# Inspire

A newsletter for cystic fibrosis patients, their families and friends Spring/Summer 2009

## Upcoming Events

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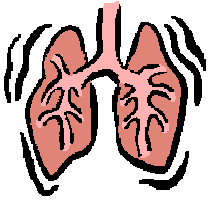
|---|---|
| **Great Strides** | **May 16, 17; June 6; Sept. 26, 27** |
| **Fairway to Hope Golf Tournament** | **August 17, 2009 Eagle Vale Golf Course** |
| **Roses of Hope Gala** | **TBA** |

greatstrides
Taking Steps to Cure Cystic Fibrosis

**Start registering your team online today!**

| | |
|---|---|
| Rochester Genesee Valley Park | **May 16, 2009** |
| Canandaigua, Sonnenberg Gardens | **May 17,2009** |
| Elmira, Eldridge Park | **June 6, 2009** |
| Hornell, Steuben Trust Co. | **June 6, 2009** |
| Geneva, Seneca Lake State Park | **Sept. 26, 2009** |
| Letchworth State Park | **Sept. 27, 2009** |

For more information, go online to **www.cff.org/chapters/rochester**.
Or contact the
CF Foundation Office (585) 697-0777.



## News from the Pediatric Center from Dr. Ren

The key to progress in treating and controlling CF is research, and the CF Foundation is very aware of this.

In 1998, the CF Foundation started something called the Therapeutics Development Network to help get therapies for CF started. The network consisted of just eight centers across the country at that time. Since then, so much progress in CF research has been made that the CF Foundation recently decided to expand the network to 77 centers, and Rochester was selected to be part of this expanded network.

A group of people from the CF Center recently returned from a meeting in Denver where we were updated on the status of new CF therapies. We are now closer than ever to having therapies that will both improve our control of CF and even overcome the basic problem in CF.

But to reach this final goal, we must complete the research that shows that these therapies are effective. All of us at the CF Center are committed to giving our patients as much access as possible to new CF research and working as a group to help advance CF care.

We will be working on ways to keep everyone informed of research progress and opportunities, and ways to help patients and their families be part of the research process.

# News from the URMC Adult Cystic Fibrosis Program

## Dr. Robert Horowitz

First, the sad news: Ann McMullen announced at our March Family Advisory Board meeting that she will be retiring this fall. Ann has been an integral and beloved part of the URMC Cystic Fibrosis Center and of the lives of patients and families for many years. However, at that meeting, she assured all participants that although her departure will be sad both for her and for patients, families and her co-workers, the Pediatric and Adult CF Programs are strong and will continue to thrive after she has left. In fact, the Center is busily preparing for this significant change, aware that while we can't replace Ann the person, we can assure continuity of the excellent patient care and communication you have come to expect. More information about Ann's retirement will be forthcoming.

Now, the good news: The Adult Cystic Fibrosis Program at Culver Medical Group is focusing attention on several projects to enhance adult patients' care and to ease the transfer of care from the pediatric to the adult program:

1. **Outpatient Plan of Care:** Data from outside the realm of CF shows clearly that even simple treatment regimens are often misunderstood and/or not followed by patients. As most of you know, the daily treatment regimen for people with CF is often very demanding, such that there is even more room for confusion and suboptimal adherence than is the case with other diseases. In an effort to assure that both you and your providers agree on and understand all the details of the recommended treatment regimen, we have been providing a Plan of Care to our adult patients after most office visits for some time. Even though this has met with satisfaction, it at times remains cumbersome, including several sheets of instructions which may be difficult to understand. We are now working on enhancing the Plan of Care so that all recommendations from all the disciplines (physician/nurse, respiratory therapist, dietitian), are on one page, in a legible and pleasing format which is compatible with the computer record system (Allscripts) in use at URMC. We are always eager to hear back from our patients about these instructions.

