# CYSTIC FIBROSIS News Wire

VOLUME 2 - NUMBER 3 - WINTER 2011

## Hello and Happy New Year!

Welcome to another edition of the Children's Hospital Boston CF Center "CF Newswire". Hope everyone has finally shoveled out and is ready for spring!

It was great to see so many of our families at the CF Center's annual dinner in November. It was a very successful evening with 150 family members and staff in attendance. Families had time to socialize with other families and staff as well as learn about ongoing initiatives within the CF center. The CF Center leadership discussed latest developments in CF as well as updates from both the pediatric and adult programs.

This past October, 24 members of the CF center team attended the North American Cystic Fibrosis Conference in Baltimore. Several members of our team presented in symposiums at the meeting. **Greg Sawicki MD** spoke on strategies to approach MRSA; **Alicia Casey MD** presented at the pediatric fellows' case conference; **Ahmet Uluer DO** presented data on "Urinary Biomarkers for Early Detection of Nephrotoxicity in Cystic Fibrosis"; and **Keri Sullivan NP** presented data on our ongoing home IV therapy program. In addition, members of our multi-disciplinary teams were able to join discussions in roundtable sessions, workshops, and other collaborative meetings during the conference.

Over the past several months, we have welcomed several new staff members. **Ashish George** and **Beatrice Duvert** have joined the clinical research team. The new PFT technicians are **Daniel Goulette, Trevor Wright,** and **Walker Del Aguila**. **Courtney Madden RN** joined the clinic nursing team and **Leah Frain FNP** joined the adult CF team. **Robin Welcher RD, LRD** is the primary inpatient nutritionist at Brigham and Women's Hospital. We have also established formal collaborations with 2 physicians at Children's Hospital: **Elizabeth Yen MD** is a pediatric gastroenterologist with a special interest in GI manifestations of CF. She will be available to see patients on Farley 4 for consults. **Georgina Garcia MD** is a child psychiatrist who will be the primary consult attending for our pediatric in-patient service.

The Patient Family Advisory Committee has been busy planning upcoming events. The group meets monthly at the Children's Waltham Hospital site on the third Tuesday of the month. We are a group of patients, families and staff working together to improve care at the CF center.

Do you have a suggestion, story, photo or an accomplishment you would like to share with the "CF Newswire"? Email to cfevents@childrens.harvard.edu.

Kate Barnico, RN, BSN
Cystic Fibrosis Center Coordinator
Children's Hospital Boston

*Patient Nina Macri with her aunt Buket Macri and Mrs. Michelle Obama Summer 2010*

## NINA'S CHANCE MEETING

By Doreen M. Cummings

On a warm summer's evening this past August, our family had the best experience at the Beach Plum Inn on Martha's Vineyard. Our family travels to the Vineyard each summer, during the last week of August to enjoy swimming, fish filled meals, long days at the beach and sunshine! This year, the Obamas happened to be visiting the Island at the same time, and we all happened to pick the same place to have dinner on Friday Night!

*(Continued on final page.)*

## AIRWAY CLEARANCE TECHNIQUES

Airway clearance techniques (ACTs) are treatments that help people with cystic fibrosis (CF) stay healthy and breathe easier. Clearing the airways reduces lung infections and improves lung function. There are several different techniques that can be used to help clear secretions; such as; chest physical therapy, the Vest, Flutter or Acapella, and/or exercise.

ACTs are often used in conjunction with other CF treatments. Your CF care team will help you choose the best ACT and therapies. It is recommended that patients formally review ACT each year with a physical therapist. We will try to schedule this at the time of one of your clinic appointments. Anne Gould PT will review and evaluate your current ACT and exercise routines. Appointments can be made by calling 617-355-6079.

