Inspire

A newsletter for cystic fibrosis patients, their families and friends Spring/Summer 2010

News from the URMC Adult Cystic Fibrosis Program

Dr. Robert Horowitz

OSPITALIZATION: Over the last several years, the acuity of illness in hospitals has become more severe; hospitalization has become reserved for the very sick. In addition, hospitals are more frequently "code red," which means there are no open inpatient beds available.

This has posed a challenge for the hospitalization of individuals with CF undergoing "tune-ups" with IV antibiotics and increased airway clearance for their lung disease. The response across the country has varied. Several adult CF programs treat all but the most unstable patients with home based tune-ups. We have been remarkably fortunate, as Highland Hospital's administration is explicitly committed to providing inpatient care for any CF patient we believe needs inpatient services.

However, sometimes our admissions, which are much longer than average acute care hospitalizations, pose a strain on resources, and so we are obliged to review when inpatient treatment is necessary, and when patients might best be managed at home.

We are among a growing number of CF programs that will be using a Pulmonary Exacerbation Score to provide more consistency in identifying a patient's degree of illness. Further complicating the decision whether to treat an individual with a tune-up is the recent trend in "routine" tune-ups.

So, in addition to the challenge of deciding when/whether to treat an individual with a tune-up, we are forced to deliberate whether hospitalization is appropriate for any individual patient. Certainly, patients who are very ill—for example, requiring oxygen, being moderately breathless with minimal activity, or having lost significant amounts of weight—will continue to be hospitalized, at least until they have stabilized. Also, individuals who do not have the home resources or support, or the ability to manage a home-based treatment course will also be hospitalized.

What about those patients who are stable and have the resources to manage a home tune-up? Is there an inherent advantage in hospitalization over home-based treatment? Certainly, we have seen attempts at home-based treatment fail because the treatment regimen is compromised, or the patient was too busy working, cleaning, managing the home to get the full benefit of treatment.

However, experience suggests that if the same treatment regimen can be fully delivered reliably at home, some of the difficulties and risks of hospitalization, including a rare but real risk of infection and medication error are averted.

We will be urging patients able to manage an aggressive regimen at home to do so, with weekly follow-up in the office.

RESEARCH RULES!!!

BY: MARISSA DIXON AND MARY PLATT

Genes are the main unit of heredity. Each chromosome carries hundreds of genes. Genes decide body traits like eye and hair color, height, facial features, and many health problems. CF is caused by an alteration of a gene. A child inherits CF when two genes are received, one from each parent. A small number of genes (less than 1 percent of the total) are slightly different between people. These small differences contribute to each person's unique features.

There are more than fourteen hundred genetic mutations that cause CF. In order for someone to inherit CF, one must inherit one copy of each gene from each parent. Most labs only test for the most common forty mutations. For instance, the lab at the New York State Department of Health tests for forty CF DNA mutations as part of the newborn screen process which started in our state five years ago.

There are a few ways a CF diagnosis may be made. It may have been because a person is exhibiting CF related symptoms, because of a diagnosis in a newborn screen based on the detection of a disease causing mutation (within the last five years), or in prenatal screening, by the presence of two mutations. All of which would be confirmed by the gold standard of CF diagnosis, the sweat chloride test.

Knowing which CF mutations your family member with cystic fibrosis can be an important of research. It helps us know the specific CF mutation involved and can help determine eligibility of a clinical trial. As we go forward with clinical trials for drugs which act on genetic modifiers, this is especially important to know. One such study that we are recruiting for is Vertex, a drug that is taken orally, and designed to treat the basic defect in CF. If you are interested in obtaining your CF genetic information, you can discuss this more with your provider.

Enrolling Studies:

ISIS 002

People with CF often have thick mucus in the airways of the lungs that is hard to cough up. Inhaling a salt solution called hypertonic saline (HS), may help to thin the mucus in the lungs. Thinning the mucus can make it easier to cough up. This helps to clear the lungs and improve lung health.

Research studies about the safety and effectiveness of the inhaled HS have been done in adults and children with CF 6 years of age and older. Patients in these studies took HS for up to a year. HS appears to be a safe treatment in these age groups. HS appears to be a safe treatment in these age groups. The main side effects were cough, throat irritation, and wheezing.

