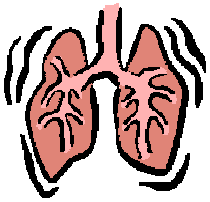
Inspire

A newsletter for cystic fibrosis patients, their families and friends Fall/Winter 2009

News from the Pediatric Center
from Dr. Ren



I and several members of the CF Team recently returned from the North American CF Conference in Minneapolis, Minnesota. Although I have been attending the conference for many years, this past one was one of the most inspirational and exciting conferences in many years. The inspiration came from Dr. Francis Collins and Danny Bessette.

Dr. Collins was a leader in the effort to clone the CF gene 20 years ago in 1989, and he is now the new director of the National Institutes of Health (NIH). The NIH is the most important medical research organization in the world, and it's wonderful to have such a strong advocate for CF as its director. Dr. Collins talked about how discovering the gene has led to increased understanding of how CF lung disease occurs and to the development of new therapies (more on this in a moment). Finally, at the end of his lecture Dr. Collins played guitar and led the entire audience of more than 3,000 people in singing a song he wrote about overcoming CF.

Danny Bessette was a 4 year old boy in 1989 when he was selected to be on the cover of the issue of *Science* magazine describing the CF gene. Today he is a 24 year old man who is about to get married. By appearing at the conference, he personified the example of how people with CF are overcoming its challenges to achieve their goals and live active, fulfilling lives. The excitement came from the many new findings presented at this year's conference.

Vertex is a company that is making oral medicines for CF. Their research program started almost 10 years ago, and it is finally starting to bear some fruit. Instead of treating infection or abnormal mucus, these medicines really try to fix the underlying problem with the CF protein. There are now two medicines in clinical trials for CF. The CF Center in Rochester is taking part in one of these trials. These medications are still a few years from clinical use, and in the meantime we will still need to control infection in CF and keep the lungs clear of mucus.

We also learned at this year's conference about new ways to use antibiotics to achieve these goals. You will hear more about these discoveries the next time you come for your clinic visit. As this conference showed, we are continuing to make steady progress in the fight against CF, and all of us at the CF Center will continue our efforts towards this goal. If you or your family has any questions about news from the CF conference or the research studies Rochester is participating, please feel free to call and speak with Dr. Ren or any of the other CF team members.

News from the URMC Adult Cystic Fibrosis Program

Dr. Robert Horowitz

This September was the 10th anniversary of Rochester's Adult Cystic Fibrosis Program. What started out in 1999 as an alternate weekly extension of the Pediatric Pulmonology Department has evolved into a robust, independent and self-sustaining program at Culver Medical Group. We are proud of our unique model of care in Rochester. Indeed, our approach to care is being followed with keen interest by the Cystic Fibrosis Foundation. I'd like to share with you two interesting and important features of our program: the primary-specialty care model; and the concept of shared care, which is our guiding approach to caring for patients.

PRIMARY-SPECIALTY CARE: The Rochester Adult Cystic Fibrosis Program is among the roughly 10 percent of United States adult CF programs that are overseen by CF physicians who are generalists rather than pulmonologists. Our program is unique among this group by being located within a primary care practice site. Specifically, the Culver Medical Group is the home base of Rochester's renowned Medicine-Pediatrics training program, which has earned kudos for its emphasis on primary care management of complex medical illnesses, like CF. Consequently, our program offers our patients "one-stop shopping," allowing them to obtain both their CF care and their primary care in this single setting, and by providers who are skilled in managing both. In addition to being convenient for our patients, this arrangement guarantees close specialist-primary physician collaboration, often a weak spot in the medical care of individuals with a "specialty" illness like CF, which most primary physicians are not well familiar with or comfortable managing.

We have frequently observed that young adults with CF come to see CF as their only medical issue, so as they mature out of their pediatrician's expertise, they do not identify a primary care physician to help them navigate the adult years. However, the reality is that getting older, with or without CF, imposes multiple non-CF-specific health and medical issues that need to be addressed for best health maintenance and treatment of acute illness. In addition, in order to best coordinate care, we wish to be in close communication with your primary physician. Hence, it is vital that all of our patients have a primary care physician, and we are happy to offer any of our patients the option of using Culver physicians for this role. If you have another primary physician with whom you are pleased, or if you travel to us from outside of the Greater Rochester area, there is no need to switch your primary care to Culver. However, if you are interested in its benefits, we will be happy to identify Culver as your primary provider.