2. **Enhancing Adult CF Program staffing:** Our multidisciplinary team of providers continues growing in number and expertise in order to assure that all patient needs are addressed thoroughly, and at all hours, as the number of adult patients increases. This is especially important while preparing for Ann's departure in September. Our team currently includes two physicians (Rob Horowitz and Steve Scofield), dietitian Melissa Berry, respiratory therapist Donna Germuga, two nurses (Meghan Greer and Aida Martinez), two social workers (Nancy Kennedy and Chris Stokes), and a full complement of office nursing and secretarial staff to manage phone calls, medication refills and logistical needs. We're thrilled to announce that another physician, Dr. Rob Fortuna, has joined the Program. He will be participating more regularly in Adult CF Program clinical care, and, wonderfully, he will bring with him his expertise in research, more of which is vital to improving CF care, and which our patients regularly express the desire to participate in. The other five Culver Medical Group physicians, all of whom have plenty of experience in caring for patients with CF, continue to pursue additional training to enhance their care of our patients, both in the hospital and in the office.

3. **Transfer of Care:** The Adult and Pediatric CF Programs meet regularly to review the process of transition and specific patients who are approaching readiness for transfer to the Adult CF Program. We have taken to heart the Family Advisory Board's strong support for a well-defined transition process, which over a period of years informs and nurtures young patients' growing independence in medical care, finally culminating in the transfer to the Adult Program.

   Each of the 96 adult CF programs across the country struggles with how best to manage this challenging transition process. The approach varies according to each location's unique personnel, facilities, patients, and other features. As with many of these programs, our unique process is evolving, in large part as a response to our patients' and families' feedback. Basically, the two important factors in determining readiness for transfer of care to the URMC Adult CF Program are:

a. **Age:** Generally, patients are considered for transfer when they reach 18, occasionally younger if especially mature and motivated. All patients will be expected to transfer by the age of 21 years.
b. **Maturity:** A transferring patient should be able to manage his/her medical needs independently. This does not mean parents and other loved ones are not involved. On the contrary, continued participation of loved ones is welcome and encouraged. However, it is vitally important that the individual with CF be as knowledgeable and involved and autonomous in self-care as possible, since this very clearly enhances treatment adherence, and possibly health outcomes.

**To facilitate the transition process, we continue to support two programs:**

a. "Meet and greet" office visits to Culver Medical Group, an unbilled service, allow patients who are beginning to consider transition to meet the staff and tour the facility. Typically, this is used by people in the 18-21 age group, but any patient is welcome to such a visit, even if years away from transition, if this would be helpful. Data shows that much of the anxiety of moving one's medical care can be alleviated by meeting the new team in this way. This has been our experience as well.
b. Highland Hospital tours can be arranged to allow patients to meet some of the providers and to see the new setting. Again, this can help lighten the worry about transferring care, and may help inform the decision for those younger patients who remain on the fence about readiness for transfer of care.

Both of these services can be arranged by discussing them with your pediatric CF providers. We will continue looking to our patients and their families for your thoughts and preferences as our unique approach to transition continues to be defined.

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## Under construction:

**We are working on a new Cystic Fibrosis Center website. We hope to début our new website later this spring. Look for our News/Events section to keep up with the latest in CF care and activities planned in our community. Our current website is:**

**http://www.stronghealth.com/services/childrens/Centers/cysticfibrosiscenter.cfm**

## FUTURE NEWSLETTERS:


We want to make Inspire a newsletter that works for you. What would you like to see in future issues? Would you like to write a Patient's Perspective column? Contact Donna Germuga, Pediatric Pulmonary, 601 Elmwood Ave. Box 667, Rochester, NY 14642.


# Routine Guidelines for Maintaining Your Health

The Cystic Fibrosis Foundation (CFF) has established guidelines for health maintenance and monitoring for all accredited CF care centers. These clinical practice guidelines are based on the most current evidence and expert opinion on the management of CF.

## What do they stress:

Individuals who practice good health maintenance with routine daily therapies and get early aggressive treatment of infection and complications have a better chance of improved health outcomes whether they are children or adults.