The use of HS decreased the need fpr antibiotics for acute respiratory infections. It also improved lung function and quality of life. This study seeks to find if HS can be used by those younger than 6 to achieve similar results.

Soon to be enrolling studies:

iCare

iCARE, I Change Adherence and Raise Expectations, is a study that seeks to find out whether providing a comprehensive adherence program with can improve medication adherence. CF patients from 11 to 20 years old can participate in the 2 year study provided they are prescribed one of the specific study followed medications. Participants will be required to complete three 45 minutes assessments that include a survey and an interview. Participants may also be asked to complete problem solving sessions as a part of their CF clinical care.

Study Name	Qualifications	Duration	Visits	Procedures	What kind of Drug?	Compensation
ISIS 002	*4 months to 5 year old *1 week not sick before screen	*48 weeks	6 visits	*surveys and questionnaires *OP swabs *physical exams * other tests	nebulized solution twice daily	Up to $210.00
iCARE	**11-20 years old *must be prescribed one of the following medications: Azithromycin, Hypertonic saline, Pulmozyme, or Tobi	*2 years	3 visits	* surveys *interview *problem-solving session	-	Up to $425.00 in gift cards

To find out more about these studies please contact Marissa or Mary at (585)-275-2464 or you can take a look at the following websites:

(ISIS 002) http://www.cff.org/Display/dsp_ClinicalResearchHTML.cfm?id=49

Life with CF by Jennifer Burt

When asked to write about my life with Cystic Fibrosis, I didn't know what to write. It's a huge part of my life, but yet I am not as affected by this disease as some are. Being a junior in high school my life is busy, without any more stress. As a two-season athlete on honor roll and a social life, I don't have time to be slowed down by cf.

Managing CF has been easy, with my medicine with food is what keeps me acting normal. I don't act different because I have CF or use it an excuse or advantage.

People know I have it, but they don't view me any different because of it. Sports have always been my life, and they are a big part of who I am. I wouldn't be anywhere today without the success of sports in my life.

I am lucky enough to have very few incidents where my CF has gotten in the way of doing what I love. I even forget sometimes that I have CF because it has been so manageable for me.

Each day is a new opportunity to become a better student, athlete, friend, sister, and daughter. Normal isn't good enough sometimes, and I always want to be extraordinary, and leave my mark somewhere in this world on many people. CF only adds to the success if I can make it through every day as healthy as the last.

THE STAFF REPORT

Meet Diane McEwen, the Newest Member of the Office Staff

Many of you have already had the opportunity to speak with Diane McEwen, the newest member of our Pediatric Pulmonology office staff. Diane officially began with us on March 1, 2010, but she has been working in our office in a temporary position since September 2009. She has a great deal of experience in an office setting and at the University and will be a valuable asset to our team. She is available to assist you by way of directing your calls and scheduling appointments, as well as helping you in any way possible. We are pleased to welcome her as a member of our team.

You are invited!!!

The 'Great Strides' CF fundraising walk will take place Saturday, May 15, at Genesee Valley Park in Rochester. If you would like to walk and aren't up to forming your own team…JOIN US!
The Rochester CF Center team is named in honor of our wonderful Ann McMullen…we are called Ann's Amblers!
If you would like to join (or offer us a donation!) go to:

http://www.cff.org/Great_Strides/DonnaGermuga

Get Moving!!!

One of the most important things any of us can do for ourselves is to exercise. We could all benefit from being more active, but if you have CF the benefits really shine! Any activity is good, but exercise that focuses on upper body strength, breathing and endurance can really pay off for CF patients. Many of our patients have the best lung function of their lives when they are extremely active. Swimming, running, gymnastics, dance…the list goes on and on. Don't ever let CF hold you back from trying to participate in an activity or sport that you are interested in (with your doctors OK of course!).

Whether you are the best or not takes a back seat to the benefits to your body and mind that regular, hard exercise gives you. In the end, you win for taking such good care of yourself and working hard to maintain your lung function and decrease the time you might need to be hospitalized.

