

CYSTIC FIBROSIS



News Wire

VOLUME 2 - NUMBER 3 - FALL 2010

WELCOME once again to the latest edition of the 'The CF Newswire'. New England offers great opportunities for summer getaways but the record heat found us scrambling for ways to stay cool. Thankfully, the official start of Fall is around the corner, arguably the best season New England has to offer, and with it comes exciting news about future treatments to fight CF. As we ponder how these treatments may impact the future of CF care, we must maintain our vigilance in maintaining your health with therapies available to us now and do better to implement what we already know.

This summer, I found myself sitting in poorly air-conditioned classrooms at the school of public health, removed from daily patient care, where I had the opportunity to consider ways to improve the delivery of health care to our CF patients. One of my courses was titled "Improving Quality in Health Care," taught by experts in the field, including Atul Gawande who has been a strong voice in CF quality improvement. I was reintroduced to the concept that great improvements in health can be achieved simply by making sure we are doing the things we already know work --just do them better. As I sat back and thought about ways to improve delivery of care to our adult patients, I realized that we are surrounded by people who already have some great ideas – our patients. In this issue, you will hear the voices of several adults with cystic fibrosis and over the coming months and years, I would like to hear from you.

Together we will strive to make the Adult CF Program, the best adult CF center in the country - a model for others to follow. We are not presenting this goal just to achieve some superficial measure or make it on a US News and World Report list. I strongly believe that the process itself, the targeted ideas that we will implement, will help us continue to be better and in turn, improve your health and quality of life.

One example that will become a reality very soon is a new inpatient exercise protocol that we hope will change how you feel about exercise and its impact on your life away from the hospital. With generous donations from his family, the Steven Vertuccio Wellness Program will utilize equipment specializing in patient fitness. Our clinicians will be able to download and review data collected from you as you exercise. The data will be stored on an electronic "key," one assigned to each patient and stored in a secure location. When the key is inserted into the exercise machines, the program resumes the patient's preferred settings. This will allow the physical therapist to show patients the progress they are making and allow for improved continuity of care during an individual's subsequent admissions.

Enjoy the latest issue of CF Newswire. If you have articles for the News Wire please submit them to cfevent@childrens.harvard.edu

Best wishes,

Ahmet Uluer, DO
Director, Adult Cystic Fibrosis Program
Brigham and Women's Hospital and Children's Hospital Boston



Pulmonary Fellows. Front: Phong Vo, Tregony Simoneau, Stephanie Zandieh, Back: Lianne Kopel, Kara May Palm, Mike McCown, Alicia Casey, Missing: Allan Dias and Devika Rao

FLU UPDATE

Preventative care includes adhering to your treatment plan, obtaining necessary immunizations and avoiding potential germ exposures where possible.

The flu spreads easily through person-to-person physical contact and through coughing and sneezing of infected people. There are a number of everyday actions that you can take to stay healthy:

- Cover your nose and mouth with a tissue when you cough or sneeze. Throw the tissue away after use.
- Wash your hands often with soap and water, especially after you cough or sneeze.
- Avoid touching your eyes, nose or mouth.
- Stay home if you get sick. Limit contact with others to keep from infecting them.
- Obtaining a yearly flu shot is recommended for all CF patient's as well as family members who come in close contact with people with CF

The CF clinic is well stocked with flu vaccines. Please call and schedule a time to come in if you do not have an appointment already scheduled.

DUM SPIRO, SPERO (WHILE I BREATHE, I HOPE.)

Of course, like anyone with an illness I would dream for a cure to get rid of my disease, but for now I live with it. My dream for the future is that people with CF would have the advantage of innovative advancements in medicine—like I have had. Four years ago my brother and I were very sick after contracting an undiscovered genus of drug resistant mycobacterium. Subsequent medical journals say that our case was the first ever reported anywhere on earth. Our doctors were perplexed about what to do to eliminate this bug and spent two years researching a treatment. They called what they did “trailblazing” because the entire process was experimental. Eventually after several attempts we were able to combat it.

