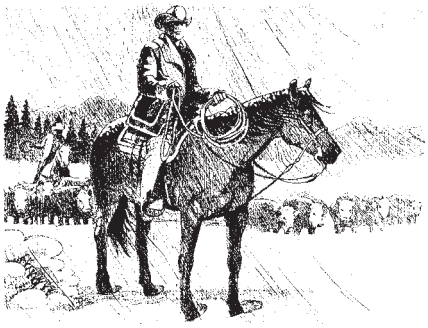
Cystic Fibrosis Association of Missouri

Courageously Fighting For A Cure



November 2008, Vol. 18, No. 1

Cystic Fibrosis on the Trail

A newsletter from the CF Association of Missouri, a group dedicated to the persons and families confronted with cystic fibrosis who share common interest in the care and management of cystic fibrosis. This publication provides information, views, and news about cystic fibrosis to all the families, and friends of CF in our area.

2684 County Rd. 4028 • Holts Summit, MO 65043 • (573)896-4737

"Cystic Fibrosis on the Trail" is a publication of the Cystic Fibrosis Association of Missouri (CFAM) and your University of Missouri Cystic Fibrosis Center in Columbia.

The Editorial Staff: Tony North, Editor; Christina Korth, Assistant Editor; Diane Carney, CFAM Treasurer; Laura Frasher; Connie Fenton, RN, BSN; Peter König, MD, PhD, CF Center Director.

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Cover Photo: Stylized Photograph of avid horseman Jamey May (of the original Jamey's Trail Ride back in the 1980's) on his horse Cody.

University of Missouri CF Center

During working hours:	please call the Child Health/CF Office at (573) 882-6978.
For emergencies after hours:	please call the University Hospital operator, (573) 882-4141, and ask to have the "cystic fibrosis doctor on call" paged.

Division News

We are trying to recruit two doctors for our Division. One is Dr. Jane Taylor, who is finishing her fellowship at Wash U next year and would be an excellent junior Faculty, very smart and interested in research also. Her first visit was very good and she liked our group, but she is also looking at other places.

The other person who visited was Dr. Christopher Oermann, whom some of you may remember. He did his residency in Columbia and worked with the CF Team for a year. He is now at Baylor University in Houston, Texas. He is considering relocating next summer and if he would agree to come, he would become the new Division Chief and CF Center Director.

Unfortunately, the recruitment process is made somewhat difficult by the fact that the Dean of the Medical School resigned and will be leaving by the end of October. That also puts a lot of uncertainty in the search for the new Department of Child Health Chairman. Dr. Ted Groshong has resigned and is acting as interim Chairman.

Peter König, MD, PhD

CFAM President's Letter

It was great to see so many people at the summer meeting in Springfield. The Pratt family did a wonderful job of making all the arrangements, Thank You! It was wonderful to meet some "new" CF families as well as visit with friends we've known for years.

The 25th Hoof-A-Thon will be the final one. It's hard to believe that something that started so small could grow so much! The first year there were less than 10 riders and now there are over 100. And, the amount of money they have raised for CF research will probably top the $1,000,000 mark this year!!! A million dollars for CF research right here at University Hospital in Columbia, MO...wow! So if you see someone out and about wearing a Hoof-A-Thon T-shirt, give them a pat on the back!

Don't miss the fall meeting this year. The trip to Cuba, MO is beautiful in the fall and the fish fry is a treat you don't want to miss!

Mary Backes

Doc's Corner

Pulmonary Function Tests (PFTs) in CF

PFTs are one of the most reliable tools in managing patients with CF.

They are very reliable in detecting worsening and improvement in the disease. Often the patient's subjective feeling is not sensitive enough to detect deterioration, when the PFTs already show significant decrease, this indicating the need to start treatment. The same is true for the end of an exacerbation, when patients sometimes feel back to their baseline, even though the PFTs may not be at their best yet.

The most frequently done PFTs are spirometry before and after an albuterol treatment. Spirometry is taking a deep breath in and blowing air out as far as one can.

The total amount of air blown out is called the forced vital capacity (FVC). In the beginning of the blow one blows out air from the large airways. Thus the amount of air blown out in the first second, called forced expiratory volume in one second (FEV_1) is considered a test for large airways.

The air blown out towards the end of the blow, comes from the small airways. Tests that measure small airway obstruction are the forced expiratory flow at the point that 75% of the air was blown out (FEF_{75}), or at the point when 50% of the air was blown out (FEF_{50}) or between 25% and 75% (FEF_{25-75}).

The ratio between FEV_1 and FVC is also an indicator of airway obstruction if it is low, or it can indicate a restrictive disease such as pneumonia or atelectasis if both FVC and FEV_1 are equally reduced and the ratio remains normal.

Sometimes we also measure lung volumes, mainly to determine the degree of air trapping (increased RV/TLC ratio) or the presence of a restrictive disease (reduced lung volumes). RV is residual volume, the amount of air left in the lung at the end of blowing out. TLC is total lung capacity, the total amount of air in the lungs.

Peter König, MD, PhD

A little information about Pseudomonas aeruginosa (PA).

PA has been on this earth way before humans existed. It is located virtually everywhere: water and soil, especially on those areas close to humans and animals. Early in the history of CF only a small percentage of patients used to be colonized with PA, most of them were colonized by Staphylococcus aureus ("Staph") but due to aggressive antibiotic treatments instituted nowadays, PA became the most common pathogen in older patients with CF. PA is a very sturdy bug and has an exceptional ability to thrive in hostile environments due to its special characteristics, one of those being the facility to produce a biofilm (thick mucus) around its colonies that protects it from aggressive chemicals and antibiotics. It is thought that PA protected by biofilm is 100-1000 times more resistant to antibiotics than bacteria not protected by this barrier. One of the main problems with PA is that several centers have reported worsening of CF if PA is acquired early, that is why we need to be very aggressive on trying to prevent and PA colonization. Two approaches that are helpful in trying to reduce the possibilities of acquiring PA are practicing good hygiene (i.e. hand washing) and avoiding contact with other patients with CF due to risk of "cross-contamination". There are many studies currently underway aiming to fight PA colonization in CF lungs and there is reason to believe that in the future fewer CF patients will become chronically infected and at an older age due to medical improvements.