This applies to ALL ages. As babies and toddlers, there are lots of fun interactive ways to work out the upper body and gain strength. Kim and Donna have lots of information guides for you if we haven't already given you one. The materials are also available on the Pediatric Pulmonary Web site for you to download and print.

Did you know that vigorous exercise can take the place of one airway clearance session per day? That's right, if you can take your inhaled meds and get out for a run or take the dog for a brisk walk, you may be able to forgo your vest or flutter valve for that treatment session! We can always be creative to try to help you maintain healthy lungs. If you are struggling with ways to stay active, let us know when you come to clinic and we will be very happy to help you figure something out!

I

THE FIVE E's OF PARENTING

Experience, Example, Empathy, Encouragement, Expectation

Join Lisa Greene and Foster Cline, MD in their fifth video discussing the 5 E's of parenting (Experience, Example, Empathy, Encouragement and Expectation).

All of the videos will remain on KnowCF.com so you may review "Parenting with E's" in the future or send links to others who may want to boost their parenting skills.

Thank you Lisa and Foster for sharing this wonderful program with us!

Also, if you are planning to attend the CFLC Continuum of Care Conference, please visit our booth and greet our team from cysticfibrosis.com. This educational conference is for CF health care professionals and patients' families.

Rich Mattingly, of the CFF, is the keynote speaker.

The conference is being held at the Hyatt Regency in Jersey City, New Jersey from April 15-17th, with free registration for patients' families.

May your knowledge of the world of CF expand through our efforts at KnowCF!

Hope to see you there!!

Kit Taylor Lecture

Tuesday Evening
April 13, 2010

At Valley Manor

Come hear Alexandra Quittner, PhD speak about Quality of Life issues related to Cystic Fibrosis

Find out more about Alexandra Quittner, PhD at
http://www.psy.miami.edu/faculty/aquittner/

Sound Bites From Social Work
Depression and CF
"Define it and Defeat it"

Feeling down from time to time is a normal part of life. But when feelings of hopelessness and despair won't go away it may be depression. Depression makes it tough to function and enjoy life.

Living with cystic fibrosis and everything that accompanies the disease can take a toll on your emotional stamina. The rates of depression are higher in people living with CF than they are in the general population. This is a concern for your health care providers as depressed patients are less likely to keep their commitment to treatment and more likely to miss clinic appointments which can exacerbate your CF symptoms and lead to further health concerns.

Here are some signs and symptoms of depression:
- Loss of interest in normal activities
- A sense of sadness
- Guilt
- Difficulty concentrating
- Crying spells for no apparent reason
- Problems making decisions
- Sleeplessness or sleeping too much
- Feeling hopeless and helpless
- Weight gain or loss

What can you do if you feel depressed? Seeking out support from others you trust and talking things though can help you feel like you are not alone and that your feelings are real. Try not to overwhelm yourself and set realistic goals each day. Surround yourself with people who you trust and know you so that you do not feel so isolated. Know that it is okay to seek professional help for your feelings. Depression can be defeated!

If you are feeling depressed and would like to get connected with mental health services, please talk with the social worker at your next visit.
*If you are having thoughts of hurting yourself or others, please contact 911, 211 (Lifeline) or the office anytime and someone will be able to assist you immediately.

Nutrition Notes

Vitamin D QI

We have begun a new Quality Initiative on the pediatric side. We are looking more intensely at vitamin D status in our patients. This is done with the annual lab blood draw. The majority of our pediatric patients had sub-optimal levels in 2009 and were asked to take additional vitamin D capsules. A follow up blood draw should occur three months after beginning the additional vitamin D. We are working hard to make sure this happens. We know it is unpleasant to have blood drawn, but it is an important piece of the nutrition puzzle. Vitamin D is necessary for bone health and with children who are growing rapidly it is very important to make sure they have adequate levels. If you have any questions regarding your or your child's vitamin levels please call Melissa Berry, RD, at 275-1457.