# LUNG TRANSPLANT PRODS LOCAL WOMAN INTO ROAD RACE

by Jim Eagan Published in the Walpole Times September 2010

Walpole High girls' track coach Conor Cashman and good friend Eileen "Meg" Henneberry of Westwood give the thumbs up to a road race three years after her lung transplants. When Eileen "Meg" Henneberry stood [ stands] on the starting line of the Walpole Road Race [this] Labor Day, she will looked just like any other young athletic woman in the crowd of nervous runners.

The difference is, Henneberry has overcome major medical issues to run the race . . . .[Meg had a] lung transplant three years ago in her fight with Cystic Fibrosis.

An intercollegiate athlete, she played lacrosse at Northeastern University and received an engineering degree graduating magna cum laude. Henneberry has a strong competitive drive and work ethic, according to those who know her.

"On my two year 'Lungversary' I said enough! Start running! You have been sitting on the sidelines way too long and being lazy," said Henneberry. "Use those lungs. Use this gift of life from your donor and appreciate it."

Walpole resident Dawn Freiberger, a nurse and the lung transplant coordinator at Children's Hospital in Boston said, "It is very hard for her to do significant exercise such as a road race. I jokingly suggested she train for and run in the Walpole Road Race. I was impressed when she said she was going to start training for it. She is a very competitive person ... she pushes herself and pushes herself. She told me she wants to go out there and not just finish the race but do it in a respectable time."

Freiberger said that even after a lung transplant operation it is "like trading one disease for another" due to frequent, ongoing medical complications. She said the new lungs will not be affected by the disease. She said Henneberry has had a "rocky road" after the lung transplants but that she is doing well now. "She is one of the most motivated patients I have seen. She takes great care in keeping herself healthy."

After the transplant operation, Henneberry said she was just 95 pounds and was so wasted she could barely eat or even change the TV channel at the hospital. "I would have dreams of running everywhere, playing lacrosse, sprinting in to make a goal and I would wake up, oxygen mask on, almost unable to get out of bed on my own accord. It was depressing," said Henneberry.

"After a long month of a drug-induced coma and many, many crazy morphine induced dreams, I awoke, totally unaware of what had happened but I was breathing and it felt easy and good. I wasn't fighting anymore, I was breathing like a normal person," she said.

Since she had been in a coma, her entire body atrophied. The muscular tone that she had been so proud of as a college athlete was gone. "I couldn't sit up, certainly couldn't stand, never mind walk, I couldn't even raise my arm and soon after I realized I couldn't hear," said Henneberry. "The hearing situation was easier to deal with than I thought, so what if I can't hear. I can breathe can't I? I was gaining strength and balance and re-learning things I had been doing since age three. I could brush my hair. I could tie my shoes. I could sit up. I could raise my hand and change the channel on the TV. I could drink from a straw and eventually I could eat applesauce. Even later I could stand up. I could take a step. I could type on a computer. I could climb stairs - with a lot of help. These were the first steps back."

She said the support of family and friends has helped her. Walpole High School Girls' Track Coach Conor Cashman has been a longtime friend and supporter. He has run the Boston Marathon for the Cystic Fibrosis Foundation for the last three years and has raised nearly $20,000. . . .

Cashman said, "So, when [she] Meg crosses that finish line, I will first experience relief, but ultimately I will feel proud of her transcendent resiliency, her confidence to dance without any music."

PHOTO COURTESTY OF CONOR CASHMAN

"I am doing this run for my donor," said Henneberry. "I hope he/she and their family have found some solace in the outcome of a devastating event. Also, I would love to be an inspiration for other patients with Cystic Fibrosis."

"I feel it is important for people to know about human organ transplant and how necessary it is," said Henneberry. "I was probably two weeks away from dying. That's hard to put into perspective. But without my donor checking the box or his/her parents deciding in a heart-wrenching moment that this was the right thing to do, it would have been 'Goodbye Meg.' That's scary. In your death you hold other lives in your hand. How powerful is that?"

Henneberry asks that people doing the road race sign up to become organ donors. . . .

Cashman is running the 2011 marathon trying to reach his goal of raising $25,000 over the past 4 years! To help him reach this unbelievable goal, please visit: **http://www.cff.org/LWC/dsp_DonationPage.cfm?idEvent=15753&idUser=218929**.