## What are the recommendations:

Visits to CF Clinic at least four times a year for routine care (not sick visits):
These routine visits allow the team to evaluate your daily care plan and make adjustments and to discuss changes that may improve your health.

Sputum cultures at least four times a year. Bacteria in the CF lung changes over time; knowing what bacteria are growing and which antibiotics work best is valuable information used to treat you.

Frequent monitoring of lung function: At the Rochester Center, spirometry is performed at each visit. Subtle changes can be detected before you are feeling worse so that treatment can be initiated earlier. We can also monitor your response to treatment using spirometry.

Annually, the following are recommended:

- Laboratory evaluations (blood work) to screen for many things including anemia, clotting dysfunction, salt imbalance, liver function, diabetes, allergic aspergillosis, nutritional status, and fat soluable vitamin deficiencies.
- Nutritional evaluation
- Respiratory care review and plan of care
- Social work evaluation

Other testing is recommended less frequently but as needed:

- Chest x-ray every two years
- Oral glucose tolerance test
- Dexascan
- Chest CT scan

## What is the most basic recommendation for maintaining health in CF:

Daily routines of care over your lifetime that are known to be beneficial to all individuals with CF

- Daily airway clearance and regular aerobic exercise
- A well balanced high calorie diet
- Early medical attention with an increase in cough and sputum production
- Consistent use of routine maintenance therapies

**Here is a list of Routine Maintenance Therapies (also known as CF Controller Therapies)**

- Tobi
- Airway clearance (Vest, Acapella, manual, autogenic drainage and active cycle of breathing)
- Hypertonic Saline
- Pulmozyme
- Azithromycin
- High Dose Ibuprofen

# WHAT ARE THE KEYS TO A SMOOTH TRANSITION?

## By Marcy Odell

We have recently been attempting to devote more attention to the process of transitioning CF patients to the Adult CF Center at Culver Medical Group. In doing so, we recognize that this is a huge milestone and one that requires a great deal of consideration. We have decided that we will not implement any rigid guidelines for this process (ie: all patients should transition on/about their 18th birthday). Our hope, however, is to reach a decision with each and every patient based on readiness.

Admittedly, this is a new process for us, as having the Adult CF Center at CMG is also relatively new. We hope that you will join with us and help us learn and grow in this process. As always we welcome any feedback about experiences you may have had in this process. In the meantime, we hope to continue to help those who are ready make the transition a smooth one!

A smooth transition begins with early preparation and a great deal of communication. Here are some tips to help prepare you and your child for adulthood and adult CF care.

**1. Encourage** your child to speak with the CF care team about questions they have, even when you are sure you know the answer. This will begin the task of your child being independent and responsible for his/her own health.

**2. Reward** adherent behavior in your child. Simply stating, "I am proud of you for remembering your enzymes without my reminding you" can have a powerful effect. Offering a favorite meal or a special outing for adherent behavior can also be effective.

**3. Remember** that teenagers are concrete thinkers. This means that they need to hear something laid out in plain language rather than abstracts. For example, "you will get sick" is vague and can be interpreted a number of ways. A more concrete example would be "you will need to be on IV antibiotics and stay at the hospital."

**4. Ask** your child what they think is most helpful to encourage them to be adherent.

**Here are some specific categories that will help determine an individual's readiness to transition.**

Independent clinic visits
Wise nutritional choices
Independent with airway clearance
School issues
Self advocacy
Understanding of annual tests
Exercise and sports including salt and fluids
Lifestyle choices
Naming medications and reason for taking them
Work issues
Answers questions independently
Direct communication w/staff
Assess communication between adolescent/parent/CF team
Comfortable bringing up concerns Monitors medications, supplies. Calls when needed

# Research Rules!!

**What is Research?**

**By Marissa Dixon**

How can we add tomorrows today? The answer is one word: Research!

As a result of the wonderful research that has been done over the last 60 years, CF patients are living fuller and longer lives every day. Every treatment or drug that a patient takes has been researched. So what is CF research?

Research is a pursuit to understand, treat, and possibly cure CF. There are two types of research: Basic and Clinical.