Please be sure to maintain an active relationship with your adult primary care provider, both to obtain comprehensive medical care, and to facilitate collaboration between him/her and the Adult CF Program; and know that Culver Medical Group will be happy to become your primary care provider if you wish.

SHARED CARE: This term, more popularly used in Britain, refers to a partnership between physician and patient in managing medical care. It is contrasted with paternalistic care, in which the medical provider dictates treatment without regard for individual patient circumstances, preferences, and goals. Shared care is our objective at the Rochester Adult Cystic Fibrosis Program. Our goal is to inform our patients in detail about the various evaluation and treatment options available, and then to work with them in determining their best options, in the context of their unique personalities and characteristics. This means there is no "cookie cutter" approach; each individual patient's ideal care plan will be unique. To achieve a successful collaboration between patient and provider team, we all need to share our impressions, and commit to following through on our agreements. Specifically, while we do not expect perfect adherence to the agreed upon treatment plan, we do encourage an honest discussion, and sincere commitment to all agreements. Anything less than this compromises the success of the shared care approach.

In order to realize the best that Shared Care can offer, we ask our patients to come to their appointments prepared to review their current treatment plans as well as the hurdles that sometimes stand in the way of honoring the

treatment plan fully. Your treatment plan should be seen as ever evolving. The provider team is eager to collaborate with you in identifying the specific plan that will work best for your unique body, health, medical challenges and life circumstances. This will become even more important as the number of available treatments continues to grow, such that no individual patient will be able to use every potentially beneficial treatment; that is, all of our patients will have to choose from an array of options.

Please come to each office visit prepared to review your treatment plan, so that you may always leave your visit with a clearly defined plan that both you and your provider team believe is the best one possible for you.

Mark Your Calendars! Kit Taylor Lectureship 2010
By Marcy Odell

After a great deal of consideration, our center has decided not to host a CF Family Day this year. We have a couple of events that we coordinate, but these have not been highly attended. This year we have decided to put our energy into encouraging more people to attend the Kit Taylor Memorial Lectureship. If you have not attended in the past or if you are new to our center, this lectureship was set up to bring knowledgeable people in the field of Cystic Fibrosis to our center to share their expertise. We are extremely fortunate to have this lectureship to offer to our families and colleagues. We feel strongly that our families could benefit greatly from the information shared at this event. Therefore, our efforts to recruit attendees are going toward this event this year.

Recent Kit Taylor Lectureships have focused on:

"The Many Faces of Cystic Fibrosis" (2009) Dr. Peter Durie, Toronto, The Hospital for Sick Children

"Treatment of CF: What's New, What's Next" (2008) Dr. James R. Yankaskas, University of North Carolina Adult Cystic Fibrosis Center, Medical Director of the Medical and Respiratory Care Units

"The New Treatments of Cystic Fibrosis on the Horizon" (2007) Dr. Bonnie W. Ramsey, Research Director Seattle Children's Hospital

"Achieving the CF Dietary Recommendations: What's Holding Families Back and How Can We Help?" (2006) Lori J. Stark, PhD, ABPP Director, Cincinnati Children's Hospital Medical Center

The Planning Committee is in the process of choosing the speaker for the 2010 lectureship. The Kit Taylor Memorial Lecture will take place in the spring of 2010. Please be sure to look for information in the months to come and be sure to mark your calendars!

Order of Nebulizer Treatments

Patients with Cystic Fibrosis (CF) should take their medications and do airway clearance in a specific order. It is important because each medication or therapy achieves a certain goal.