Jesus Guajardo, MD

Guidelines for CF Care and The CF Foundation's Seven Worthy Goals:

I suspect that readers of this newsletter are a well-informed and knowledgeable group! Nevertheless, I will take up a bit of ink and paper to discuss a couple of important "lists" which have been formulated by members of the CF foundation. The first is the "**Seven Worthy Goals**" and the second is the new "**Cystic Fibrosis Pulmonary Guidelines**". These documents have been drafted as a result of a great deal of data-gathering. That "data" comes from all the information collected over the years from the patients who are cared for in all the CF care centers.

About 40 years ago, the Cystic Fibrosis Foundation started a **Patient Registry** to track the health of people with CF across the United States. Information in this Patient Registry has helped caregivers and researchers see new trends, design clinical trials to test new therapies and improve the delivery of care for people with CF. Through the Patient Registry, our care center receives reports about our patients. These reports help us communicate with you (our patients and families), giving you some of the important aspects of this disease. This information gives us feedback about the success of our health recommendations and treatments. It is also a sort of report card which reflects the efforts of our patients. We do make recommendations that we realize often **can be** or **are** very difficult or impossible to follow! These recommendations come from the published "guidelines." This information is now available to you, your family, and your care "team" from a variety of resources such as: the CF website, at CF center education days (such as the one done in Columbia last fall) and from the CF foundation literature.

We encourage you our patients and families, to ask questions and/or engage in discussion about the CF recommendations at visits to the clinic, hospitalizations or any other opportunity. Each patient must have some understanding of the CF guidelines and find a regimen which works for their disease and life. A strong partnership between patients and healthcare providers working as a team is critical to achieve the best possible health outcomes. **You** are the expert in receiving care from our CF center and living with the day-to-day challenges of CF. The CF Foundation has made a great effort to build upon the concept of the *Team*, and the importance of teamwork. That is why the very first of the goals is to make you and your family a member of that team.

Seven Worthy Goals:

1) To make people with CF and their families full members of the care team;
2) To help people with CF achieve normal growth and nutrition;
3) To receive respiratory therapies that keep lung function steady and to diagnose infections early;
4) To decrease the spread of germs between people with CF;
5) To prevent complications and/or to diagnose and treat them early;
6) To provide care regardless of race, age, education or insurance coverage; and
7) To support all transplantation and end-of-life care decisions.

As I mentioned above, I would also like to let you know a bit about the **Cystic Fibrosis Pulmonary Guidelines.** Since there are now quite few treatment options being used and even more being researched, this list was created. This list of recommendations for the use of specific drugs or treatments is based once again on the information gained from the patient registry and the published research done on CF patients. These guidelines rate the effectiveness of some of the treatments that are being used. The guidelines are an attempt to help us help you choose the right therapies!

The grade **"A"** (best outcomes, strongly recommended) recommendations include:

1. The use of inhaled tobramycin (TOBI) to suppress chronic *Pseudomonas aeruginosa* infections in patients with moderate to severe disease. This has been shown to improve lung function and reduce exacerbations.
2. The regular use of Dornase alfa (pulmozyme) to break down or degrade the free DNA that accumulates in mucus. This is used to loosen mucus, which helps to improves airway clearance and leads also to improved lung function and reduction of exacerbations.

Grade **"B"** (likely to benefit, recommended) ecommendations were given for:

1. Use of inhaled TOBI to suppress *Pseudomonas aeruginosa* infections in CF patients with mild disease or who are asymptomatic to reduce exacerbations.
2. Pulmozyme for CF patients with mild disease, to improve lung function and reduce exacerbations.
3. Hypertonic saline to hydrate or improve the water content of mucus and surface liquids in all patients with CF, to improve lung function and reduce exacerbations.
4. The use of inhalers which relax smooth muscles and dilate bronchial passages (such as albuterol) to improve lung function.

Grade "**D**" (recommend this therapy NOT be routinely provided)

1. Inhaled steroids (excluding asthma patients)
2. Oral steroids (excluding asthma patients)
3. Antibiotics to cover staphylococcus in the sputum when there is no exacerbation, because they don't seem to work and because *P. aeruginosa* may increase.

So this list should be what you hear us talking about at your visits to the clinic. If you have questions, please let us help find answers. This list is only the medication recommendations, and as you already have found out, we have other recommendations for you such as airway clearance, exercise, diet/nutrition and blood sugar control! I would recommend that you find your "coach" in a CF center and become an active member of your ***Team CF***!

Melissa Kouba, MD

Springfield Clinic

We need your help to have Springfield Clinic run smoothly. We are asking that you follow the guidelines below regarding your Springfield Clinic appointment. We will be mailing out reminders two weeks before your clinic appointment.

Guidelines:

1. Please arrive on time for your appointment.
2. If you are more than 1 hour late for your appointment, you will need to reschedule for the next month's clinic.
3. If you arrive prior to your scheduled appointment you may have to wait until your scheduled time depending on how the clinic is moving.
4. Please call our office at 573-882-6978 by the Monday before your clinic appointment to cancel if you are not going to be able to keep you appointment. This will allow us to make any changes necessary to our schedule.
5. Please call the office to schedule an appointment if you think that you need to be seen, surprise appointments only make the other scheduled patients wait to be seen.

By everyone following these guidelines, we will be able to see everyone on time. We strive to make your clinic visit as efficient as possible.

Thank you in advance for your cooperation.

Nutrition Nitch

Fat Soluble Vitamins: Why Are They Important?

Fat soluble vitamin levels are part of your annual lab draw. You might ask what those are. Fat soluble vitamins are Vitamin A, Vitamin D, Vitamin E and Vitamin K. Fat soluble means that they are absorbed into the body with fat. After digestion, the vitamins are stored in the fatty tissue ready for later use. Since patients with CF have problems digesting fatty foods, they also have difficulty getting the right amount of fat soluble vitamins. For this reason, patients with CF are prescribed a CF specific vitamin which contains higher amounts of the fat soluble vitamins. To ensure good absorption it is important to take your vitamins at the same time that you take your enzymes, such as at meal time or with a snack.

Vitamin A: Like all vitamins it has many roles. It helps with normal vision, bone and tooth formation, cell function and immunity. It works in the lining of the lungs to help fight infection and also helps to keep your intestines healthy. If you don't get enough Vitamin A it can lead to night blindness. Foods that are high in Vitamin A are whole milk, dark colored fruits and vegetables like carrots, sweet potatoes, spinach, broccoli and peaches.