**Basic Research** is usually done in a laboratory. These researchers strive to find how the symptoms that are seen in CF are produced by studying cells, tissues, or organisms with CF-like disease patterns. Once a researcher observes an abnormal phenomenon in the CF body, it is traced back to the action of the CF gene. Then it is further examined to determine if a treatment or drug could normalize this phenomenon. If this new treatment or drug is found to correct an abnormality without causing harm to cells, tissues, or the organisms studied, it can be formulated to safely be given to patients.

**Clinical Trials Research** is done at centers like ours. The new treatments or drugs that were discovered in basic research are now safe to be tested to see if they can truly improve the health of a CF patient. Each trial has a set of requirements that it will need from its participants. For example, age, $FEV_1$, and the presence of certain microbiologic organisms in sputum may determine whether or not one can participate in a study.

These trials are done in phases

**Phase 1 trial**: First step in drug development to test a drug's safety and to find out how the human body reacts to the drug. The purpose of Phase 1 trials is to discover the side effects of increased doses and collect early evidence of drug effectiveness. Healthy volunteers or people who do not have the disease or condition being studied, are often included.

**Phase 2 trial**: Research that tests the effectiveness and safety of a new drug. Identifies common side effects and risks.

**Phase 3 trial**: Usually the last type of clinical trial before a drug is approved by the FDA. Intended to gather more information about 1) the general risk-benefit of the drug, and 2) how to administer the drug

**Phase 4 trial**: Research conducted after FDA approval to get additional information about the drug's long-term risks, benefits, and best possible use.

**Our center offers several opportunities for CF patients and families to actively become part of adding tomorrows by hosting clinical trials. We will offer these opportunities to participate when you or your CF child is eligible!**

Sub Topic: Research Highlights:

Preschool Pulmozyme (PiP) [B]

Purpose:
Your child could be asked to participate in this research study because your child has cystic fibrosis (CF). Pulmozyme® is an FDA-approved drug used to thin mucus in patients with CF. While Pulmozyme® is an approved drug for all ages, the purpose of this study is to gain further information about the use of Pulmozyme® in children younger than 6. The study will be conducted at about eight study clinics in the United States. Approximately 40 subjects will be enrolled in the study. Your child's participation in this study should last no more than 46 days and will involve three visits to the study clinic and one follow-up telephone call.

As part of your child's participation in this study, he/she will be randomly assigned (by chance) to treatment with either Pulmozyme® or placebo (salt water without active drug), for about 16 days. Your child will have a one in two chance (like flipping a coin) of being assigned to treatment with placebo. Your child's study doctor and the study staff will not know if he/she is receiving Pulmozyme® or placebo. However, this information is available to the study doctor if needed in an emergency. Whether you believe that your child is assigned to the placebo group or the Pulmozyme® group, you should tell the study staff if your child's health changes.

**Length:**
46 days
3 visits
1 phone call

**What is involved?**
Physical exams
OP swabs
Spirometry
Oscillometry
Questionnaires

**Requirements:**
3-5 years of age
Can perform oscillometry
Can tolerate placebo
***not taking Pulmozyme currently; or can go off this drug for a period of 4 weeks prior to study
Not taking hypertonic saline 56 days prior to study

[A] Definition for phases found at www.cff.org/clincalresearch/glossary
[B] Information from informed consent for this study.

Want to see a CF patients experience with research?
Check out
http://www.cff.org/research/clinicalresearch/participate/
There is a youtube video of a college student's experience in a CF Clinical Trial.

Want to know more about research in CF?
Visit www.cff.org and click on research or contact us here at the University of Rochester Center. We would be happy to speak to you about any research questions you may have and send your very own 'We are the Key' brochure, button, and pen.