MEDICATIONS (Not all patients will take all medications listed)

a) Bronchodilators (Albuterol, Ventolin, Pro-air, Xopenex): Always taken first. A bronchodilator helps relax the muscles around the airway, opening up the airways and helping move air into and out of the lungs. Sometimes given with an aerochamber or via a nebulizer**.**

b) Hypertonic Saline (3% or 7%-Hyper-Sal): helps to hydrate mucus and make it easier to move out of the lungs. May tend to taste very salty!

c) Pulmozyme (DNAse): a mucolytic, will break down the bond of the DNA in the mucus making it easier to help cough out the mucus. Usually given with a ***side stream*** nebulizer

AIRWAY CLEARANCE (Listed will be various forms)

a. Chest Physical Therapy (CPT): involves lying in various positions and having someone clap or percuss over different areas to help loosen mucus in that region (kind of like tapping on a new bottle to get the ketchup out the first time!)

b. Vest Therapy (High **F**requency **C**hest **W**all **C**ompression-**HFCWC)**- Patients put on a special vest that attaches to a machine that moves air at a very fast pace in and out of the vest, vibrating the mucus loose from the side of the air tubes, making it easier to cough out.

c. Flutter or Acapella (Oscillatory positive expiratory pressure): Looks like a small pipe or football shape. Patients take in a deep breath and blow into the device which vibrates and shakes mucus free making it easier to loosen and cough out. (These usually are not used by small children because the device requires effort and enough flow to make it work properly.)

d. Positive Expiratory Pressure (PEP) device: This is a device that attaches to your nebulizer or may be used on its own in which you exhale through it and it helps keep the airways open longer. By doing this more medication reaches the

lower parts of the airway or it just helps hold the lung open longer getting more air behind the mucus so you can cough it out easier.

d) <u>Autogenic drainage</u>: This is a special way of breathing which requires lots of practice but may be done anywhere (with no special equipment required!) to help move mucus. (Very hard for children to perform).

e) <u>Exercise:</u> Any form of movement helps with airway clearance. Running, jumping, hanging from monkey bars, swimming, playing Wii games. These make you take big breaths in and cough.

f) <u>Cough:</u> A staple in everyone's life. **<u>Huff cough</u>:** a gentle form of a cough in which you take a breath of air in and huff or exhale like you are fogging up a mirror or glasses to clean in multiple breathes before coughing hard.

g) <u>Inhaled Steroids:</u> Flovent, Pulmicort, Qvar. These help reduce inflammation in the airways. *Some are combination steroid and bronchodilator combined such as Advair or Symbicort.*

6 **<u>Antibiotics:</u>** TOBI or Colistin. These drugs should always be given last after doing your airway clearance. The object of these drugs is to attack the bacteria (Pseudomonas) within the lungs. It is very important that the airways be opened and cleared of as much mucus as possible to give these drugs a better chance to knock down the count of bacteria in the mucus of the lungs. These should be given with the ***Pari LC plus*** nebulizer only.

These are meant to be guidelines. If you are experiencing a respiratory illness or change in symptoms (increased cough) increase airway clearance to 3-4 times per day. Use breathing treatments as ordered; you can use bronchodilators every four hours as directed by your doctor and add extra vest or saline treatments are useful.

Contact your CF doctors or nurses to see if additional antibiotics or treatment are needed**. *If you start coughing blood-STOP Pulmozyme, saline, inhaled antibiotics and airway clearance techniques and call your CF center (585-275-2464)* for further advice.**

Golisano Children's Hospital
☺ Pediatric Pulmonary Lab ☺

Transitions

By Anne Governor

Life with Cystic Fibrosis offers many opportunities to experience the great transitions of life. Not every transition is fun or easy, but each transition provides a chance to grow and become stronger in spirit.

As a 29 year old with Cystic Fibrosis, living a very full life, I have learned to deal with the ups and downs, the transitions of life and all that CF throws my way. Some of the transitions are difficult and mentally trying, but I always find a way to get through it all and come out stronger.

As I made the transition from a child with CF to an adult with CF, I took the tools and knowledge gained from my incredible CF team to take control of my health. As an adult with CF it is my responsibility to take care of myself. I live a beautiful and full life while still doing the added treatments and medical routines CF brings to my life. I do all of this so I can achieve my hopes and dreams for the future, so I can truly live life to the fullest.

Adult life with CF has handed me some unpleasant transitions, my first hospitalization in many years, my first PICC line, my first experience with home IVs, and my first bout of hemoptysis. All of this while I was doing everything I could to stay healthy.