Getting rid of that bug gave me the opportunity to live. I have been healthy enough to excel at school, play on the school’s Varsity tennis team (becoming captain this year) and achieve the



rank of Eagle Scout. I look forward to studying astrophysics at college next year.

During this low point I faced my own mortality. I lost my innocence but I emerged from the experience a different person with a different perspective. Everyone should have a second chance. That experience in retrospect has not only given me an

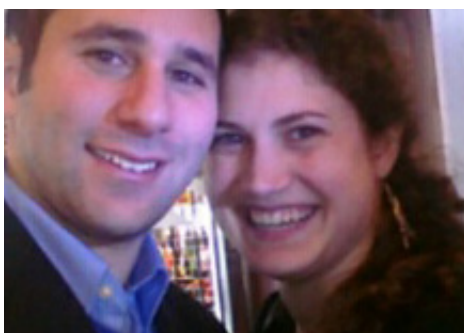
unparalleled respect for my medical team and Cystic Fibrosis research, but has also given me both breath and hope.

Josh Napolitano, winner, creative entry Solvay scholarship 2009
“While I breathe, I Hope”

PROACTIVE AND PERSISTENT by Nora Miriam Levy

It never occurred to me that I would not attend college. Moving 440 miles away from my family to a city devoid of friends or relatives was difficult, but worthwhile. For the first three semesters I attended classes and school events, struggling through illnesses without asking my school for help. Once I finally registered with the Office of Disability Services, I felt both sad and relieved. I didn’t feel like I had a handicap, but at the same time I was glad to have a safety net. Later that semester, when I ended up in the hospital with pneumonia, my parents drove to Massachusetts and stayed with

me for several days. It was a truly terrifying experience, and I can’t say that I am grateful for it, but I did learn a lot about myself, my support network, and hospitals. During the following semesters I became more proactive, monitoring my health and paying attention during my doctor appointments. I took it upon myself to begin taking over the tasks that my parents usually did for me, scheduling appointments, filling prescriptions, and calling my doctors when I had questions. Additionally, being isolated in the hospital made me realize that I could do more to reach out to people and create a support network nearby. When I was hospitalized again during this past semester, my illness was much less severe, I knew how to talk to nurses and monitor my treatment, and I quickly alerted my friends, who were definitely up to the challenge of supporting me. Friends are my “Boston family” and during my most recent hospitalization my thoughtful visitors brought me crayons, magazines, and takeout food, and slept on a cot next to my bed. Of course, another important aspect of this network of care was the staff, the doctors and nurses who provided constant support and assistance. What I have found most helpful in transitioning to take care of my own health needs is remembering to be my own advocate, not take anything for granted, and to ask for help when I need it. It is hard, especially in a college setting, to balance between “work” and “play,” especially with a regimen of medications to worry about. But I finally figured out how to focus on the good things and stay positive, and I graduated this past May, magna cum laude. When I feel sorry for myself and wish I could have more fun, I try to remember that taking care of my health will allow me to do more, and learn more. On a practical level, my cousin once told me to think of my health care as a “date,” and so I use that “date” with myself to do something fun, multitasking, like playing a game or surfing the Internet. Life really is what you make of it, so I try to focus on what I can do, and what I can do for others.



TIPS ON ORGANIZING PRESCRIPTIONS by Amory P. Hunnewell

I want to share my story about tackling prescriptions. I hope this gives families some ideas on how to improve a continuous process that is one of the more systematic parts of living with Cystic Fibrosis.

I am a mother of an eleven-year old daughter with CF. I started using a local pharmacy, which seemed easy enough, but as the medications became more numerous and complicated, it was getting difficult to manage. Medications would need to be special ordered, sometimes availability wasn't immediate, and sometimes the pharmacist wasn't familiar with the medications and couldn't answer questions about them. And there was the constant refilling process! I didn't think to get scripts written for more than 30-day supplies... and some needed special insurance overrides and authorizations each time. Sometimes the pharmacy would try to help me deal with insurance problems, but they didn't really have the time or resources. Dealing with prescriptions was consuming too much valuable time. I tried mail order pharmacies, but they didn't have any particular knowledge about CF medications, plus the same issues with insurance existed.