Center number: (585) 285-2464
Marissa Dixon (585) 285-8580

## SOME HELPFUL WEBSITES

**Government help assistance programs:** www.cff.org/LivingWithCF/AssistancePrograms

**Financial assistance for patients who need inhaled medications:** www.cfpaf.org or call (888) 315-4154.

**Information on clinical trials:** https://cfclinicalresearchnet.cff.org

# What's in a number?

**By Kim Bordeaux**
**Respiratory therapist**

Numbers tell us a lot of things. What time it is; where we live; how tall we are; how old we are.

For CF patients, numbers also tell us how our lungs are doing. How, you ask? Well, let's start with the basics of breathing. The purpose of the lungs is gas exchange - good air (oxygen) in, bad air (carbon dioxide) out. Air travels in the nose and mouth down the air pipes (bronchi) to the air sac (bronchioles) which has many capillaries wrapped around it. This is where the gas exchange is made between the good air and bad air.

In patients with Cystic Fibrosis, there is a defective gene that causes the lining of the lung to produce a defective protein which leads to a thickening of the lining of the lung that produces sticky mucus that blocks the air tubes. Bacteria and germs like to hide out in moist, dark places. Your lungs are the perfect breeding ground for this! If left untreated mucus can built up in the lungs get infected and lead to a lot of inflammation and obstruction. This is where the numbers come in….Are you following?

At your clinic visit you do a test called spirometry. We put in your birthday to tell us your age, we put in your height and weight - that helps us find out what number you should be compared to other children and adults your age and height. Then we start the test. We have you take a great, big breath in and blow out as hard as you can. We can tell if you are not doing your best because all values should be exactly the same. That's why you have to blow many times in the same test! We look at the numbers….

- **FVC-F**orced **V**ital **C**apacity: This is the total amount of air that can be measured and tells us how much air your lungs can hold.
- **FEV1**-**F**orced **E**xpiratory **V**olume in **1** second: This is how much air you can blow out in 1 second and tells us how the large and medium size airways (bronchi) are doing.

  ***Interpretations of values for FEV1 are as follows:***
  ***Normal: 80-100%***
  ***Mild obstruction: 70-79%***
  ***Moderate obstruction: 60-69%***
  ***Moderately-severe: 50-59%***
  ***Severe: 35-49%***
  ***Very severe: < 35%***
- **FEV1/FVC:** This is the ratio of how much air you can blow out in 1 second compared to how much air your lungs can hold. A decrease in this number is specific for obstructive lung disease and inflammation in the lungs.

**What number is probably most important:** your FEV1. When your airways get clogged with mucus that affects how fast you can blow the air out. The more infected your lungs are, the longer it takes for the same amount of air to get past the mucus and inflammation in your lungs. When your lungs are working well your FEV1 should be above 80%. When you are not feeling as good this number drops… Sometimes the doctors will give you antibiotics to help clean out the bacteria as well as other medicine that you may breathe in to help. If really decreased, you may have to make a trip into the hospital for some stronger medications to help clean out your bacteria in your lungs (sometimes called a "tune-up").

**What can you do to help keep your numbers good?** Take care of your lungs. It's important to do your airway clearance and exercise every day, even if you are feeling great! As well as take the medication that the folks in the CF center told you to take. Everyone is different and everybody's numbers are different too! So, what's your number? Ask the next time you are in.

# Patient's perspective

**By Forrest Hess**

Every step that we take through life takes us somewhere, be it up, down or in the same direction. That is something that I learned early. Therefore, it is imperative to look at every situation in the most positive light. As someone who has been dealing with Cystic Fibrosis since the age of three, and Cystic Fibrosis related Diabetes since the age of 13, this thought has essentially kept me alive. This year I began a new experience; going to college. Through all of its high and lows, I have learned more than I will ever be able to convey into words.