These transitions have taught me to let go a little and allow others to help. I have learned it is OK to be sad, mad, even totally scared when dealing with CF. It is OK to let others know how I am feeling. It is OK for others to experience various emotions when dealing with my CF. Yes, I

I am the one that has to deal with the physical aspect of CF but my family and friends are along on the Cystic Fibrosis roller coaster ride with me.

The most important lesson I have learned from the transitions of life with CF is that life goes on. I must go on living! I can have bad days, but life should not be spent sitting around and feeling sorry for myself. I have a wonderful life, Cystic Fibrosis and all. A life that is meant to be spent **LIVING** and enjoying all of the beauties in life.

My desire to really **LIVE** has given me the opportunity to experience many great life events, going away to college, graduating from college, getting my first job, getting married, buying our first home, two pregnancies and the joy of welcoming two amazing daughters into the world!

These experiences are what keep me going when CF times get tough. There are times when I feel scared beyond words. There are times I do not know how I will fight on. When I stop to reflect on the amazing life transitions I have experienced and all there is to come, I am able to lift myself up to fight on. I may have to fight like crazy, but I know the rewards. I know the amazing joys of life waiting for me as I continue to live this life!

A Short Walk on a Road Less Traveled
A Mom's Story by Lauren White

"We do not remember days, we remember moments." ~ Cesare Pavese

I answered the telephone and a woman introduced herself as being from the Genetics Department at the University of Rochester. My heart began to beat faster. I had been waiting for what seemed like forever for that phone call. I choked on a lump in my throat. She continued softly, "We have the results of your amniocentesis. Your child has received two copies of the gene that causes Cystic Fibrosis and will have CF."

The picture of my child that I had been painting in my head shattered into a million pieces. My breath was taken from my lungs. My heart stopped beating. The room began to spin. I dropped to my knees. Emotions flooded my mind, heart and soul - shock, denial, fear, anger, sadness, and pain. I put my head in my hands and began to cry. My husband did not even ask what the phone call was about. He just held me and was silent while I sobbed. In that one moment, our life, what we had pictured, what we had dreamed of for ourselves, for our children and our family had radically changed. It was the beginning of the grieving process. I was not sure how we would get though it, but we would have to pick up the pieces of our broken picture and put it back together. We were not going to let Cystic Fibrosis make our family victims. We began to fight CF right away. Our family participated in our first Great Strides about a month before Cassidy's birth. Being part of Great Strides and helping to raise funds and awareness for CF was really the beginning of the healing process. We could do to change Cassidy's diagnosis, but Great Strides was a way for us to take action - to actually do something to fight for a cure for CF. We were terrified that our lives would be spent in and out of doctors offices and hospitals, caring for a sick child with an incurable disease. We spent the first four days of Cassidy's life in the NICU watching for a suspected bowel obstruction – a common complication of newborns with CF. We couldn't help but think, "This is what life is going to be like." Cassidy pulled through without any major procedures. When we brought her home we were surprised at how normal things actually were. Initially, the only differences were that she had to be cupped and she had to take enzymes. I told her curious sister that the enzymes were "spoonfuls of pearls". Life went on. Everything was going to be okay.

Cassidy was about 6 months old and CF reared its ugly head. Cassidy was in and out of the doctor's office, on antibiotics one after the other, until she was admitted to the hospital for her first "tune up". It challenged our family to stay strong and to stick together. Cassidy is now a little over a year and we know that she will be hospitalized again at some point, but we don't focus on that. We go swimming. We go to the zoo. When we first found out that Cassidy would have CF we were overwhelmed by the challenges we were going to face as parents, husband and wife, big sister and little sister living with a life-threatening disease. We are only a short distance on this road, living with CF, but we have learned a great deal about CF, life, our family and ourselves. We live for today and don't worry so much about tomorrow. Cystic Fibrosis has only changed the picture of our life. It will not ruin it.