# THE FACE OF CF

by Lauren Bombardier

I had SUCH a good time on Sunday. I threw all my inhibitions aside, and marched around showing strangers a clear view of what I deal with every day. For my creative process class, we had to make masks which display our personalities, complete the costume, and march around in a parade at a local harvest festival. Well I got really creative and found a way to recycle a lot of the old supplies I had lying around. I saved those vials of medicine (hypertonic, tobi, and pulmozyme) that are usually cluttering every space I use them in and created a crown/mane of sorts. Then, I took all of my extra Ultrase (that I no longer take since they didn't get FDA approval and since I like zenpep so much more) and made a mosaic on the face of my mask. Some saw me as just a lion, but I felt empowered. True, I was marching around dressed as a lion with pills on her face, but it was so much more than that.

Marching around the other day dressed so ridiculously, I was displaying the source of my personality on the outside. Many people in my class (several whom I do not know) were curious as to why I had so many pills, and what those funny things were outlining my face. Imagine if your disease was just displayed on your face without any explanation. In some ways, those questions were uncomfortable, and I'm glad that I don't have to wear cystic fibrosis on my sleeve on a daily basis. But in normal circumstances, just by looking at me, those people wouldn't have known that I take so many pills a day, that I do so many breathing treatments, or that I struggle with breathing sometimes. However, they might notice how light-hearted I am, how much I smile, and how I don't cower in front of difficulties. I owe a lot of that to CF.

Though I am a firm believer in not letting cystic fibrosis define me, it cannot be avoided how much CF has affected my personality, and I'm thankful for many of the ways it has shaped me. Having cystic fibrosis has made me strong like a lion.

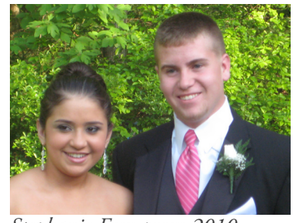
It takes a storm to know the beauty of the warm sunshine. If I had never fought with a chronic illness, I would not be able to appreciate the beauty of so many things in this world. And in the other direction, I would not be able to deal with how terrible so many things are in this world or even in every day life. CF has taught me to smile even when things aren't so good. It has taught me that its important to have a positive attitude and to persevere when it seems impossible to keep going. Many of these aspects of my personality are reflected each and every day, each time I brush off a small problem, each time I ignore a negative comment or person, each time I laugh. On sunday, I wore the cause of my personality on my face, people saw the inside struggle that is shaping who I am every single day. It might have caused some people to think, some people to wonder, some to empathize, but it made me feel incredible. CF doesn't scare me, and though it may be an incredibly difficult part of my life, it has made me who I am.

# ICARE UPDATE

The i.C.A.R.E. (I Change Adherence And Raise Expectations) study is starting to wrap up its first year with some of its participants. The study started in November of 2009 at Children's. Participants are from ages 11-20 years old and through this study they have the opportunity to discuss a variety of barriers that may prevent them from completing any of the treatments that they are currently on. The iCARE team works with the participants to conduct these "Problem-Solving" sessions, which involves discussing their barriers in depth, as well as brainstorming ideas that can help them to overcome these barriers.

*Steph Fren and Nate Demars iCARE session*

iCARE
I Change Adherence & Raise Expectations



*Stephanie Fren prom 2010*

# CYSTIC FIBROSIS GI SPECIALIST by Elizabeth Yen, MD

I am very excited to join the Cystic Fibrosis Center at Children's Hospital Boston as a Pediatric Gastroenterologist specializing in CF. I did my training in Pediatric Gastroenterology here at Children's Hospital, and for over 3 years, have been on faculty. I see patients with GI complaints in outpatient clinics in Boston. I also perform endoscopies, and supervise residents and GI fellows caring for hospitalized patients. My current research focuses on the role of nutrition in improving outcomes in cystic fibrosis. Prior to joining the CF team, my research focused on eosinophilic esophagitis, an allergic condition affecting the esophagus and resulting in difficulty swallowing.