Vitamin D: Is special because your body can make its own when your skin is exposed to sunlight. Vitamin D helps to build and maintain strong bones and teeth by keeping the right amount of the minerals calcium and phosphorus in your blood. Without enough Vitamin D bones can become thin and brittle. Milk is usually fortified with Vitamin D. In general, few foods have large amounts of Vitamin D. Skin exposure to sunshine provides a great source of Vitamin D but too much sunshine can put people at risk for skin cancer.

Vitamin E: Is a strong antioxidant which means that it protects compounds in the body from combining with oxygen. Oxidized compounds become useless or harmful in the body. Vitamin E also helps to keep red blood cells healthy. It works in the lining of the lungs to help fight infection and helps to maintain the health of your intestines. Vitamin E deficiency can lead to muscle and nerve problems. Foods that are high in Vitamin E include vegetable oils, nuts, green leafy vegetables and fortified cereals.

Vitamin K: Helps blood clot. Without enough Vitamin K in your body your blood takes longer to clot. It also helps keep bones healthy. The best sources of Vitamin K are green leafy vegetables like spinach and broccoli.

Vitamins are a big part of living a healthy life. Questions about these vitamins should be directed to your CF care team.

Christina Korth RD, LD

Importance of Exercise

People diagnosed with CF may benefit from regular aerobic exercise. Aerobic exercise uses the larger muscles in the body and requires some endurance. It includes some activities such as walking, jogging, cycling or swimming. All of these activities make you breathe harder, make your heart beat faster and increase delivery of oxygen to your body. Regular exercise can improve your physical fitness and help you tolerate almost any daily activity with easier breathing and less fatigue. You may benefit from simply walking or doing endurance activities that you enjoy, such as riding a bike, swimming or going for a walk.

Some benefits of exercise for people with CF are:

- Increasing the endurance of your breathing muscles
- Makes your heart and muscles work more efficiently
- Makes your bones stronger
- Help to clear mucus easier
- Slow down the gradual deterioration in lung function that occurs with CF

Higher levels of aerobic fitness have been associated with better quality of life and greater longevity. Strength training or weight lifting, which focus on your muscles and skeleton, help to strengthen bones and may reduce the amount of air that gets trapped in your lungs.

Talk to your CF healthcare provider before beginning an exercise program.

Exercise may help your growth as you may gain muscle instead of fat. The weight that you gain may be "better weight" as it may be more muscle than fat. Exercise causes your body to release a substance called growth hormone, which helps build bones and muscles.

You do burn calories during exercise; the number may

be relatively small. You burn about 100 calories for every mile walked or jogged. You can get those calories back by eating a candy bar or a couple pieces of cheese. As long as you eat enough calories, your ability to maintain or gain weight should not be a problem. Keep in mind that if you are doing a fairly strenuous activity for several hours (like running a marathon or hiking all day) you might want to add some salty foods to your diet.

Overall, regular exercise can improve you physical fitness and help you tolerate most daily activities with easier breathing and less fatigue. It is important to choose an activity you enjoy so that you will stick with your exercise program and feel better as a result.

Article adapted from mycysticfibrosis.com

Christina Korth RD, LD

Dietitian Mentoring Program Trip

This spring I was chosen to participate in the CF Foundation Dietitian Mentoring Program. The purpose of this program is to provide resources and information for dietitians that are new to CF. I am paired with an experienced dietitian who serves as a mentor for resources, information and materials. Her name is Brigid Mordeson the dietitian for the adult CF program at The Nebraska Medical Center. Part of the program was for me to observe my mentor for a day.

My trip to The Nebraska Medical Center CF Center was very exciting. The team greeted me with a wonderful dinner which gave me an opportunity to meet both the pediatric and adult CF teams. During my one day visit I followed Brigid while she visited with her in-patients and attended CF clinic in the afternoon. I was also able to spend some time with the pediatric program dietitian.

This was an eye opening experience. It was a great opportunity to learn from another CF dietitian. When I started with the CF team here at University Hospital I did not get any training from the previous dietitian so I had to learn CF from books, my other team members and by going to the national CF conference. Brigid is a great mentor, as she has great resources & information. This experience helped me learn from someone else but also confirmed that I am on the right track.

Christina Korth RD, LD

No Bake Cookies

2 cups sugar
1 stick margarine or butter
¼ cup cocoa
½ cup whole milk

Combine ingredients in a sauce pot and bring to a boil slowly. Boil for 1 minute and remove from heat. Then add:

3 cups quick oats
1 cup peanut butter
1 tsp vanilla

Mix all ingredients well. Drop by teaspoonfuls onto wax paper and let cool. Enjoy!

Christina Korth RD, LD

Here are the two recipes that I made at our CF Awareness Day last year. Most people seemed to like the peanut butter drink the best.

Christina Korth RD, LD

1. **Strawberry Shake**
   2 cups Whole Milk
   2/3 cup Dry Milk Powder
   2 cups Strawberry Ice Cream
   Blend until smooth. Makes 3 servings.
- 330 kcal/serving

2. **Peanut Butter Drink**
   ½ cup Heavy Whipping cream
   3 T smooth Peanut Butter
   3 T Chocolate Syrup
   ½ cup Vanilla Ice Cream
   Blend until smooth. Makes 2 servings.
- 580 kcal/serving

Monster Cookies

6 eggs
2 cups brown sugar
2 cups white sugar
2 tsp vanilla
2 tsp salt
4 tsp baking soda
1 stick margarine
½ cup Crisco
2½ cup peanut butter
9 cups quick oatmeal
1 cup M&Ms
1 cup chocolate chips

Mix ingredients together in order given. Place by heaping spoonful on greased cookie sheets. Bake at 350° for 10-12 minutes.

Lorna Fisk

Fruit Dip

1 box (8oz) of cream cheese
1 jar marshmallow crème

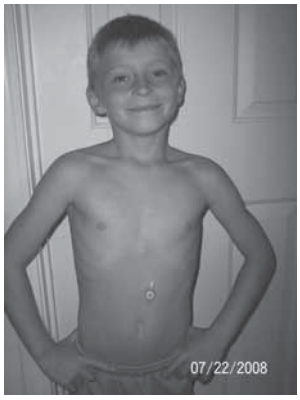
Blend well. Dip all your favorite fruits in it.