Nurses Nook

2009-2010 Flu Season: What You Need to Know

By Elaine Philipson, RN, MS, PNP

Each year the cold and flu season presents a challenge to people with cystic fibrosis to remain healthy despite how common the germs are. This year presents a special challenge as we all face not only the usual seasonal flu, but also the spread of the H1N1 flu virus (commonly called Swine Flu). The CF Foundation shares the concern and met with an advisory board recently to establish recommendations for people with CF to meet this challenge. Below are recommended highlights:

- People with CF and all the members of the household should receive both seasonal and H1N1 flu vaccines. **http://www.fluclinicIocator.org**

- Implementing daily, personal infection control practices in your life at home, work, and school can minimize the spread and likelihood of catching the flu virus.
  -Frequent hand washing with soap or use of alcohol-based hand gel.
  - Consistent use of tissues for cough or sneezing, following with hand washing. If you don't have a tissue, cough into the bend at your elbow. Keep at least an arm's distance from people who have a cough.
  -Avoid touching your eyes, nose or mouth. That is the typical way flu germs enter your system and the disease spreads.
  -Stay away from people who are ill. If ***you*** are ill, stay away from other people – especially if they have CF!
  -Avoid places where many people are expected to gather when H1N1 flu is known to be prevalent in your community.

- People with cystic fibrosis should be treated with oral anti-viral medication, such as oseltamivir (Tamiflu) for 10 days if they develop active symptoms of flu (fever >100 degrees F and a sore throat or cough). It is important to begin treatment very early in the illness for the medication to be effective, so promptly reporting symptoms to your care providers will be essential to getting the treatment started.

- It may also be advisable, in specific circumstances, to give the anti-viral as a preventative treatment to people with CF if they have had very close contact with a person who develops influenza. Each case should be handled individually, so discussing with your care provider is advised.

Using the guidelines outlined above should give you and your family the fundamental information you need to protect yourselves during this cold & flu season. If you would like more specific information regarding the seasonal or H1N1 influenzas, please check out **http://cdc.gov/flu/ or http://cdc.gov/h1n1flu .**

Sound bites from Social Work

The year is slowly coming to an end and it's that time of year again where you may be getting notices about changing or updating your insurance coverage. Having good health insurance is important but understanding or choosing your health insurance is not easy. **Here are some tips to remember:**

- Review your health insurance plan as they change from year to year. Be familiar with sections of your health insurance that are important for cystic fibrosis which include home healthcare and prescription drug coverage. Do not assume that your prescription drug and health care coverage is the same from year to year.
- Call your insurance company and get your questions answered. Get the name and the extension of the person you are talking to and document what they said for your own records.
- If you have a choice between two or more health insurance plans review each one carefully. Compare benefits to find out which is best.

- **Remember the six C's of insurance:**
  - Coverage
  - Co-pays
  - Claim Payment
  - Conditions That Affect Payment
  - Caps on Benefits
  - Cost of Insurance Premiums

Although there is no "best" insurance, there are some that will be better than others for you and your family. It may seem overwhelming and confusing but take time to get the information and don't be afraid to ask questions or ask them to explain things. Don't wait until the last minute or just pick something that you "think" it may work. The important thing to remember is that you are the priority and need the right coverage, right now for your illness.

Please call us anytime and we can talk things out with you or help anyway we can.

Tiffany Passalacqua Social Worker Culver Medical Group 654-5432 ext. 1050
Christine Stokes, Social Worker Culver Medical Group 654-5432 ext. 1050

Food, Glorious Food!!

Macaroni and Cheese

This classic is now packed with more calories and fat. The creamy cheese flavor is sure to win over even the pickiest eater.

Prep time: 20 minutes **Serves:** 3 **Serving size:** 1 cup
Ingredients:

- 6 c. water
- 1 (7.25 oz.) package of macaroni and cheese dinner
- ¼ c. butter
- ¼ c. heavy whipping cream
- 2 tbsp. skim milk powder
- ½ c. cheddar cheese, shredded

Directions:

1. Boil the water in a medium pan.
2. Stir in the macaroni.
3. Boil for 7 to 10 minutes, stirring occasionally.
4. Drain the macaroni and return it to the pan.
5. Add butter, whipping cream, skim milk powder, cheese, and cheese sauce mix (from the macaroni and cheese dinner package).
6. Reduce heat to low and mix well until the cheese has melted.