I grew up in Miami, but moved to Boston to attend college. I attended medical school in New York (where I met my husband Karl), and completed pediatrics residency in Seattle. We came back to Boston to be close to his family, complete subspecialty training and start our own family. My one-year-old Emilio has given me a new perspective on parenthood, and is helping me be a better doctor.

As a specialist in CF GI disease, I look forward to working with the CF center's pulmonary physicians, dieticians and other care providers to best manage CF-related conditions such as acid reflux, malabsorption, malnutrition, liver disease, as well as constipation and diarrhea.

# SOCIAL WORK CORNER

by Judy Bond SW, Lynn Hellfand SW, Isabel Bailey SW

Living with CF is about living with hope and about living with some denial, about living with optimism and about living with realism, about living with uncertainty and about living with possibility. Everyone with CF and every family member touched by CF knows that life is more tricky and at times more challenging because of cystic fibrosis. Denial as a mechanism for coping can be useful and healthy or fruitless and harmful. Healthy denial allows you to get up every morning, to face the realities of the day, to do what you have to do, to enjoy the moment, and to plan for the future. Unhealthy denial can cause you not to set daily CF care as a priority, nor make or keep CF clinic appointments, nor consistently do treatments, nor be vigilant about diet and exercise, and delay in getting medical attention. While the intensity of denial may be altered when you or your family member is confronted with a change in health, attitude and perspective can help you get through these times.

Hope is likewise a critical mechanism for coping. CF is a diagnosis and not an illness or sickness. When problematic symptoms arise, your CF care team partners with you to treat these episodes. Information on CF is ever-evolving and Internet and written materials may often be out-of-date. You should always feel comfortable asking questions of your health care team about new advances in research and treatment of CF and about resources for you and your family members.

People with CF are living long and productive lives. Daily treatments do make a difference, enhancing and improving quality of life and increasing energy and strength so that you ( or your family member) can accomplish the things you want and need to do. At times, however, even when being conscientious about your daily care, a CF exacerbation may occur and it may be no one's fault. Putting hope into your life is working hard to stay as healthy as you possibly can so that you are in good shape when new treatments become available. Hope can also lead you to participate in clinical trials and fundraising for CF. The primary challenge is to keep some balance between hoping for the best, ie to feel well on an upcoming vacation, to play in the soccer tournament, and preparing or being ready for the need for an alteration in plans, ie to purchase trip insurance, to do extra treatments/pack extra food and water.

Everyone with CF is on their own journey and has different circumstances that may contribute to their health. Everything in life with CF involves choices, ie making and keeping connections with friends and family, staying informed and being knowledgeable about CF and treatments, working to have open communication with family, friends, and your health care team, and making positive lifestyle choices.

Living with CF is about living with balance, about living with passion, and about living with meaning. Finding ways to take care of daily CF care while maintaining a rich family, work, and social life is crucial. Living with hope and joy is too.

# SAVE THE DATES

**MARCH 21ST EXERCISE IN CF: LIFE IS DOIN' STUFF; EXERCISE IS MEDICINE**
*David Orenstien, MD*

**MARCH 26TH CF INFANCY THROUGH AGE FIVE**
*CF Center Staff*

**APRIL 12TH HOW THE LAW CAN HELP WITH EDUCATION, INSURANCE, EMPLOYMENT, AND ACCESS TO GOVERNMENT BENEFITS**
*Beth Sufian, JD, Attorney and Director of the CF Legal Information Hotline, 45 years old with CF*

**DEVELOPING PRACTICAL CF SELF MANAGEMENT SKILLS**
*Joan Fennegan Brooks, President, Patient-Focused Market Research, 50 years old with CF*