G-Tube

As a mother of a child with cystic fibrosis, I often find myself thinking about the future. When Derek was diagnosed, I was told two things about the future: 1) CF children tend to have higher intelligence; 2) CF children who grow well when they are younger, live longer, healthier lives. The latter is supported by research. At that point, my mission became giving him as many calories as I could get him to consume. He ate when he wanted, what he wanted. Despite my best efforts and growing ability as a short-order cook, he failed to grow and sank deeper into the label of "nutritional failure." We tried nutritional drinks, calorie sprinkles, incentives, appetite stimulants. None of these methods were successful for Derek. When the recommendation for a feeding tube came from Christina and the CF team, it was not a surprise, but the decision still did not come easy.

Derek wasn't sure, tears built up in his eyes when he heard. His main question was "can I still play football, baseball, basketball?" Christina, the CF dietician, shared with

him stories from other children who are gymnasts, baseball and soccer players. His decision was made. A feeding tube will help him grow and get stronger and be an even better athlete; he was for it. For Greg, Derek's father, it was a more complicated decision. Greg wanted to know why, why did we have to do this. Why can't he just eat more, why can't he choke down the nutritional drinks. Is it really going to help, is his growth so out of line with our family genetics, and how long will he have to have it. Connie, Kecia and Christina took the time to sit down with Greg and me and share with us Derek's pattern of growth, the research on the correlation between lung function and growth throughout the life span. Greg was able to talk openly about his concerns and he left the meeting consenting to the procedure. My decision was made when I first saw the label of nutritional failure – if it extends his life, we are doing it.



Dr. Ramachandran and especially Scott, the pediatric surgical nurse, answered all our questions and explained the entire procedure to us. They walked us through the GI assessment, what they would do during surgery for the G-tube placement, let us look at the tube itself, and gave Derek an idea of how he would feel after surgery.

Derek was admitted to the hospital a couple days prior to surgery to begin preventative IV antibiotics. You have to love the time spent with a healthy child in the hospital, made bearable by a visit from a few special people. We went with Derek down to the OR the morning of surgery and after being bumped a few times for more critical surgeries, he was taken into surgery. The G-tube placement procedure went very smoothly and he was back in the room in just a couple of hours. Any doubts I had about the decision to have the G-tube hit then as I looked down at my groggy boy who I had elected to have this "object" placed into him, who was in pain as he tried to sit up. That was the only time I have had doubts over our decision. True to his character, he was up walking (albeit slowly) and teasing the nurses by dinner and down the hallway watching the MU football game the next day. Surgery was Friday and we came home with a full-functioning G-tube on Monday.

Derek receives his feeding overnight. After a few leaks, the worse one in a hotel in Alabama, the feedings have worked itself into our routine fairly smoothly. Our main leaks were coming from the small valve on the end of the extender. I place medical tape over it to keep it closed during the night. I use long pipe cleaners purchased from a craft store to clean out his tube extension each morning. Derek washes around the button when he showers and checks the placement and fit weekly.

The G-tube has been in for 5 months now. I wondered if he would be self-conscious about the button in his stomach. He isn't. Not even a month after surgery we traveled to Alabama for a football tournament, in front of his brother's entire football team, he pulled off his shirt and jumped straight into the pool. When they asked what was in his stomach, he told them it was his feeding tube to make him strong so they had better watch out. I did put a stop to Derek tackling them in the sand. His BMI has gone from the 14th percentile to the 38th in the short period of time. I am often told how much better he is looking, how he looks like he has grown. And, he has!! Now, when I think about the future, I can smile.

Cystic Fibrosis Research Updates

I should begin by stating that the focus of my research program is not cystic fibrosis. I am a pig reproductive physiologist. One of the foci of my research program is to reduce the 30% loss of potential piglets that occurs during the first month of development. To study the lack of early embryo development we have developed the techniques to create embryos in vitro, or in the laboratory. Part of the study of early embryo development is to understand the genetic control of the developmental program. You might think of this as dominos falling over. Each domino that falls over represents the turn-on of a different repertoire of the 20,000+ genes that are present in the genome. Fertilization causes the first domino to fall over. The embryo divides to the 2-cell stage, and then to the 4-cell stage. During the 4-cell stage another domino falls over as the embryonic genes turn-on. After about 5 days of development two different cell types form; one becomes the fetus proper, while the other becomes the outer layer of the placenta. At this time point two dominos fall over as there are now two different sets of genes that are turned-on and thus two pathways. The rest of development is similar, i.e. as tissues specialize a new pathway of dominos falls over. This results in a large number of pathways with each representing a different cell type in the body. An understanding of the normal developmental pattern of gene expression should provide clues to the problems that result in the major loss of potential piglets. As an aid to understanding what controls normal development, we have begun to transfer somatic cell nuclei back to unfertilized eggs. Our goal here is to understand how the nuclei are reprogrammed, i.e. since the somatic cells are derived from tissues at the end of the pathway of dominos; for them to be reprogrammed the dominos need to be stood back up so that the nucleus starts over in its pattern of genes that turn-on. While we use this tool, nuclear transfer or cloning, to study development there are a couple of side benefits. The first is that pigs that result from the procedure are clones and have research uses. The second is that if you genetically modify the somatic cell and then perform nuclear transfer you can create a pig with the genetic modification made in the somatic cell. In 2002 we reported that we could disrupt a gene in the pig somatic cells and then we cloned that cell to create a pig with the altered gene whose organs were less likely to be

rejected when transferred to a human. Shortly thereafter Dr. Michael Welsh from the University of Iowa contacted me as he wanted to create a pig with the same mutation that results in cystic fibrosis in humans. This was important since similar mutations in the mouse did not replicate what occurs in humans. So we wrote a proposal to the National Institutes of Health to make two different types of mutation. The first was to make a pig that had a null mutation, i.e. the sequence was disrupted so that no functional cystic fibrosis transmembrane conductance regulator (CFTR) protein was produced. Secondly a deletion of the amino acid phenylalanine at the 508 position of the CFTR protein was proposed. After review and funding we began the project in earnest in the spring of 2003. Our first pigs with one copy (heterozygous null) of the CFTR gene mutated were born on May 30, 2006. The founder males were grown to sexual maturity and then were bred to wild type females. This mating produced both males and females that were carriers (heterozygous). When they reached sexual maturity and were mated we produced our first homozygous mutant pigs in February 2008. The homozygous mutant pigs have many of the early symptoms of CF, i.e. the defective chloride ion transport has resulted in partial pancreatic destruction, meconium ileus, some liver lesions and focal biliary cirrhosis. We continue to be hopeful that these animals will also develop airway disease. In addition to the null animals, the first 508 mutation founder animals were born July 9, 2007. The 508 founder males have reached sexual maturity and produced male and female carriers. These heterozygote 508 pigs are beginning to reach sexual maturity and we might have homozygous 508 animals in early 2009.