CF Services Pharmacy, a wholly owned subsidiary of the CF Foundation, has been the best solution for us. My daughter's prescriptions are now written for a 60-day supply, so they are refilled only 6 times a year. I like the convenience of refilling prescriptions on-line (although by phone is also available), and receiving all the medications in the mail. For special refrigerated medications like Pulmozyme®, shipments are packaged to stay chilled, shipped overnight and for free. Compared to many general pharmacies, CF Services Pharmacy has more knowledge about CF medications. It orders CF medications

in large quantities for good pricing, and most importantly, is committed to supporting their customers. CF is complicated enough - getting CF medications shouldn't be.

Earlier this year my insurance company notified me that they would no longer allow me to use CF Services to fill my daughter's Pulmozyme® prescription. It certainly wasn't going to make sense to fill one prescription somewhere else and the rest at CF Services. I also realized that potentially my insurer would not allow me to use CF Services at all, as MassHealth had done in 2009. I wanted to continue to use CF Services – and I was able to. If your insurance company has told you that they won't allow you to use CF Services, call Case Management to help you out!

I contacted the Group Administrator of my insurance plan and explained that it was actually going to cost the insurer even more if I filled Pulmozyme® through a different pharmacy than all my daughter's other medications. I would receive separate shipments, costing more. I was granted an exception and continue to use CF Services for all my daughter's medications. Additionally, my insurer is now negotiating a contract with CF Services to be a contracted provider for all their customers.

Most importantly, the CF Services Pharmacy supports patients with CF and their families and shares in the CF Foundation's mission to help the CF population manage their prescription medication needs. To that end, the CF Services Pharmacy provides other services including: case management, patient education and assistance programs, and reimbursement support. Their understanding of our needs and their commitment to helping lets us all breathe a little easier.

And finally, when patients use the CF Services Pharmacy, they are also helping to support the CF Foundation. By using the CF Services Pharmacy, any co-payments for your medications are funds that go towards supporting the CF Foundation! So by using CF Services you are helping to fund the research the Foundation supports towards finding better treatments and ultimately a cure.

For more information, go to their website at: www.cfservicespharmacy.com or contact Customer Support at (800) 541-4959. Also the members of the CHB CF Center staff, including physicians, nurses, and social workers, are always available to discuss this and other options for your family in regards to making the prescription process easier.

A SPECIAL NOTE FOR FAMILIES THAT HAVE MASS HEALTH AS THEIR INSURANCE:

In March 2009, The CF Services Pharmacy received notification from MassHealth that their application for participation in MassHealth was denied. This decision was based in accordance with MassHealth regulations stating that to be eligible to participate in MassHealth, a pharmacy provider must have a retail establishment located and doing business in the Commonwealth of Massachusetts. Currently there are other options for mail order medications for all families, including those with MassHealth, including a CF specialty program at CVS-Caremark. The CF Center staff can help to discuss these options for prescription services with you.

THE SUMMER OF MY ASTHMA

by Carolyn Shute

I have CF, but June 14–Flag Day–was the beginning of the summer of my asthma. My town celebrates Flag Day in a particularly enthusiastic fashion–streets close down for a parade robust with marching bands, fire trucks, local politicians hurling candy at kids, unicyclists, clowns, and karate classes showing off their kicks. Even the Wells-Fargo stagecoach puts in an appearance.

My husband and I were invited to a neighbor's for pre-parade pizza and beer. I wound up talking to a man named Oskar; originally from Sweden, he had a noticeable accent. In the middle of our conversation, he suddenly asked: "Do you have asthma?" A bit surprised (was I wheezing?), I smiled but said nothing. He took my silence as confirmation. "I only know," Oskar continued confidently, "because I had asthma when I was young. But it went away. If I could get rid of it, anyone can. Do you exercise? Maybe you should run to – how do you say? – make strong your lungs. Running is good. I ran and ran and ran and soon my asthma went away." Oskar made fists with his hands and pumped his arms up and down to emphasize his point.