Be sure to check out our new CF Center website:
http://www.urmc.rochester.edu/childrens-hospital/patient-care/pulmonology/cystic-fibrosis/index.cfm

- **Our Educational Resources page offers downloadable PDFs on various respiratory and nutrition topics as well as Web site links to local resources.**
- **We have an Events page that lists and links to area CFF fundraising opportunities and Center happenings.**
- **The Research page lists and links the research projects currently underway at our center and the criteria to participate in them.**

The Web site is still being developed and updated so check back often to see what's new!

Summer is just around the corner! Make sure you wear sun screen as many antibiotics make your skin more sensitive and more likely to burn! Stay hydrated too!!!

Feel free to contact me, Melissa Berry, your personal CF dietitian with any nutrition, supplement, or vitamin related questions at 275-1457. My office hours are Tuesday and Thursday, 8:30-5:00. I am also available on select Wednesdays 8:30-2:00.

***"No man can know where her is going unless he knows exactly where he has been and exactly how he arrived at his present place"* -Maya Angelou**

By Rachel Hess, sister of Foster Hess

I have an always will be, the other child.

I listen to him wake up every day, each morning, after a long night of coughing, restless. The hard thumps down the stairs to eat breakfast…but it's not that simple. Pricking his skin. Piercing. The bruised area from daily shots to test himself…then to insert his long shot of insulin. He argues for me not to stare but I cannot look away. Breakfast, along with every meal: four pills each. He carries on. I walk downstairs, well-rested, eat and go on without any troubles.

He's almost 20 now and each day I cherish the time I have spent with him. He is my brother, Forrest, a witty man who strives to learn anything he can get his hands on. He was diagnosed at age 3 with Cystic Fibrosis, right after I was born, and found to be a carrier of. My parents were desperate as to what actions to take for his health. Cystic Fibrosis, as researched in 1990, was unfortunate news to any parent. Doctors believed Forrest's life would be short the amount of years anyone should live and that they should be lived to the fullest. Indeed, as my brother grew up, he became aware of his lifestyle and adapted to the taking of about 20 pills each day.

In middle school, fitting in was difficult for Forrest. He was different. He learned at a young age to appreciate the little things and love each person he met…even if they didn't acknowledge him. Other kids bullied Forrest and picked on him for his differences. They teased him for his maturity and aptitude to love learning, but never did he complain. "I go to school, learn, and then come home. Simple,"

Every day after school he would come home and take on a new adventure that intrigued him. He took apart engines and rebuilt them, he went down the street and found old lawnmowers in the garbage and he would fix and sell them, he would take apart old cars and repair them. Around the age of 15 he had already owned and sold about six cars. His intelligence and ability to learn was incredible and blew my parents and myself away.

At that point in my life, my brother had just entered high school. He was growing up and I was worried. One day, I was about to work on the computer and search through the Internet, I found that children diagnosed with CF would live to the age range of eighteen. Eighteen short years. I couldn't believe it, I was frightened. I was afraid. This couldn't be happening to my family, not to his friends, not to me.

I wished for a chance for him to open up and express how he felt, but he contently said he was fine. I tried to feel the pain he felt inside, but I couldn't do it. I could not see any wrong happening

to his life and it hurt me. I was comfortable and so was he. I knew at the time it could not get any worse.

It did. A lot worse. Weeks later he was diagnosed with diabetes. I held my breath for weeks, which turned into months and then soon, years.

Forrest got granted a wish from the Make-a-Wish Foundation where my family and I went to International Falls, Minnesota for a vintage snowmobiling event which was specially organized for Forrest and almost 150 men came just for him.

That was a turning point in his life—his ability to connect with people and to keep annual plans of meeting each year. Later on, he got accepted at SUNY Oswego for Technology Education. For living with such hardships, the accomplishments he made in his short nineteen years is astonishing and his future is based on the actions he successfully completed from his past.

No man can know where he is headed. Forrest has no clue where he will be the next day but with positive intentions and actions that support his ongoing ability to learn, he will live his life to the fullest. He is completely informed as to where he is today and he knows specifically what he has accomplished.

Forrest knows that he has made every choice for a specific reason and will continue to stay healthy—which makes my family and I happy and gives us all a reason to smile.

But under that smile, I feel fear.