# NUTRITION: BACK TO THE BASICS by Kristen Leavitt, RD, LDN and Ashley O'Brien, RD, LDN

Happy New Year! As we enter 2011 and a new year is upon us, we realized that it is sometimes helpful to reflect on the past. A recent project completed at our CF center in 2010 asked parents and their adolescent children which nutrient had the most calories: protein, carbohydrate or fat. Do you know the answer? It is fat! Fat has 9 calories for every gram eaten where protein and carbohydrate have only 4 calories per gram. Did you get the answer wrong? Don't worry. Most people asked did! When parents were asked this question they got it wrong **87% of the time.** Our adolescents got this question wrong **89% of the time.** Because of this, we thought we would dedicate this Nutrition article to the basics of CF nutrition.

As many of you know, it can be very challenging to eat large amounts of food at a sitting. To help those with CF consume the calories necessary for either weight gain or maintenance, meals and snacks must be packed with calories. As stated above, fat contains more calories than protein or carbohydrate, and can often make foods taste better. Foods high in fat, such as cheese, milk, ice cream and meat, are also good sources of protein. Protein is important for building muscle and helping the body prevent and recover from illness or infection. Foods high in fat can also be high in carbohydrate (think baked goods and granolas), which provide the body with energy and fiber.

**WAYS TO BOOST CALORIES**

Although fruits and vegetables are important to include in the diet, it may be necessary to limit the amounts of these foods, as they will fill up the stomach without providing many calories. Adding sources of fat to these foods will increase calories and can make eating them daily a healthy possibility: Add butter, margarine or oil to breads, cereals, rice, noodles, potatoes and vegetables. Add sour cream to meat, potatoes, vegetables, and casseroles. Dress up fruit with cream cheese, whipped cream and chocolate sauce. Add extra salad dressing, nuts, dried fruit and cheese to salads.

Added fat can also be used for meats and starches to boost calories. Meats can be marinated with oils before cooking. Use creamy and cheesy sauces or gravies with meat, and casseroles. Mayonnaise can be added to sandwiches and the fillings used in them.

You can add fat to additional foods by using whipped cream on hot chocolate, fruit, pudding, pie and other desserts.

Add syrup, jam, jelly or hard toppings to ice cream. Use peanut or other nut butters, or extra jam, jelly and honey on toast, bread, muffins, biscuits and crackers.

Full-fat dairy is a good source of fat, too. Prepare soup, cereal, hot chocolate and pudding with half-and-half or heavy cream.

Serve whole milk and other whole-fat dairy products such as cheese and yogurt. Add cheese to scrambled eggs, sauces, vegetables, soups, casseroles and salads. Lastly, try adding extra eggs or just egg yolks to sauces, casseroles and salads.

**USING SNACKS WISELY**

Children may complain during a meal that they are too full to continue eating. Rather than pushing your child to eat large quantities during meals, it is helpful to give high-calorie snacks in between regular mealtimes. You may want to give snacks ("small meals") more often throughout the day if your child often feels full and cannot eat very much during mealtimes. However, it is important that snacks are given at a certain time in between each meal rather than allowing your child to snack or "graze" throughout the day. This will cause preemptive fullness and lessens appetite prior to mealtimes. This concept applies to those with CF of all ages!

**TIPS FOR HIGH CALORIE SNACK**

Here are a few ways to make eating high fat foods easier:

- Make a list of high-calorie bedtime snacks for you or your child to choose from.
- Think of ways to turn lower-calorie snacks (such as crackers, apples and cereal) into higher calorie ones by adding peanut butter, butter or cheese.
- Keep nut butters, cheese and full-fat dairy stocked in the house for easy access.
- Find or create recipes for milkshakes and smoothies made with a combination of ice cream, powdered milk, cream, instant breakfast powders, yogurt, and fruit.
- Keep meal bars, granola, nuts and potato chips in the cabinet for high-calorie eating on the run.

This article provides a short list of ideas on increasing your caloric intake. We encourage you to make an appointment with one of the CF dietitian's—either Kristen or Ashley—to discuss new, creative strategies for high calorie eating! We look forward to seeing you in clinic.