Nutritional analysis (per serving):
563 calories 16 g protein 32 g fat
870 mg sodium 305 mg calcium

Mashed Potatoes

This easy side dish tastes great when served with turkey, chicken, or beef.

Prep time: 5 minutes **Serves:** 2 **Serving size:** ½ cup
Ingredients:

- 2/3 c. water
- 2/3 c. heavy cream
- ¼ tsp. salt
- 2 tbsp. butter
- 2/3 c. mashed potato flakes
- 3 tbsp. sour cream

Directions:

1. Combine water, heavy cream, salt, and butter in a microwave-proof bowl.
2. Microwave on high setting for approximately 2 minutes. (All microwaves vary and heating times may need to be adjusted.)
3. Remove from microwave.
4. Stir in potato flakes to moisten.
5. Add sour cream and mix well.

Nutritional analysis (per serving):
496 calories 4 g protein 45 g fat
403 mg sodium 76 mg calcium

Mighty Milk

Give your milk a boost by adding extra calories. This creamy milk tastes great by itself, with flavored syrup, and in recipes that call for milk.

Prep time: 1 minute **Serves:** 1 **Serving size:** 1 cup
Ingredients:

- ½ c. whole milk
- ½ c. heavy cream

Directions:

1. Pour whole milk and heavy cream in a cup.
2. Stir with spoon until blended.

Nutritional analysis (per serving):
491 calories 49 g fat 6 g protein
108 mg sodium 226 mg calcium

Powerful Oatmeal

Prep time: 5 minutes **Serves:** 1 **Serving size:** ¾ c.
Ingredients:

- ½ c. quick oats
- ½ c. heavy whipping cream
- ½ c. water

Directions:

1. Combine oats, heavy whipping cream, and water in a microwave-safe bowl.
2. Microwave on high for 2 minutes.
3. Remove from microwave and mix well.

Dirt Pudding

Tastier than a mud pie and packed with calcium and calories, this fun snack is an easy-to-make treat.

Prep time: 15 minutes **Serves:** 4 **Serving size:** 1/2 cup
Ingredients:

- 1 c. whole milk
- 1 c. heavy cream
- 4.5 oz. package of vanilla instant pudding
- ¾ c. dry milk powder
- 8 Oreo cookies, crushed
- 4 gummy worms

Directions:

1. Stir together milk and heavy cream.
2. With wire whisk, beat pudding mix and dry milk powder into milk and cream mixture for 2 minutes.
3. Stir in crushed Oreo cookies.
4. Immediately pour pudding into 4 6-oz. clear cups.
5. Put pudding into the refrigerator. Pudding will be soft-set and ready to eat within 5 minutes.
6. Serve with a gummy worm on top.

Nutritional analysis (per serving):
549 calories 10 g protein 31 g fat
282 mg calcium 650 mg sodium

RECIPES FROM KIDSHEALTH.ORG

Cystic Fibrosis Foundation
...adding tomorrows every day.

A Note from the Cystic Fibrosis Foundation...

2010 Events:

Amerks'/Knighthawks' Celbrity Waiter Dinner
March 9, 2010

Fairway to Hope Golf Tournament
August 16, 2010

Stairclimb at the First Federal Plaza
October 16, 2010

GREAT STRIDES 2010:

Rochester-May 15th
Genesee Valley Park

Canandaigua- May 16th
Sonnenberg Gardens

Geneva- May 16th
Seneca Lake State Park

Elmira- June 5th
Eldridge Park

Hornell- June 5th
Steuben Trust Company

Letchworth- September 26th
Letchworth State Park

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We would like to say Thank You to Eric Wright, Chairperson for the 2009 Roses of Hope Gala

Eric Wright was interested in becoming more involved with Cystic Fibrosis Foundation when he found that this year's of Hope Gala matched up perfectly with his schedule. As Chairperson, he has stepped up in a big way making phone calls, sending e-mails, and attending meetings with the CF team, volunteers, and sponsors. "Doing this represents accomplishment. I have CF and have struggled with it all my life. I underwent a double lung transplant surgery in 2006 and I am still here living a full and happy life" says Eric about taking on the role of Chairperson. Thanks to all of his hard work, and the dedication of many CFF volunteers and supporters, the expectations were high and we were pleased that this year's Gala was the most successful one yet.