Making Wishes and Dreams Come True

There are many wonderful organizations in our community that want to offer support and respite from a chronic illness. Many families have heard of the "Make a Wish" foundation that grants wished to chronically ill children but there are also other opportunities available. The following organizations invite you to call if you would like to be considered for participation.

The Dream Factory. Laura Walitsky is the executive director. She can be reached either by website www.dreamfactoryrochester.com or phone 585-820-7629

Great Escapes is offered in Rochester by the Starlight Organization and hold events for children with chronic conditions and their families. Their information is www.starlight-newyork.org. The local contact is Elizabeth Agnello at Elizabeth@starlightnyc.org.

If you have other questions, feel free to bring them up at your next clinic appointment.

NURSES NOOK: Who to Call / Who to Visit ??

It is often confusing to figure out when to call your child's primary care office or the CF Center. Here is a quick guide. Please note that we always encourage you to call one of the nurses at 585-275-2464 for any situation that is unclear and we will help guide you to make sure your child receives the best care possible.

"Call" means you may be able to get the information or help you need over the telephone

"Visit" means you should call and make an appointment to bring your child in to see either your CF Center health care team or your child's primary care provider

Situation	CF Center			Primary Care Provider	
	Call	Visit		Call	Visit
If my child:					
Needs a well-child visit					x
Needs a routine immunization (shot)					x
Needs a flu shot		x	or		x
Has chickenpox				x	
Has a rash				x	
Needs a regular CF checkup		x			
If I think my child has:					
A cold / cough	x		or	x	
Allergies				x	
Bronchitis or pneumonia		x	or		x
Diarrhea				x	
Stomach Ache	x		or	x	
Symptoms of malabsorption (greasy or shiny stools, increased stooling, abdominal cramping, increase in foul smell, frothy in appearance)	x				
Fever	x		or	x	
If I'm worried that my child:					
Has been exposed to an illness	x		or	x	
Isn't responding to treatment	x		or	x	
Isn't gaining enough weight	x				
If I'm having trouble with:					
Respiratory treatments	x				
Airway clearance	x				
Giving my child enzymes	x				
Getting my child to eat	x		or	x	
Watching for signs of infection	x		or	x	
Telling the difference between colds, or allergies or bronchitis	x		or	x	
Coping with my child's illness	x		or	x	
Behaviors that worry me				x	

Cystic Fibrosis Scholarship Foundation

Helping young adults with CF pursue their dreams

The Cystic Fibrosis Scholarship Foundation ("CFSF"), founded by a parent of a young adult with CF, is pleased to announce a scholarship program for students with cystic fibrosis. CFSF is not part of nor is it funded by the Cystic Fibrosis Foundation. The program is available to those who will be enrolled in an undergraduate college program or a vocational school in the fall of 2010.

Scholarships will be awarded based on a combination of financial need, academic achievement, and leadership. In the past, approximately 25% of the students who apply have been awarded scholarships. Awards may be used for tuition, books and room and board. Awards will be sent directly to the institution that the student is attending. Both multi-year awards and single year scholarships are awarded. Most awards are for $1,000 per year. All high school seniors will automatically be considered for the Kevin Tidwell Memorial Scholarship and the Glen Parsons Memorial Scholarship which is a $10,000 award ($2500 per year). Students granted a single year award may apply in subsequent years for further awards although there is no guarantee of future awards. Multi-year award recipients must maintain a 2.0 grade point average or above to maintain their scholarship and continue to be a full time student. All students will be considered for both the multi-year and single year awards.

Recipients of awards will be notified by April 20, 2010. Scholarship application forms will be accepted after January 15, 2010 and are due to the Foundation by March 21, 2010. Application forms are available via e-mail to MKBCFSF@aol.com, or by phone by calling 847-328-0127. The application forms are also available at our website: cfscholarship.org. Applications for the 2010 – 2011 school year will not be available until early November. When requesting an application please indicate your current status in school (i.e., high school senior, freshman in college, etc.). This is important in order to be able to send the appropriate application form.