**Have a CF nutrition tip or recipe? Share it with other patients and families at cfevents@childrens.harvard.edu**

**TIP: Vitamins are absorbed better when taken with enzymes.**

# LIVING WITH HOPE AND CYSTIC FIBROSIS By Katherine Low

For many young people, May is a time for graduation and planning for the future. They look forward to getting out into the real world, their first job, meeting their life mate. These days especially, they are likely to worry about money, career, and expectations for success.

As I approach my own graduation from the Suffolk University program at Cape Cod Community College, I have a different perspective.

I was born with cystic fibrosis. I was baptized right away, not weighed and measured, because the doctors weren't sure I would survive. As I was rushed down the hospital corridor to intensive care, my parents were very frightened. I grew up with constant medical treatment and the reality of a limited life expectancy always hanging over my head.

As you might imagine, this has been a huge burden for my family and me. But you might be surprised to hear that I also consider it a blessing.

Every birthday is truly a time for celebration. Most people worry about aging, but I yearn to experience graying hair and laugh lines circling my mouth. I don't expect them. I can't.

But I do live by hope. I hope to see smiles of children that I can call mine, and hope to feed my grandchildren chocolate chip cookies around a hearth I can call my own. I hope that one day someone with CF won't have to weigh the risks of having their own children die of CF, or they themselves dying when their children are young.

And then there are things I don't even have to hope for, because I already have them: knowing I am loved and cherished by my family and friends, including my wonderful boyfriend who makes me feel like the world is pure.

I spent the last semester interning at Hospice & Palliative Care of Cape Cod, learning about the resources available for the many patients and families coping with serious illness. I saw that everyone has a story to tell. At every hospice event I went to, someone came up to me and shared their experience dealing with loss. I saw how their perspective on life and death gave them a special appreciation that echoed some of mine.

I believe that the most important things in life are the relationships we nurture. Death is uncontrollable; it can touch anyone at any time, without notice. I know that. There is not one day that I am not appreciating being alive.

I urge you to go out of your element and experience something or someone that makes you think differently. Life was not designed to be easy, but it is worthwhile. I live for experiences, for picnics with good food and wine, and moments when I don't want to go home.

People live their whole lives working; only at the end might they consider what gave their life meaning. Every day ask yourself: What are your goals for your life? What is important to you? I have been blessed because I know the importance of figuring out life's meaning and then living accordingly.

I am not so different from you; I don't look like a sick person. I could be sitting next to you at your office, or waiting on your family at dinner. Everyone is similar, with goals, fears, hopes and a lot of stress. We are all special. Including you!

Life is a terminal illness for all of us. It might last 10 more years, or 30; you never know. I have had several friends die from cystic fibrosis in the past few years and every time I wonder: why not me? Why am I stuck in this paradox of being sick, yet outliving others? Why do I feel like I'm the only one of us left? No one who is loved ever truly dies. So long as their memories are alive, stories can be told and passed on, keeping their spirit with us.

I have had the pleasure of knowing amazing people who never complained, had great senses of humor and took every day as a time for happiness — regret just wasn't a word in their vocabulary. They lived too briefly, but so unconditionally and with such passion that thinking of them makes me cry. I miss being close to others who have the same burdens. Every time I do something special, I think of them, and carry them with me as I continue on my life's journey.

This month I am off to Italy to study photojournalism with Suffolk University, and then to Puerto Rico to celebrate the joys of my relationship. Afterward I will return home to Cape Cod, to fulfill my dreams of a home and family, much like many others graduating soon. May we all find the hope and joys in each of our unique lives, for whatever time we each may have.