Normally, the whole college experience is stereotypically filled with partying and extreme acts of stupidity. As a norm over the last 6 months, I have felt very poorly. This whole experience has weighed heavily on my health, causing me to almost be a different person. In high school, I was always floating on a cloud, being my typically excited self. Lately, I have felt much different. At one point my lung function dropped to a level that was below where it had ever been. This is something that I had a very difficult time dealing with. I had begun to slip in my treatment, due to the fact that my vest was unavailable. However, I was still extremely disappointed because I was doing everything in my power to maintain my health, and it was declining. Between schoolwork, living away from home, and feeling poorly, I was living right on the edge. Having a stress level this high made everything much harder, and I was about at my breaking point. When I finally came home for my break, we realized how much lower than normal my lung function was. At this point, my treatment was completely revised, and our insurance request for the vest was finally accepted. So, for the next few weeks it was all about my health and it worked. My lung function was restored to the best it had been in a few years. As a result of this, my overall morale was boosted and I was ready to go again.

During this stint of feeling very poorly, I gained a new insight. Before, I sort of took my health for granted. I always had my family around to support me, and really had always felt well. Once this was gone, I was forced to realize that I needed to be responsible for my health for the rest of my life, which I am determined will be for a long time. I will maximize my health by following my strict treatment regimens. Having this set of thoughts in my mind made my last hurdle easier to handle. I came down with a cold in mid-February that lasted until late March. Although it came and went, it was there for over a month and seriously began to affect me. The only way I made it through was with the care of my family and great friends. At one point, I just wanted to come home and stay home for what would have been the rest of the semester. However, it became clear that would be the equivalent of giving up; something that people with Cystic Fibrosis can never succumb to, ever! Cystic Fibrosis could be considered a curse, or could be considered a blessing. Although it has its obvious pitfalls, and a cure would change my life, I have to make the best of it. Maybe life would have been easy without this weight on my shoulders, but then, would I really have such a positive outlook and want to help everyone? CF has not hindered me, but only acted as a tool to help me mold myself to be the person that I want to be.

# Are you taking your VITAMINS??

## Here is why it is important for CF patients to take vitamins

We are talking, of course, about the fat soluble vitamins A, D, E, and K. Do you know why it is so important to take your vitamins? Below is a brief description of each of the vitamins and why they are particularly important for those with CF.

**Melissa Berry**
**nutritionist**

**Vitamin A**

- Promotes a healthy lining in the eyes, lungs, intestines and urinary tract which help fight infection.
- Helps the skin and mucous membranes function as a barrier to bacteria and viruses. When those linings break down, it becomes easier for bacteria to enter the body and cause infection (think lungs).
- Not getting enough vitamin A increases your risk of developing respiratory and intestinal infections.
- Vitamin A deficiency can also cause decreased growth rate, slow bone development, and night blindness.

**Vitamin D**

- Helps build and maintain strong bones and teeth. It does this by keeping the right amount of the minerals calcium and phosphorus in your blood.
- Without enough vitamin D, bones can become thin and brittle.
- Bone pain and muscle weakness can be signs of low vitamin D levels.
- Some people who have CF need extra vitamin D in order to reach normal blood levels.

**Vitamin E**

- Helps to keep red blood cells healthy.
- Works in the lining of your lungs to help fight infection.
- Also helps maintain the health of your intestines.
- Not getting enough vitamin E over a long time can lead to vitamin E deficiency and problems with muscles and nerves.

**Vitamin K**

- Best known for its role in helping blood clot. Without enough vitamin K in the body, your blood takes longer to clot, which means you bleed longer when you are injured. This can be dangerous. Easy bruising may be a sign of deficiency.
- Also helps keep bones healthy.

So, you see, these vitamins are very important to help maintain overall good health and, in particular, healthy lungs and digestive tract. If you take enzymes, it is even more important to make sure you are taking ADEK, AquADEK, Source CF or Vitamax vitamins every day. These vitamins are formulated specifically for people with cystic fibrosis who are pancreatic insufficient and take enzymes. Those who are not taking enzymes, or are pancreatic sufficient, should take a general multivitamin that includes A, D, E and K. Your blood levels of these vitamins are checked every year. If you don't know your levels, ask about them at your next clinic visit.