We look forward to finding out how well these animals will exhibit the symptoms of CF.

Research Update: Working to prevent recurrent infections in CF

Jason Furrer, Ph.D., and Mark McIntosh, Ph.D.
University of Missouri
Dept of Molecular Microbiology & Immunology
furrerj@missouri.edu

Thanks to CFAM's generosity, our lab recently received a gift to fund our new exploratory research on a serious unsolved complication in CF patients – chronic and recurrent bacterial infection. In normal lung function, the mucus layer traps and removes invading bacteria. But in the viscous CF mucus, the body's natural immune function of trapping and clearing bacteria that invade the airway is severely impaired, giving rise to the colonization and persistence of chronic bacterial infections that cannot be efficiently removed such as *Haemophilus influenzae*, *Staphylococcus aureus*, and *Burkholderia cepacia*. Yet, CF is most commonly characterized by the emergence and persistence of the Gram-negative organism *Pseudomonas aeruginosa*. *P.aeruginosa* is found in up to 80% of patients by age 20, and has been associated with deteriorating pulmonary function, worsening mortality rate, and shorter median survival. As such, a critical challenge for CF treatment is the prevention of *P.aeruginosa* chronic colonization to increase the patient's quality of life and survival.

We are investigating how the bacteria produce a chronic or recurrent infection. The goal is to explore a novel mechanism termed 'Contact-Dependent Inhibition' (CDI) as a potential way for *P.aeruginosa* to set up its niche in the lung. CDI was originally described in *E.coli* causing persistent and recurring urinary tract infections, and we have found that the genome of *P.aeruginosa* harbors very similar sets of CDI-like genes. When a bacterium carrying CDI genes is mixed with other bacterial target strains, the ability of the target to multiply is substantially inhibited. This mechanism could account for the high rate of infection by helping *P.aeruginosa* to 'dominate' other competing bacteria, including beneficial organisms. Published studies have shown *P.aeruginosa* co-cultured with varied microorganisms shows reductions in target cell counts. Additionally, the mechanism may be used within the *Pseudomonas* population itself, causing some *Pseudomonas* cells in the population to be intentionally 'quieted'. Data indicate that some inhibited target cells seem to remain intact and possibly viable, leading to speculation that these 'self-inhibited *P.aeruginosa* comatose cells' serve as a source for recurrent and chronic infections. Antibiotics and immune responses would be ineffective against such non-dividing cells. When the initial population is destroyed by conventional treatments, the quiescent cells repopulate the infection when therapies cease.

With CFAM's support, we have started work on a *Pseudomonas* gene, *PA0041*, which is similar to known CDI genes. Studies show that deletion of *PA0041* markedly decreases virulence in a rat model of chronic respiratory infection. In cooperation with the University of Missouri Hospitals & Clinics bacteriology lab, we have initiated screening of *P.aeruginosa* isolates from CF patient samples to see how many *P.aeruginosa* isolates carry the genes. Preliminary results estimate at least 30-40% of isolates tested positive for the presence of the *PA0041* gene. No patient records or identifiers are collected at this time, but if our search proves fruitful, this search could be expanded to gain information regarding CF patient recurrent or chronic *P.aeruginosa* infection. We have also begun co-culture experiments on *P.aeruginosa* strains either containing or missing the *PA0041* gene mixed with another CF villain, *Staphylococcus aureus*, to see if they can inhibit S.aureus and other target organisms. The initial data suggest the *P.aeruginosa* may indeed inhibit in a fashion consistent with CDI.

As our experiments progress, we hope to elaborate the mechanisms by which CDI works in P.aeruginosa by identifying signaling cascades in target organisms to identify the specific mechanism of inhibition, monitor of inhibited bacterial target cells for conditions that 'rescue' them, and analyze the P.aeruginosa and target cell proteins involved in the interaction. While we likely won't cure chronic infection in CF, we would like to lay the framework for understanding how the bacteria succeed. If we can decrypt how CDI works, the potential exists for the harnessing of the CDI system for controlling infections using engineered CDI components as therapeutic targets.

Kecia's Korner

Support Group for Bereaved Families

The Journeys Program is sponsored through Children's Hospital providing support to patients and families with complex, chronic and life threatening or limiting conditions. Through the Journeys Program there is a support group for parents who have lost a child. The support group is facilitated by the Social Workers at University of Missouri Children's Hospital. The Child Life staff also provides a support group for the surviving children. The group meets every other month in Columbia and lunch is provided. If you would like to join or get more information on the group, contact Kecia Nelson at 573-882-6978 or Meredith Lehman at 573-882-2977. Next group meeting is October 25th.

Continue to empower yourself with CF knowledge. Turn to CF Living for more

Living with CF requires a long-term commitment to your own or your child's health. Part of this commitment means staying active in your search for information. Enrolling in CF Living, a customized information resource is a great step.

Heros of Hope

What is the mission of *Heroes of Hope Living with Cystic Fibrosis?*

The Heroes of Hope program is sponsored by Genentech, Inc., to recognize and salute unique individuals with cystic fibrosis who are stars in their own right for striving to live full and productive lives, and for being role models of hope to others, while continuing to manage their healthcare needs. Won't you join us in celebrating the shared inspiration a hopeful spirit can bring into our lives? Nominate someone you know to be a Hero of Hope today.

Heroes of Hope Living with CF can be nominated by family members, friends, healthcare professionals, teachers, and community members.