I did some walking, I said, and tried to change the subject. "But what more, exactly, are you doing for your asthma?"

he insisted. "Oh, well, I manage," I murmured. "It's a terrible thing not to be able to breathe well," Oskar said, looking at me penetratingly. I nodded in assent and made a desperate grab for a slice of pepperoni pizza that was passing by. Thankfully, eating served as a diversion.

After pizza, our group meandered to the town center to watch the parade. Midway through the music and the marching, Oskar sidled over to me. "Do something about your asthma," he continued. "Run, run, run!" Again he pumped his arms in demonstration. Maybe I should pump my fist in your face, I thought. Luckily, my neighbor turned toward us at that moment and the conversation drifted in another direction.

A few weeks later I was browsing in a bookshop in my town's center. I coughed. An older woman turned toward me. "Are you sick?" she asked. "No," I replied. "Allergies?" she probed. I shook my head no. "Well, you must have asthma then," she said decisively. "I do, too. Doesn't everyone these days? What kind of an inhaler do you use?" She waited for my answer. I sighed, but responded. A conversation about Advair ensued, after which I ducked out of the shop as quickly as I could.

Not long after I ran into the asthmatic older lady, I popped into the local convenience store to buy my daily iced tea. I set my pocketbook on the counter to dig out my wallet. I have a friendly relationship with Mike, the clerk. "I didn't know you have asthma," he said, noting my inhaler as I fumbled through my purse. I looked up and smiled. "I had asthma as a kid, but I grew out of it. No more inhalers for me." Mike went on to expound on all the things I should do: pull up my rugs, take down my curtains, get rid of any pets I might have (fish, though, I could keep). And don't wear perfume! (his sister had asthma, too). When I smiled again, he decided I doubted his advice. "No, really," Mike insisted. "These things will help you get better." The thing I should do now, I thought, was to get the hell out of the store.

Shortly after receiving Mike's recommendations, I was making a purchase in a department store. Perhaps I cleared my throat or coughed–I'm not sure. "Hope you're not getting sick," the salesperson said as she handed me my receipt. I smiled. "No, I have asthma," I replied.

UPCOMING CLINICAL RESEARCH OPPORTUNITIES by Erin Leone

The CF Clinical Research Team at Children's is beginning several exciting studies this fall. These studies are described in greater detail below. If you are interested in participating in any of these studies, please contact the designated research staff member.

PTC ATALUREN (FORMERLY PTC124)

Ataluren is an investigational CFTR modulator. Several studies have been completed examining the safety and efficacy of Ataluren in patients 6 years and older. This study is examining the safety and efficacy of Ataluren in patients 6 years and older with nonsense mutations (mutation contains the letter X) over 1 year. If you are interested in participating, please contact Robert Fowler.

INVESTIGATIONAL DRUG DESIGNED TO RESTORE AIRWAY SURFACE HYDRATION.

Several studies have been completed investigating the safety and efficacy of the study drug in patients 5 years and older. This study is examining the safety of the drug in 2–4 year old patients over 7 days. If you are interested in participating, please contact Jane Solomon, RN.

INVESTIGATIONAL ANTIBIOTIC THERAPY

Several studies have been completed investigating the safety and efficacy of the therapy in patients 16 years and older. This study is examining the safety and efficacy of the drug in patients 12 years and older over 28 days. If you are interested in participating, please contact Robert Fowler.

COMBINATION INVESTIGATIONAL CFTR MODULATORS

Several studies have been conducted

examining the safety and efficacy of one therapy in patients 18 years and older and the other therapy in patients 6 years and older. This study is examining the safety and efficacy of the drugs administered in combination in patients 18 years and older with F508del for 21 days. If you are interested in participating, please contact Catherine Correia.

If you would like to learn more about CF clinical research, please contact a member of our Clinical Research Team or visit www.cff.org!