1555 Sherman Ave., #116, Evanston, IL 60201
Phone: 847-328-0127 Fax: 847-328-0127
E-mail: MKBCFSF@aol.com
Website: cfscholarship.org

What's Happening at the Cystic Fibrosis Foundation?
Greater Rochester Chapter News

Upcoming 2010 Events:

CF Fairway to Hope
Golf Tournament
August 16

Roses of Hope Gala- *Rochester Riverside Convention Center*
September 11

Stair Climb for Life – *First Federal Plaza*
October 16

2010 GREAT STRIDES

Rochester - May 15
Genesee Valley Park

Canandaigua - May 16
Sonnenberg Gardens

Geneva - May 16
Seneca Lake State Park

Elmira - June 5
Eldridge Park

Southern Tier / Hornell - June 6
Steuben Trust Company

Letchworth - September 26
Letchworth State Park

For more information regarding these events please go to: www.cff.org/Chapters/Rochester or contact us at:

Rochester Chapter
550 Latona Road
Building D, Suite 408
Rochester, NY 14626
Office: (585) 697-0777
Fax: (585) 697-0949
Email: rochester-ny@cff.org

Upcoming Events

Great Strides is our largest fundraising event and we have a big revenue goal this year… **$190,000** from all walk sites. (See sidebar for complete list.) As of St. Patrick's Day we've reached 8% of our goal… with a little Luck O' the Irish, **Sheriff Patrick O'Flynn** is the **Honorary Chair in Rochester**, and with your help by **becoming a Team Leader** or a **Fundraising Walker** we can make our goal. **Sara Hart**, **Lauren White**, and **Colleen Argentieri** are chairing the walk committees in **Rochester**, **Canandaigua**, and **Hornell**, respectively. If you have an interest in getting involved on a committee at any of the walk sites, please contact CFF or the chairpersons. Most importantly, think about forming a team with your co-workers or family and begin fundraising immediately online – its fun, fast and easy. And the CFF Chapter Team is here to assist. To be a part of a Great Strides visit: http://www.cff.org/Chapters/rochester/greatstrides/ or contact Kristen at 585-697-0777.

Save the Date: **September 11** at the **Rochester Riverside Convention Center**. **Gene and Debbie Caccamise** had so much fun last year they are back as the 9th Annual Gala's **Honorary Chairpersons**. We **welcome** your assistance and i**nvolvement** - please consider donating auction items, being a sponsor or joining the committee. Contact Susanne at 585-697-0777.

Lots of FUNdraising

The **20th Anniversary of the Amerks/Knighthawks' Celebrity Waiter Dinner & Auction** held March 9th at the Blue Cross Arena raised a record-breaking **$54,000**. **Wendy Staats.** Amerks / Knighthawks, worked with **Dolly Kujawa** and **Bobbi Coats,** event chairs**,** and were assisted by committee members: **Mary Dibble**, **Milly and Bob Schenkel**, **Michelle Bryant**, **Virginia Paddock** and **Jackie Wilke**. This event has now raised over $754,000 to help fund on-going, groundbreaking medical research aimed at curing and controlling CF. The Chapter presented two CFF **Partner of Hope Awards** to **Toshiba Business Solutions and the Rochester Americans** for their long time partnership, leadership and contributions to the CF Foundation Greater Rochester Chapter.

In February, **Family First Federal Credit Union,** sponsor of the **B.C.B. Home Fair Expo,** named CFF the charity of choice for the 2010 event. Many exhibitors gave generously to the silent auction which raised nearly $7,000. Special thanks to **Family First, Federal Credit Union,** the **Better Contractors Bureau**, the exhibitors and donors as well as the **many volunteers** that helped make the auction a huge success.

What's Happening at the Cystic Fibrosis Foundation?
Greater Rochester Chapter News