On Saturday, November 7th, the generous supporters of the CF Foundation gathered with Eric Wright and musical guests Giuseppe Scungili and the Screamin' Seagull Review for an evening of dining, dancing, and silent and live auctions.

Meet the Team at the CF Foundation

- Susanne Peronne (center) is the Executive Director at the foundation. She joined the CF team in November 2007, bringing a successful background in marketing communications and strategic management.
- Patti Carter-Morrison (right) joined the CF team in February 2008 and took on the role of Special Events Director. She has a diverse background in human resources, marketing, and special events work.
- Kristen Phillips (left) is the newest face at the Foundation joining in July 2008 to fill the role of Special Events Specialist. She has previous not-for-profit experience and a background in marketing communications.

We are very excited about the new Volunteer Leadership Committee chaired by Nicole DeBraal, the mother of 10-month-old Nathan who has CF. This committee is helping our chapter fill critical volunteer leadership positions by reaching out to our network of contacts. We hope to extend the reach of our mission through the development of new relationships in the community along with established volunteers and partners.

Volunteers, donors, and sponsors are key to our success. To continue our lifesaving mission we depend on the generosity of individuals- we depend on people like you. We are willing to work with you in order to match your needs, availability, talents, and business objectives. There is no limit to what you can do to help. Whether you volunteer or participate at an event, make a difference. We welcome anyone with an interest in supporting the CF Foundation and its mission of making CF stand for Cure Found!

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

HERE TO HELP

The Strong Family Advisory Board (FAB)

We would like to take a few minutes of your time to introduce you to the Strong Family Advisory Board. Our team has been meeting for about a year and we are here to serve you. Our mission, to gather for a quarterly discussion as patients, families, care providers and local resources with the common goal of identifying potential areas of improvement in the care of the CF patient. We address both inpatient and outpatient issues. Our members commit to work on the board for a minimum of one year.

The FAB has worked on improving communications to families (this newsletter is one result of that work) and enhancing the in-patient care experience at Highland Hospital. Other potential areas of improvement include additional communications and in-patient experience issues, the clinic process and knowledge and experience sharing opportunities.

We would like to hear from you about your ideas and concerns. This information will help us decide on new projects and potential improvements to your experience. E-mail us at RochesterFAB@yahoo.com. We will gather your ideas and update you on our progress.

If anyone is interested in becoming a FAB member, all are welcome. Please contact Donna Germuga or Marcy Odell at the care center and we will put you on the list!

Cystic Fibrosis Family Connection

Who we are… We are parents, siblings, spouses, children, friends, and loved ones of people living with CF. Each day, we are the primary caregivers to people who struggle to breathe. CFFC helps ease the financial and emotional burden of repeated hospitalizations and clinic visits. We are a non-profit organization. We are not affiliated with the hospitals or the CF Foundation.

What we provide… Our services have changed. We provide packets for hospital admissions when requested through Social Work. We may cover TV and phone charges during hospitalizations. A limited number of parking passes are also available.

How you can help… We exist solely on fundraising and donations from the community. If you can help, please e-mail or call (see below). Both the pediatric and adult programs are in desperate need of physical therapy equipment. If you have exercise equipment available for donation (bikes are wonderful), contact us. We would also like to make Wii Fit available for hospital stays. Highland Hospital is trying to build a DVD library, if you have any DVDs available, please consider donating them. We also need help updating our Web site and creating an on-line chat community for people with CF.

Please contact us… E-mail: kyoung42@rochester.rr.com with CFFC in the subject line or call (585) 330-7994 (leave a message during the day, we will call back in the evening or weekend)

Helpful websites:

CFF.org --so much information!!

Website for those interested in the Family Advisory Board. Lots of great conversations and ideas:
CFF-PFA@LISTSERV.DARTMOUTH.EDU – if you are not a member of the Listserv, you can email resources@cff.org and request to join.

If you are on Facebook, check out the local connection,
Search for: Rochester NY area Cystic Fibrosis family network

Archived webcasts with great info:
http://www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/#CF_Healthcare

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!