CLINICAL RESEARCH PROGRAM MANAGERS:

Erin Leone, MPH, CCRC (617) 355-3197
Jane Solomon, RN (857) 218-4062

RESEARCH COORDINATORS:

Catherine Correia (617) 355-2446
Robert Fowler, CCRC (617) 355-1834

HEALTH CARE REFORM by Judy Bond, SW, Lynne Helfiand, SW, and Isabel Bailey, SW

Managing your health insurance and understanding policies and regulations for patients with CF can be challenging and time consuming. Federal and state government regulations of insurance are in flux as the health care reform bill was recently passed. With these regulatory changes insurance policies can be quite confusing. You may feel that you have to fight to get medications covered or for benefits that you thought were included in your insurance. Some of the challenges that you may be facing are addressed by the new health care reform bill. People living with CF who receive medical insurance under private, state and federal programs should find these changes beneficial.

The following is from the June 2010 Network News – a publication for the CF foundation’s Care Center and Clinical Research Networks. The new regulations that are covered in this bill will begin in September 2010:

New Healthcare Reform Beneficial to People With CF Beginning September 2010

New healthcare regulations, including some that are considered beneficial to people with CF, are scheduled to begin in September, 2010. These include regulations that pertain to:

Pre-existing conditions: People with pre-existing conditions will find it easier to get healthcare coverage and have more protection against losing coverage. Insurance plans will be prohibited from excluding children from health coverage due to pre-existing conditions

starting in September. This protection will also extend to adults beginning in 2014.

Annual and lifetime spending caps: Insurers may no longer establish annual and lifetime coverage limits on their healthcare plans. Some group and individual plans will see the elimination of limits on annual and yearly caps starting this year.

Coverage for dependents: Children will be able to remain on their parents’ or guardians’ insurance plans up until age 26.

The CF Foundation continues to follow the changes to healthcare reform. While the Foundation has not taken a position on any health reform bill, it has consistently and aggressively encouraged officials to include specific reforms important for people with CF.

THE PROVIDENT BANK'S AMESBURY LOBBY FOR THE ARTS "EVERY BREATH I TAKE"

Personal Inspirations By Jennifer Delaney

*Jennifer Delaney is exhibiting her Artwork and Photographs
now through October 1st at*

*The Provident Bank,
5 Market Street, Amesbury, MA.
Monday–Wednesday: 8 am to 4 pm
Thursday–Friday: 8 am to 6 pm
Saturday: 8 am to 12 noon*

AND

*The Provident Bank at the Corner of
Main Street &
Route 110 Amesbury, MA.
Monday–Friday: 7 am to 7 pm
Saturday: 8 am to 3 pm
Sunday: 10 am to 2 pm*



5TH ANNUAL STEVEN J. VERTUCCIO MEMORIAL RIDE FOR CYSTIC FIBROSIS

Please join us for the 5th Annual SJV Memorial Ride for Cystic Fibrosis. All proceeds benefit to the Cystic Fibrosis Center at Children’s Hospital Boston.

Saturday September 11, 2010 (rain date 9/12/10)

For more information: www.sjvride.com

GRAB AND GO!

By Kristen Leavitt, RD LDN

With the summer coming to an end the next school year is rapidly approaching. In my discussions with families in the clinic I find that a big barrier for some people with eating is finding the time to eat breakfast, and having easy to prepare snacks. The CF Foundation recommends that all patients with CF have a BMI at the 50th percentile or greater. In order to achieve this it is important to eat 3 meals per day with snacks to get enough calories. Making meals and snacks a part of your routine is very important. Here are some suggestions for using foods that you can just Grab and Go throughout the day.

It is important that you always take your enzymes with foods and beverages, even if it is just a snack. Keep enzymes with you wherever you go (coat pockets, book bags). Think about your day and where you will be spending your time. Where can you stash food that is convenient for you (backpack, purse, briefcase, desk drawer, locker and cooler in your car)?

BREAKFAST

Trying to get out the door to work or school in the morning can be very stressful. Leaving the house hungry is not a good idea. With a little planning you can make your meals easy to Grab and Go!