# Vitamin recommendations for people with Cystic Fibrosis

| vitamin | How much do I need? | Food sources |
|---|---|---|
| A | 0 – 12 mos 1,500 IU<br>1 – 3 yrs 5,000 IU<br>4 – 8 yrs 5,000-10,000 IU<br>8 yrs + 10,000 IU | Liver, egg yolk, whole milk, fortified low fat milk, cheddar cheese, fortified cereals and oatmeal, dark fruits and vegetables like carrots, sweet potato, spinach, broccoli, red pepper, peas, apricots, papaya, mango, cantaloupe, peaches |
| D | 0 – 12 mos 400 IU<br>1 yr and older 400-800 IU | Mackerel, canned sardines, cod liver oil, fortified milk, fortified cereals and soy products. |
| E | 0 – 12 mos 40-50 IU<br>1 – 3 yrs 80-150 IU<br>4 – 8 yrs 100-200 IU<br>8 yrs + 200-400 IU | Vegetable oils, nuts, wheat germ, green leafy vegetables, fortified cereals |
| K | All ages 300 – 500 mcg | dark green leafy vegetables, especially spinach, broccoli, turnip greens, and Swiss chard |

## IT IS WHAT IT IS

**By Destinie Quick, 18**

I spent a lot of time in and out of my pediatrician's office with respiratory infections, sinus infections, failure to thrive, etc.

It was not until I had a major coughing fit in the pediatrician's office that he sent me to see Dr. McBride, a pulmonologist at Strong Hospital, where I had some tests done. It was there at Strong where I was diagnosed with Cystic Fibrosis (CF) at three years old.

Living with CF is very challenging and definitely demanding. CF has brought me to face some crucial decisions that could have an impact on my health.

The demanding part about CF is that I have to keep up with the treatments and sometimes I have to sacrifice going to the football game or even my spring break for the routine tune-ups.

CF has also helped me learn how to prioritize. My ways of dealing with CF are to just try to keep a positive attitude and keep telling myself "it is what it is."

It definitely helps to talk to other people, they're usually pretty encouraging.

If I didn't keep hold of my faith it would be nearly impossible to for me to deal with CF.

# Nurses Nook


One of our Quality Improvement Initiatives for the 2009 year is **infection control** in the outpatient clinic. Our goal is to minimize the transmission of germs.

There are multiple "bugs" and bacteria that we all come in contact with each day. Some bacteria are healthy for us to be exposed to and help us boost our immune system. These are found both inside and outside and are found in common things like drinking water and at places we go every day like school or the grocery store.

Because of the thick mucous in the lungs of people with CF, bacteria often harbor and grow in the dark, warm, moist environment. An overgrowth of bacteria can sometimes cause a worsening of cough or sinus symptoms, but many times there are no symptoms when bacteria are present.

**Good hand washing** is the key to stopping the spread of germs. This is important for both the health care team and for you as the patient and family. Hand washing with either soap and water or an alcohol-based hand sanitizer are effective ways to minimize germ transmission. Sometimes other things like gowns, gloves, or masks may be used as well.

We have a few suggestions for other strategies to address the goal of minimizing germ transmission in our clinic.

**Suggestions for Children / Families when they visit clinic:**

- Bring your own toys/books/activities for your child to use in both the waiting room and the exam room
- Have your child wear a mask in the waiting area if s/he has an active cough
- If you do not see a dispenser of alcohol based hand sanitizer in the area you are waiting and would like to wash your hands, please ask staff for a supply
- PLEASE do not use the computer in the exam room. Although tempting, this is intended for use by the health care team only and is a likely source to spread bacteria between patients.
- Wash your hands when you leave clinic at the completion of your visit

**Changes that you may see in Pediatric Pulmonary Clinic:**

- A sign posted in the waiting room suggesting that all children with an active cough wear a mask
- The use of gloves and / or a gown by the health care team, even if your child is not "sick".
- A sign posted in the exam room requesting that children and adults do not use the computer

We are always happy to answer any questions you may have about your child and his/her care. Happy hand washing!!