Thank You

13WHAM-TV
Amerks Booster Club
Applebee's / T L Canon
B & B Equestrian
Better Contractors Bureau
Blue Cross Arena
Bricklayers & Allied Craftsmen,
CASCO Securities
CFF Care Centers
CMI Communications
Delta Phi Epsilon
East Ridge Printing
Family First Federal Credit Union
Get it Straight
IFCO
J. T. Genier Security Services
Karpus Investment Management
Knighthawks Booster Club
Knights of Pythias
Kroner Gamble & Company
M & T Bank
Manning & Napier
Massa Construction
Monroe Community College
Monroe County Sheriff's Office
Natalie Sinisgalli Photography
Network Rochester
PACE Windows & Doors
Pike Company
Richards Manufacturing
Roberts Communications
Rochester Americans
Rochester Knighthawks
Rochester Woman Magazine
Segal
Signs Now
Spatola's Party Rental
Steuben Trust Company
The Bonadio Group
The Finishing Touch
The Great Frame Up
Tim Hortons
Toshiba Business Solutions
Town of Penfield
Tuxedo Junction
UNICON
U of R Medical Center
University Accounting & Tax
USA Payroll
Ward Diesel
WARM101.3
Wegmans Property Management

Back by popular demand...

cfCLIMB for Life
Stepping Up to Cure Cystic Fibrosis

Calling all firefighters, police officers, athletes, and civilians! Join us **October 16, 2010** at the First Federal Plaza for the new and improved CF Climb for Life Stairclimb. For more information, please call Patti at 585-697-0777.

Leadership - Partnership - Commitment

Meet Nicole DeBraal- mother of 16 month old Nathan, who has CF, wife of Peter, internal communications manager at Oracle, active member of the CF Family Advisory Board and committed leadership partner with the CF Foundation. She passionately will tell you "the day I found out Nate had CF is the day I vowed I would do whatever it takes to rewrite the book on this disease, for Nate and 29,999 others just like him." In the short time she learned about Nate's CF, Nicole joined the GS Rochester Walk committee, formed a family team raising over $8,000, supported the Roses of Hope Gala and is helping our Chapter to develop a new Advisory Board of Directors. If you or someone you know would like to learn more about this initiative please contact Nicole at ndebraal@yahoo.com

Call for Award Nominations

Eric Wright, 2009 Roses of Hope Gala Chairperson, is leading the nominating committee for two of the Chapter's distinguished awards, the Young Leadership Award and the Mary Jane Taylor Award. These awards will be presented at the Roses of Hope Gala. Last year's recipients were **Kyle Schuhart** and **Dr. Rob Horowitz**, respectively. Selection criteria and nomination forms will be posted at http://rochester.cff.org/rosesofhope or call the Chapter at (585) 697-0777. **Deadline for submission is May 26, 2010.**

It's spring and the Chapter is buzzing!

CFF Team: Kristen Phillips, Susanne Perrone & Patti Carter-Morrison

Did you know ?

•Nearly **400 Monroe Community College students** are working on CFF fundraising projects during the spring semester

•The Chapter has 3 interns: **Dan Kampff** (SUNY Geneseo), **Kristen MacDonald** (MCC) and **Alex Parrotta** (Nazareth) and we are currently interviewing for summer and fall internships

•**Karen**, **Judy** and **Jenna** join our team weekly to help us in the office and help our event committees

MORE (and Different!) Helpful websites:

CF Practice Guidelines

The CF Foundation is pleased to let you know that the CF Practice Guidelines for care, based on medical evidence and expertise, are now available on the CF Foundation's Web site at http://www.cff.org/treatments/CFCareGuidelines/.

Additionally, 2 new pages have been to the QI section of the Web site. This information list tips for choosing quality healthcare and ways that people with CF and their families can become more involved in their healthcare.

Learn about "**Germs, Infection Control and People with CF**" and how to avoid germs like H1N1 flu, *pseudomonas, B. cepacia* complex and more by watching a CF Education Web cast on the CF Foundation's Web site

www.cff.org/signup to receive the CF Foundation's e-newsletter, *Connections*, and learn about progress in cystic fibrosis research; fundraising events; and people just like you helping to make a difference in the lives of those with this disease.

You also can look for the CF Foundation on your favorite social networking sites.
Follow us on
Twitter (www.twitter.com/CF_Foundation),
view the latest videos on our YouTube channel
(www.youtube.com/CysticFibrosisUSA)
and join the conversation on our Facebook fan page
(www.facebook.com/cysticfibrosisfoundation)

Recipes for kids, including a section for kids with CF.
http://kidshealth.org/parent/recipes/index.html

Save this for future reference!