# A TYPICAL RESEARCH STUDY VISIT

by Erin Leone Thakkallapalli, MPH, CCRC, Reasearch Specialist

If you have never participated in a research study of an investigational drug, you may wonder exactly what happens during a study visit. Although each study is a little different, many of the same procedures happen during any study visit. Before you begin a study, you will have a chance to learn about the study and discuss it with your doctor and the research coordinator. An informed consent form will be reviewed with you, which includes information about the purpose of the study, the study procedures, expected risks and/or benefits, your rights and responsibilities as a research volunteer, and privacy/confidentiality provisions. After you have agreed to participate in the study, you will be scheduled for regular study visits. If possible your study visits will be scheduled to occur at the same time as your clinic visits.

When you arrive in clinic, you will be brought directly to the designated research exam room by the research coordinator. At the start of the study visit, you may be asked to complete one or more study questionnaires. Next, the research coordinator or clinical assistant will complete your vital signs, height and weight. You will be asked about your medical history, health status and any medications you have used. Depending on the study, you may need to complete special tests such as pulmonary function tests (or PFTs, also known as breathing tests), a throat or sputum culture, bloodwork, a chest xray, an ultrasound, an electrocardiogram (or ECG, to check your heart rhythms), or audiogram (hearing test). Some of these tests may be done by the research coordinator using specialized research eqtpment, while other tests may be done in the hospital by technicians. Your doctor or one of the study doctors will review your test results and complete a physical exam. After the exam, you may be asked to take the study medication and be observed by the research coordinator. When the study procedures are complete, you will receive instructions for taking the study drug at home and when you will need to return to the clinic for your next visit. You will be given contact information for the study doctor and research coordinator if you have any questions or concerns during your study participation.

If you are interested in participating in a research study, please contact the Research Office at 617-355-6665.

- Erin Leone Thakkallapalli, MPH, CCRC, Research Specialist, Program Co-Manager
- Jane Solomon, RN, BSN, Research Nurse, Program Co-Manager
- Catherine Correia, Research Coordinator
- Robert Fowler, Research Coordinator
- Beatrice Duvert, Research Assistant
- Ashish George, Research Assistant

| STUDY | MAIN ELIGIBILITY CRITERIA |
|---|---|
| Vertex VX-809-102 | • 18 years and older, FEV1 greater than 40%, F508del-CFTR mutation |
| Mpex Inhaled Levofloxacin | • 12 years and older, FEV1 between 25% and 85%<br>• Positive Pseudomonas cultures |
| Twin/Sibling Study | • Any family with at least 2 siblings with CF |
| Gene Mutation Test Validation | • Any patient or family member with a rare gene mutation |

greatstrides®

TAKING STEPS TO CURE CYSTIC FIBROSIS


The "Great Strides" walk for Massachusetts and Rhode Island is the weekend of May 21st and 22nd. The CF Center will be holding a t-shirt design contest for a design for the shirts worn for the center team. If you would like, please submit your design at **cfevents@childrens.harvard.edu** or bring them to clinic by April 9, 2011.

## MEDICATION TIPS

## CFF GUIDELINES RECOMMENDED ORDER OF MEDICATIONS

- **albuterol/Xopenex**
- **hypertonic saline**
- **Pulmozyme**
- **Airway clearance**
- **Inhaled antibiotic**
- **Inhaled steroids**

*Nico Auriti and parents celebrate Halloween*

# 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

*Continued from page 1*

One minute we were ordering our dinner and the next, there was a fever in the air as our President, and Mrs. Obama made their way through the restaurant and outside to view the gorgeous sunset. The Beach Plum Inn is one of the favorite spots in Chilmark for viewing the beautiful summer sunsets. Nina and her Aunt Buket walked through the small crowd and greeted Mrs. Obama who was full of warm energy and who posed for a quick photo. Then, Nina and Aunt Buket waited for President Obama to finish talking with someone to have their turn for quick chat. President Obama sweetly talked with Nina, and asked Nina if she enjoyed her dinner if she was swimming a lot during her vacation. Then, we all returned to our tables and had a wonderful meal.

*Patient Nina Macri with her aunt Buket Macri and President Obama*

CYSTIC FIBROSIS News Wire

Children's Hospital Boston
300 Longwood Avenue
Boston, MA 02115