- Scramble an egg with cheese and warm up a tortilla. Wrap the egg in the tortilla and off you go.
- Microwave a breakfast sandwich while you are dressing. Grab it and run.
- Keep containers of shakes, yogurt drinks and other high calorie beverages in your book bag or briefcase.

- Buy giant muffins in bulk, wrap and freeze each.
- Fill a water bottle with your favorite shake each night before you go to bed. Grab it before you head out in the morning.
- Make a batch of French toast or pancakes, wrap individual servings and freeze. In the morning, pop a serving in the microwave and it will be ready to eat before you know it.
- Single serving oatmeal (comes by the packet or in its own insulated bowl). Add hot milk and cream and take it with you.
- Buy cold cereal in individual containers or pour your favorite cereal into a plastic container. Take along single servings of boxed liquid milk.

SNACKS

Keep these snacks cool with an ice pack in an insulated lunch bag or in a cooler:

- High-fat deli meat and cheese "roll ups"
- Cheese sticks
- Single servings of whole milk cottage cheese
- Whole milk yogurt and yogurt drinks
- Hummus in a small container and a pita cut into triangles Individual peanut butter packets

Keep these anywhere:

- Trail mix
- Granola, protein and snack bars
- Fig bars
- Cheese and cracker packs
- Shakes, canned or bottled
- Single serving canned pears, peaches or fruit cocktail
- Muffins

- Graham crackers, vanilla wafers, gingersnap cookies, animal crackers
- Nuts (Peanuts, cashews, macadamia nuts, almonds, walnuts, etc)
- unflower seeds
- Raisin or banana bread
- Pretzels
- Cereal
- Single-serving juice or milk boxes
- Dried fruit
- Bottles of frappuccino
- Pudding snacks (brand that doesn't need refrigeration)
- Hot cocoa mix
- Fresh fruit

TRAIL MIX

Prep time: 10 minutes

Ingredients:

- 3/4 c. cashews
- 1 c. walnuts
- 1 c. raisins
- 3/4 c. peanuts
- 3/4 c. shredded coconut
- 3/4 c. chocolate chips

Directions: Mix all ingredients in a large bowl. Store in an airtight container and refrigerate for up to one month.

Serves: 10

Serving size: 1/2 cup

Nutritional analysis (per serving): 349 calories,

7 g protein, 24 g fat, 69 mg sodium, 23 mg calcium

Note: Nutritional analysis may vary depending on the ingredient brands used.

Variations and Suggestions: Try this recipe with other kinds of nuts or dried fruits. Be creative!

WELCOME TO NEW STAFF

Angela Adamson and Mauve Bacon join Rachael Whitaker at the front desk. *Ashley McCarthy* joins Brandon Duque as a clinical assistant, *Leslie Leary and Trevor Wright* joins the PFT team. We are pleased to welcome *Ashley O'Brien RD, LDN* as a full time nutritionist. *Leah Frain NP* has joined the adult CF program and *Robin Welcher RD* has joined the Brigham and Woman nutrition program.

I AM PROUD

to be part of a generation of CF patients that is always right in pace with science—When I was born in 1980, the life expectancy for a child with CF was about 10 years old. Now that I'm almost 30, it's about 37. This strange race against time and facts has given CF patients who are my age a willfulness, determination, and almost arrogance in their ability to beat this disease. For better or worse, I was handed this cocky attitude by my parents, who never let CF scare them into raising their children differently. I was always expected to grow up strong, go to the best college I could get into, and start a career. I am grateful to have surpassed even these childhood dreams by earning my Master's Degree, moving to Boston, and now approaching my 30th birthday. I can't wait!

Getting to age 30 has not been without struggles. I had much worse health in adolescence. I missed a great deal of high school, but still maintained good grades by continuing my work diligently from home, and attending classes enough to remain involved with my high school's drama program. I learned that I had to keep my health up to par in order to do what I loved. Though I was not a competitive athlete in high school, I swam for my main form of exercise. At school, I performed in plays while maintaining a crazy, active lifestyle like any so-called normal teenager. In the summers, I swam and worked as a lifeguard and swim instructor through college.