# THE STAFF REPORT

## Spotlight on… When scheduling an appointment:

As the support staff of the Pediatric Pulmonology Division at Golisano Children's Hospital, we welcome the opportunity to assist you in any way we can. The employees in our office work together as a team to provide you and your family with the utmost support whether it is in scheduling an appointment, answering insurance or billing questions, or receiving messages for our providers. CF clinics are held Tuesday afternoons and Thursday mornings. Some things you may want to keep in mind when calling to schedule an appointment are:

- If you have had any changes since your last appointment, please have your updated information available, including your insurance card.
- All of our CF patients are assigned to a doctor and a nurse practitioner who are both familiar with them. This way, if one provider is out of the office, there is usually someone here who will be familiar with your history.
- In urgent situations, we will take some basic information and forward a message to our team of nurses, who will return your call to gather more detailed information, at which point they will speak with the physician on call to determine the next step and decide if the patient should be seen right away.

Please do not hesitate to contact us if you have any questions. We welcome your comments and suggestions. The clinic phone number is (585) 275-2464.

**You can call and speak to any of us: Marianne Machaby, Debbie Longbine, Victoria Adams or Peg Garlock.**

## Come to clinic prepared..._
## By Donna Germuga

**We recently had the opportunity to review the survey responses that many of you have filled out at recent clinic appointments. Two of the main things that people had comments about were the waiting time to see various providers, and that the children did not have enough toys, books etc. to entertain them while they waited.**

**Please be aware that we are constantly looking at our clinic flow and trying to streamline the process so patients and families get the most benefit from contact with your health care providers as well as getting in and out of clinic in a reasonable time.**

**The second issue with books and toys to entertain kids while they wait is a little trickier. Because of infection control guidelines, we should not have items available in exam rooms that your child might touch after someone else has been handling them. We are trying to decrease the chance that germs are spread from contact of common items available in clinic.**

**Consider having a special bag to bring to your appointment with favorite toys or books that is only available to your child while waiting in clinic. The items maintain their appeal because they are not available every day and the wait may not seem as long.**

**We would welcome any other suggestions people might have to make your time with us in clinic both timely and pleasant.**

# A note from the Cystic Fibrosis Foundation

Cystic Fibrosis Foundation
...adding tomorrows every day.

As Great Strides season is upon us, we invite you to consider joining us as a walker, team leader or volunteer. We need your support more than ever as many exciting medical breakthroughs are within reach! In April, Vertex Pharmaceuticals announced that **a potential drug that treats the basic genetic defect in CF moved into Phase 2a clinical trials**. Join us in ***adding more tomorrows every day.***

There are 6 different Great Strides walks to participate in:

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| GS Rochester Genesee Valley Park | **May 16, 2009** |
| GS Canandaigua, Sonnenberg Gardens | **May 17, 2009** |
| GS Elmira, Eldridge Park | **June 6, 2009** |
| GS Hornell, Steuben Trust Co. | **June 6, 2009** |
| GS Geneva, Seneca Lake State Park | **Sept. 26, 2009** |
| GS Letchworth State Park | **Sept. 27, 2009** |

**To register, please go to http://www.cff.org/great_strides/**

**Golf swings more your thing?**

Join us August 17th at Eagle Vale Golf Course for our 2nd Annual Fairway to Hope Golf Tournament. Meet Honorary Chair Andrew Meloni for a day of golf, raffle prizes, dinner and auctions.

**CFF Office Supply Needs:**

The CFF Office is in need of a new refrigerator to store food and beverages for special events. If you know of someone who would be willing to donate a full sized refrigerator, please contact the office at (585) 697-0777.

The CFF Office also needs auction items, including but not limited to: event tickets, spa packages, sports memorabilia, fine jewelry, artwork, restaurant gift certificates, hotel packages, etc.

**We need your help!**

Please consider volunteering for the CFF. Many opportunities are available -- everything from serving on an event committee to helping with daily office tasks. We will find a role that fits your needs and talents.

**For more information about any of these events or volunteer opportunities, please go to www.cff.org/chapters/rochester or call the CFF Office at (585) 697-0777.**