have a home spirometer and notebook, you will be used to doing this at home and should continue in the hospital. We hope this system ensures that you getting the treatments you need, and helps us know when you are ready for discharge. We are looking forward to helping you get the most out of the time you're in the hospital.

Inside this issue:

Regular exercise is very important for your CF. It can increase your lung capacity, enhance mucus clearance, help your digestive tract, and improve your general well-being. One of the physical therapists at UNC, Allison Driver, says that cardiovascular exercise is the most beneficial thing to do. This includes walking briskly, jogging, running, swimming, climbing stairs, bicycling, dancing, aerobics, etc. As you exercise more, you will be able to do more without being tired out. Other forms of exercise include strength training, which can improve bone mass, and posture exercises, such as core strengthening and stretching (ex: pilates, yoga), which can help you to breathe more effectively. You should aim to exercise everyday at a moderate pace and make it a part of your normal routine. You do not have to exercise strenuously to reap the benefits. Although exercise that is tough enough to make you sweat will also make your airways more moist, helping you cough up phlegm more effectively. To know how hard you should work during exercise, you can use the Rate of Perceived Exertion (RPE) scale, which ranges from 6 to 20, with 6 being "no exertion at all" and 20 being "maximal exertion." You want to be around a 13, which means that you are working "somewhat hard."

WHEN IT COMES TO EXERCISE, YOU SHOULD DO WHAT YOU ENJOY.

Allison Driver, a UNC physical therapist, gives exercise advice.

Finally, the hardest part of exercise is staying motivated. When it comes to exercise, you should do what you enjoy. You could turn one of your hobbies into an exercise routine or you could involve your kids so that it does not take away from family time. You do not need a gym membership to get exercise. Activities like taking a brisk walk or playing basketball in the park with your family or friends are good and inexpensive. Most of all, pick a goal for yourself, something reasonable and definite, so that you will be able to see how much progress you've made

To learn more about the benefits of exercise, talk to your doctor. Also, with a doctor's prescription, you can setup an appointment with the UNC PT team to create an exercise program. To do this, you can call 919-966-2056 and you can ask for an appointment with the cardiopulmonary physical therapist.

CF Fundraising

Much of the work that translates scientific research into treatments for patients with CF is supported by the Cystic Fibrosis Foundation (CFF). In fact, over the past five years, the CFF has invested more than 21 million dollars to CF research and care at UNC, Duke and Wake Forest Medical Centers.

The CFF is a non-profit, donor-supported organization that is driving the search for a cure, and is committed to improving the quality of life for patients with CF. As you can imagine, the economic downturn has substantially influenced charitable donations, and runs the risk of reducing the amount of resources available to support this work.

If you would like to learn how you can help, contact your local CFF chapter (Raleigh area: Carolinas@cff.org, or call 919-845-2155 or 800-822-9941; Charlotte area: charlotte-nc@cff.org, or call 704-321-7852 or 800-336-0329), visit the CFF website to learn how to get involved (http://www.cff.org/GetInvolved/), and/or to participate in a "***Great Strides***" fundraising walk. Last year alone, ***Great Strides*** raised almost $37 million. This year, there are more than 20 walks scheduled across the state. Now, more than ever, volunteer efforts are needed to maintain this life changing progress. Call now to find out how you can support CFF in its fight against cystic fibrosis.

This is an incredibly exciting time for people who care about CF because, more than ever before, there are a large number of very promising treatments being tested. Your UNC CF Center continues to work very hard in the effort to bring these new treatments to people living with CF.

In this newsletter, we'd like to introduce you to several new studies that are about to start! All of these studies are being done in collaboration with other centers across the country and receive support from the Cystic Fibrosis Foundation, as well as industry sponsors. Let us know if you are interested in learning more about any of these studies, or might be willing to participate. We cannot bring these new therapies to patients without your help, and we appreciate all that our patients continue to do.

A Phase 2, Double-Blind, Multicenter, Randomized, Placebo-Controlled Trial Evaluating Fosfomycin/Tobramycin for Inhalation in Patients with Cystic Fibrosis and *Pseudomonas aeruginosa* (IRB/CTRC# 090051)

This study is testing a new combination antibiotic product in patients who grow Pseudomonas. This drug combination not only appears to be effective against the Pseudomonas bacteria that many patients are infected with, but also kills other common CF germs, including drug-resistant Staph aureus ("MRSA"). Patients who are at least 18 years of age, with an FEV_1 value between 25% and 75% of predicted are eligible. The study involves 6 visits to UNC. (contact: cbarlow@med.unc.edu, or call 919-966-9146)

Mucus Clearance During Acute Exacerbations of Cystic Fibrosis (GCRC 2483)

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 trigger (like a virus infection), which then leads to an exacerbation. Patients who are at least 18 years old, have an FEV_1 of at least 30%, and who have required IV antibiotics at least twice in the last 2 years are eligible. The study involves 8 visits to UNC. (Contact Nadia Bendahmane: nadiab@med.unc.edu or call 919-966-9198)

A Double Blind, Cross-Over Study Comparing Aerosolized Lucinactant and Vehicle on Mucus Clearance for CF Lung Disease (GCRC 2710)

Lucinactant (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. CF 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. (Contact Nadia Bendahmane: nadiab@med.unc.edu or call 919-966-9198)

This information has been approved by the UNC IRB.