***Heroes of Hope Living with CF* are individuals who:**

- Serve as role models and portray hope to others with CF
- Proactively maintain their health with the recommended treatment regimen
- Take initiative and have a spark to pursue goals and dreams
- Are motivated to live life to the fullest
- Do not let the limitations of cystic fibrosis get in their way of pursuing dreams
- Have a positive approach to life
- Use their special skills to help others as well as themselves
- Contribute to their community
- Talk openly about having cystic fibrosis
- Are proud of who they are and what they have accomplished
- Have a special attitude that helps them respond in a positive way to life's challenges

Who qualifies to be *Heroes of Hope Living with CF*?

Persons of all ages with the diagnosis of cystic fibrosis living in the United States are eligible for nomination to the *Heroes of Hope Living with CF* program. Although this program is brought to you by Genentech, Inc., use and/or purchase of any Genentech products is not required for nomination or selection.

Sharing Spot

2008 Scholarship Winners

Cystic Fibrosis of Missouri, West Plains Chapter is proud to announce this year's winners of the 2008 Dr. Guillio Barbero Memorial Scholarships. This year we have one new and one renewal cystic fibrosis patient winners, and one parent winner.

The committee would like to take this opportunity to thank all the applicants for taking the time to apply for our scholarships. We would also like to say a very special thank you to Tony North in Dr. Konig's office for assisting us with this process. We are so very grateful to our special donors this year, Mrs. Marj Barbero and Mrs. Leigh Konig.

Megan Suzanne Pratt, Springfield, Missouri is the daughter of James (Mike) and Dana Pratt. Pratt is a high school senior at Willard High School, Willard, Missouri and will be graduating in May. Pratt was very active in band during and other various activities with the Phi Sigma Pi coed honors fraternity. She is also a Sunday school teacher at her local church and works with children's safety programs during the summer.

Pratt explains, "Living with cystic fibrosis was once something I considered a burden. As I have gotten older, I have realized, living with cystic fibrosis has been an aid in my life and has had many positive influences on me. Living with CF has taught me many valuable life lessons." Pratt plans on going to college to become a neonatologist. With her caring personality and determination we are sure she will reach her goals. Pratt is awarded a $1,000.00 scholarship to be used at the college of her choice.

Sophie Backes, the daughter of Gary and Mary Backes, Linn, Missouri is a 2004 graduate of Osage County R-II, Linn, Missouri. She has completed four years at the St. Louis College of Pharmacy, St. Louis, Missouri. For

the past four years Backes has worked in the information technology center at St. Louis College of Pharmacy. She is currently working at Schnuck's Pharmacy in Ladue, Missouri as a pharmacy intern.

Backes is very active in raising money for the American Heart Association, Relay for Life and for Cystic Fibrosis Association of Missouri Hoof-A-Thon. She is also a very active member of St. George Church.

Backes is awarded a $1,000.00 scholarship to be used at the college of her choice. Upon graduation, we look forward to walking into her pharmacy someday. Maybe she will even have an old fashion soda fountain that we can set down and have a coke to go with her smile.

Mary McCutcheon, Springfield, Missouri is the mother of two cystic fibrosis children. Robert Massey who passed away in 1995 and Lucas Massey 19 years old. She is currently attending Southwest Baptist University, St. John's College of Nursing.

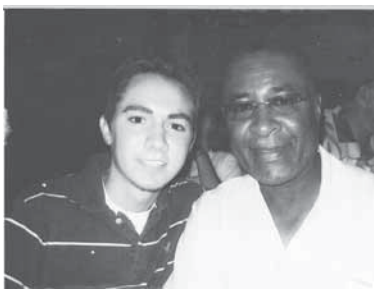
McCutcheon say "One of the first few days at this new campus, I was looking for my instructor's office. When I finally found it, I was struck by a photo hanging under her name plate. This photo was taken when she was a nursing student. She was helping a young man with his homework; this young man was Robert (McCutcheon's son)." McCutcheon has been taking college classes since 1984. She is amazed at how far CF awareness has come in that amount of time.

McCutcheon will be a wonderful nurse someday in the very near future. It is an honor to award her a $500.00 scholarship to be used at the college of her choice. She has never lost sight of her goals in life. Way to go and our hats are off to you.

Dr. Barbero would be so very proud of each one of our applicants. He always felt like no matter if you were the patient, parent or sibling, you should live life to the fullest. He believed that a person could overcome the biggest mountain and the lowest valley with God's help. By looking at Pratt, Backes, McCutcheon and their families, you know Dr. B must have been right.

If you would like to be a scholarship winner for the school year 2009- 2010, please contact Tony in Dr. Konig's office and he will be glad to send you an application. Deadline is March 1, 2009.

The 2008 recipient of the Jeff Wester Memorial Endowed Scholarship is Nick Jackson. This was presented during recognition and graduation ceremonies this May. Nick is going to MU and hopes to become a physician. As a family we are happy to be able to help in a small way. There were no CF kids in Kickapoo this past year.



Parent Advisory Board News

The Cystic Fibrosis Parent Advisory Board is comprised of families whose children receive their care at the University of Missouri – Columbia's Children's Hospital. The primary goals of the Parent Advisory Board are:

1. to serve as a liaison between CF families and the hospital in an effort to improve the quality of care received at the CF Center
2. to serve as a support network and resource for families affected by CF.

To those ends, the board is currently organizing baskets for newly diagnosed families that include a variety of resources, useful supplies, etc. The board is also in the early stages of developing a survey for patients and families in an effort to identify areas to focus on for quality improvement.

The Parent Advisory Board also sends out a regular newsletter. We want to continue to include you on our mailing list! Please visit **www.cftigers.com** to register your mailing address. This information will only be used to provide CF-related information. You will not receive our newsletter if you do not register.

CF Tigers is a non-profit organization whose purpose is to raise the funds necessary to financially assist the CF Advisory Board and Mid-Missouri CF patients and families. Many of the same people are involved in this organization although it operates as a separate entity. Much is being done to raise funds that support local CF families.

If you are interested in being involved with the CF Parent Advisory Board or CF Tigers or you do not have Internet access to register for the newsletter, please call Michelle at 573-220-5568.

Michelle Kemp

Recent CF Events

Cystic Fibrosis Music Show

Twenty years ago when Brenda Land and Julia Sheldon started the Cystic Fibrosis Music Show, in West Plains, Missouri, they had no idea how big and how long this annual event would run.