Here's the catch—I'm no star athlete. I'm no marathon runner. I don't even like to exercise in front of other people. However, I work out every day. I think it's important for CFers to know that exercise is a necessary part of taking care of yourself, but it's not an all or nothing proposition. You don't have to prove to the world that you're overcoming your disease through extreme exercise goals. You just have to take care of yourself and live the active lifestyle that you choose.

Some people told me that I was crazy to pursue a career in the theatre—the crazy schedules, the late nights, the unpredictable income. However, theatre is my passion. I found that pursuing my true passion, with all of its active demands, was actually the best thing for me, personally and even physically. Now, I am able to do much of my work as a playwright, director or producer from the first row of a theatre if I need to—so I can be as active or passive as I need to be on a given day, while still living my passion.

I am also a poet, and invite you to check out my new publishing group, Patient Press, at patientpress.blogspot.com. I wrote this poem, *No Dragon Slayer*, during a fundraiser for the Cystic Fibrosis Foundation called "Unleash Your Story."

At Patient Press, we are coordinating a poetry contest: "Putting It In Words: Poems About Cystic Fibrosis." The contest is open to all ages, Kindergarten through 110 years old! We like funny poems. We like sad poems. We like goofy poems. We like angry poems. We like poems. You can win a nifty t-shirt and a small cash prize! WINNERS will be announced on the Patient Press Blog and on CysticLife.org. Check it out! <http://patientpress.blogspot.com/>

—Mary ElizaBeth Peters



No Dragon Slayer

© 2010 Mary ElizaBeth Peters

I am a dragon.

I fly through the sky though heavy with wings like steel, never tiring.

I land upon the sea perched on delicate feet, never sinking.

I plunge to the deepest depth of the ocean, never gasping.

I do not need to breathe like you.

I do no need to breathe.

I am a green white pink white purple white dragon.

I float into clouds and am invisible.

I climb among trees and am a giant.

I balance on the mountaintop only to witness.

I do not need to rest like you.

I do not need to rest.

I am a mythical, imaginary, remembered and forgotten dragon.

I do not fly among you, but I would.

I may not fly forever, but I could.

I will not fly in silence, though I should.

I am not defeated by you.

I am not defeated.

I am a dragon.

CONTACT INFORMATION

PHONE NUMBERS:

Appointments: 617-355-1900 option #3

Nursing line: 617-355-7018

Prescription line: 617-355-7078

Home IV Program: 617-355-6499

Pulmonary Function Test: 617-355-7510

Page Operator: 617-355-6369

Hospital Main Number: 617-355-6000

It is recommended by the CF Foundation for CF patients to see a nutritionist, physical therapist and social work once year and as needed. To schedule an appointment with one of these disciplines call the scheduling center at 617-355-1900.

PHYSICAL THERAPY

Anne Gould, PT

NUTRITION

Ashley O'Brien, RD, LDN

Kristen Leavitt, RD, LDN

SOCIAL WORK

Judy Bond, SW

Isabel Bailey, SW

Lynne Helfand, SW

THE CYSTIC FIBROSIS CENTER AT CHILDREN'S HOSPITAL
BOSTON & BRIGHAM AND WOMAN'S HOSPITAL

SAVE THE DATE FOR

Cystic Fibrosis Night

HEAR ABOUT THE LATEST NEWS AND UPDATES FROM
THE CF CENTER

TUESDAY, NOVEMBER 2ND 2010
BEST WESTERN - THE INN AT LONGWOOD MEDICAL

INVITATION TO FOLLOW

This event will be available via live webcast at childrenshospital.org/cf

We follow Cystic Fibrosis Foundation Infection Control Guidelines. Because of the potential risk posed to the patient spread of bacteria, we regret that we are unable to invite patients with CF to attend this event. In light of this precaution, we encourage all patients to send family and friend representatives. We invite patients and families unable to attend the event to view our presentation live via webcast beginning at 7:00 p.m. To do so, follow the link from our CF center home page listed above.

During the webcast, you will be able to view all presentations and submit questions online in real-time.

News Wire
CYSTIC FIBROSIS

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