The 20th Year Show still carried on several of the same features that the very first Show had. One of the biggest things that didn't change was the surprise of the size of the crowd. The 1st Annual Show was held at You'va's Theater in West Plains. Our goal was to sell 400 tickets. The night of the Show, the marquee on the sign outside of the build, much to our surprise, said "SOLD OUT". There was standing room only that night and we were putting down folding chairs in the isles for people to set in and turning people away. The whole town, it seemed liked, had turned out to see the "Foggy River Boys", of Branson, Missouri.

Twenty years later the same thing happened. The night before the Show, just to be on the safe side, extra chairs were put down in the floor, at the West Plains Civic Center, to accommodate a larger than usual crowd to be on the safe side. Family members of Jessica's Friends were encouraged to buy their tickets early to make sure they had a seat.

Starting early Saturday morning before the Show, everyone wanted tickets. There was a feeling in the air that this maybe the largest Show ever. The feeling turned out to be correct. The doors had to be opened early due to the large crowd gathering outside. By 6:15 p.m., there were few seats left and everyone was asked to move to the center to open up seats, by 6:30 p.m. friends from the crowd jump in to help set up every available chair. By 6:45 p.m. there was standing room only and even sponsors of the Show and friends started giving up their chairs so others could have a seat. There was a full house with standing room only. We had done it again.

Not only were the ticket sales the best ever, so were the donations for the Show and the items for the auction. Our auctioneer was at a very disadvantage, because while he was trying his hardest to sell the items, we were working putting down chairs. As we think back, we must have looked like a bunch of ants busy at work.

Jessica's Friends under the direction of Jody Sharp took the stage and sang many of the songs from the previous year's Show. These kids performed and sang their hearts out each year. We are so very blessed to have them. This year we were so happy that Taylor Durham and her brothers Dylan and Keith, from Kirksville joined the Show.

Awards were given out to recognize workers that had helped with the Music Show all twenty years. These people each year show how dedicated they are by putting in many hours. They too are working for a cure for cystic fibrosis.

The mood had been set, the crowd was ready and the Bellamy Brothers took the stage. Howard and David are both so very talented. They both play the guitar, mandolin and banjo. David can also play the accordion, fiddle, organ and piano. Their distinct style of music is a combination of county, rock & roll and the calypso music sung by Jamaicans. Their first big hit came in the late 70's on the pop market with their song "Let Your Love Flow". Then a few years later their next big hit "If I Said You Had a Beautiful Body (Would You Hold It Against Me) rocketed them to the top of the country charts. It proved to be the first of a string of fourteen #1 singles in the U. S. alone. Everyone's favorite songs like "Sugar Daddy", "Redneck Girl", "Old Hippie", "Kids of the Baby Boom" and many, many more. In May, 2007 they released their most recent project an album of gospel music, titled "Jesus Is Coming".

What a wonderful concert all the way round. Everything and everyone was a winner that night. The biggest winner of all was cystic fibrosis research. A grand total of over $41,000 was raised that evening. A special thank you to Brenda Land, Julia Sheldon, Joe & Gayla Auffert, Jess & Patsy Atkinson, Jody Sharp, Libby Grisham, Linda Cates and many others that work hard each year to make this Show possible.

Our 2009 Music Show will be on Saturday, Mach 21st. Please mark your calendars now. It will be another show you will not want to miss.

CF Buddy Bass Tournament

The 23rd Annual Cystic Fibrosis Buddy Bass Tournament was very successful again this year. Once again, fighting against odds, just like cystic fibrosis victims, the Tournament went on and the fishermen still came. Our area had flood rains for about a week and the lake was rising. Many local people said they had never seen the lake that high. The Lake level was up 570 feet. But the rains stopped and the tournament went on bringing a total of 231 boats on a cool, early March morning. Bo Pace of West Plains called off the numbers and the fishermen and women was off to a very challenging day of fishing. Left on the banks were all the CF families and friends to get ready for a big day.

The 101's Great American Diner has become the official breakfast spot for all the workers before the start the next step of their eventful day. After breakfast everyone gets busy writing thank you notes and getting ready for the weigh in. This year there was a very different twist to the event because of the high water, the camp ground where the weigh in is usually, was under water so the weigh in had to be moved across the lake to Panther Bay.

When we could smell the smoke from the bar-b-que grill, we knew the afternoon's events were ready to start. Jim Connor and Marvin Ball were getting busy frying up all the burgers to feed the hungry workers and fishermen. Also helping to feed the group was Marie Hensley, Irene Frazier, Sally Hicks and Gayla Auffert. Jessica Joice was busy selling the cokes and the grandpas, Leroy Frazier and Duane Hensley, tired to keep everything going in the right direction.

The weigh in is always a busy place to be. Jake Shasseree and Colter Billings were waiting on the banks to help the fishermen get bags to put their fish in to carry them up to the weigh in. James Adam Guilliams and David Goodman stayed busy on the water tanks this year where the fishermen checked back in with their fish. The girls, Patsy Atkinson, Patty Stone, Ashley Bean, Deborah Chance, Debbie Shassrree and Shelly Surface stayed busy helping the fishermen get their fish weighed in. Jason Willard and Robert Burtrum did an outstanding job measuring and weighing the fish and Bo Pace kept the crowd entertained with all the fishing stories. It takes lots of help to get the fish back in the water and we were lucky that Bill Manville, Jess Atkinson, Roy Hicks and the Mammoth Spring National Fish Hatchery were there to help get the fish back in the water. We did not lose a single fish again the year. Another busy place is the girls in the van, Brenda Guilliams, Mary Kay Ball, Jeannie Bax and Diane Carney. These girls are responsible for keeping the entire total and determining who our winners are.

There were two different raffles held this year. We had a 70cc Wildfire all-terrain vehicle that was donated by Ozark Auto & Marine, owner Charlie Whisnant. The winner of it was Ray Ward of Willow Springs. Each year we have a rod and reel donated to raffle off. This year it was a Stetyr rod and a reel, donated by Gayle Julian of Jewel Bait. We would like to thank Betty Wester, Mary McCutcheon, Jackie Durham, Tracy Ellis, Jennifer Wharton, Deborah Chance, Scott Carlstrom, Vondie Arthur and all the others that helped to sell the tickets this year. The CF families and friends raised $1,176 before the tournament through their efforts. This was a huge support for us. The winner of the rod and reel was a fisherman from Jonesboro, Arkansas.

By the end of the day, we had 59 boats that weigh in fish. With a total of 119 fish weight in and the total weight of all fish was 281 lbs. First place winners were Fred Hale and Waco Johnson of West Plains with 12.47 lbs. They won the Bass Cat Boat and $2,000. Second place winners were Brand Garringer of Mtn. Home, AR and Donnie James, Gainesville, MO with a total weight of 12.46 lbs. They won $1,000. Third place winners were Michael Holts and Tracy Hunter of Batesville, AR with a total weight of 12.27 lbs. They won $675. Big Bass winners were Henry Porter and Jimmie Kasinger of Mtn. Home, AR. They weighed in a small mouth bass at 5.46 lbs and won $850.

The Fishing Tournament is put together by tournament director Dan Singletary, Bo Pace, Rick Frazier, Fred Hale, Waco Johnson, Jason Willard, Robert Burtrum and many other volunteers each year. The success of this tournament each year is because of their deep dedication and support of cystic fibrosis. They all put in many hours before and after the event. Thank you for caring so very much. Rick Pierce and BassCat Boats, Mtn. Home, Arkansas understands the importance of this event. They have helped us with this event from almost the start. We appreciate their friendship and continued support in helping us raise money in search for a cure.

We raised $10,770 for cystic fibrosis that day. Thanks to everyone that sold raffle tickets and came and worked that weekend. We could not do this event without lots of help. Please know that you are as much a part of raising the $10,770 as Rick, Jessica and I am.

Special Friends Take Extra Steps to Raise Money for Cystic Fibrosis

French Style Luncheon to Benefit Cystic Fibrosis

Kelly McGinnis and her daughter, Mindy Williams opened up their home on June 14th to friends to enjoy a French style luncheon with proceeds going to cystic fibrosis. Other hostess helping with the event included Libby Grisham, Carol Johnson, Jessica Joice and Lois Frazier.

It was a beautiful day for an outside luncheon. It had rained the night before and everything looked so very crisp and green. It was a very nice, sunny, late spring day with the temperature in the high 70's. The McGinnis' back porch patio was set up with tables with red and white checkered table clothes and "Springtime in Paris" music was playing in the back ground. The flowers that decorated the outside fireplace with the wooded area in the background, helped to set the warm, cozy feeling of come, set down awhile and enjoy the wonderful atmosphere and the food that had been prepared for you.

Approximately 22 people enjoyed the menu of Croquet Monsieur Ham & Cheese Sandwiches, Chicken Salad on a croissant, Tomato-Mozzarella Skewers, Fruity Pasta Salad, Fresh Fruit on a stick with Berry Dip, Elephant Ears Cookies, Crème Brûle, Raspberry Blueberry Chocolate Truffle, Cheese Straws, Fresh baked White & Wheat Bread Braid, Cucumber Water and Mocha Punch. Just to look at the food was enough to take a person's breath away. Your eyes did not deceive you, because the taste was as wonderful as the look was appealing to say the least. Everyone was very curious about the food they were getting the opportunity to try. And soon the whole outside was filled with voices and laughter.

All of the guest enjoyed just a small piece of Paris or maybe Marseille that afternoon. While cystic fibrosis will enjoy the proceeds to the tune of $905. What an exciting way to raise money for cystic fibrosis.

Thank you Kelly and Mindy for opening up your home to this event and also to Carol and Libby for helping out. Also, a very special thank you to all the CF families that shared their family stories with us. It is always hard to write on paper what is in your heart. Thank you for allowing us to step into your hearts.

Mary McCutcheon's Story

My story begins on Valentine's Day 1982. Robert Tyler Massey came into this world at a healthy 7 pounds, 7 ounces. Fast forwarding to September, my son was admitted to the ICU needing life support. The doctors said he probably would not make it 24 hours. They were wrong. He was a fighter, he was on the ventilator for a week and continued to get stronger each day. He was hospitalized for 9 weeks. A diagnosis of Cystic Fibrosis (CF) was given.

With this diagnosis a new chapter of our journey began. We knew nothing about CF. No one on either side of the family tree had been documented with CF. There were several infant deaths listed, but years ago CF did not have a name, just listed as pneumonia or weaken lunged. A person learns quickly what it takes to keep a CFer healthy.

May 1988, we were blessed with another baby boy, Lucas (Luke) Edward. Back in 1988, a baby is not tested for CF until the age of about 3 or 4 months, unless there were obvious indications. I took Luke to see Dr. Barbero at the Springfield CF Clinic when he was 2 weeks old. I told Dr. Barbero that I didn't know if it was paranoia or baby blues but there were signs to me that was too familiar. Luke was diagnosed with CF at 3 weeks old. I was shocked that Robert was excited about the diagnosis until he told me that "now someone was just like me!".

Cystic Fibrosis Association of Missouri (CFAM) began with the need for support and fund raising for a cure. Support from people that knew what the other person was experiencing. A shoulder to cry on, or how similar experiences could be approached. To be there when the heartbreak of losing someone happened.

Robert lost his battle with CF in February 1995. Luke celebrated his 20th birthday this year. He told me that this year was a milestone for him. I thought to myself, milestone? usually you hear about the 21st birthday being a milestone, legal age to drink. Then he continued to say that this was the year that was suppose to be his lifespan age.

Thank you for coming to Lois' Luncheon for CF. Thank you for allowing me to share my story. I truly believe everyone makes a difference, the cure for CF is just down the road.

Sincerely,truly
Mary McCutcheon

The Columbia Great Strides Walk reached new levels with remarkable growth!

Walk This Way!

It may seem like a long time ago, but the Great Strides Walk which occurred at Stephens Lake Park last April is still on the minds of a lot of the people who helped plan the event and those that participated.

The third annual Great Strides Walk was a huge success, surpassing it's fundraising goal and raising more than $40,000 – a nearly $13,000 increase from the previous year. Perhaps equally exciting was the participation of 28 teams this year, many new additions to the walk.

Those who came out for the Great Strides Walk were entertained by dancers from a local children's dance school and the dance troupe, Poetry in Motion. Children also enjoyed carnival games and mascots from Columbia College and the University Hospital.

Participants won great prizes through the raffles, gained valuable information at the educational booths and enjoyed a delicious barbecue.

In all, more than 300 people took part in this important day.

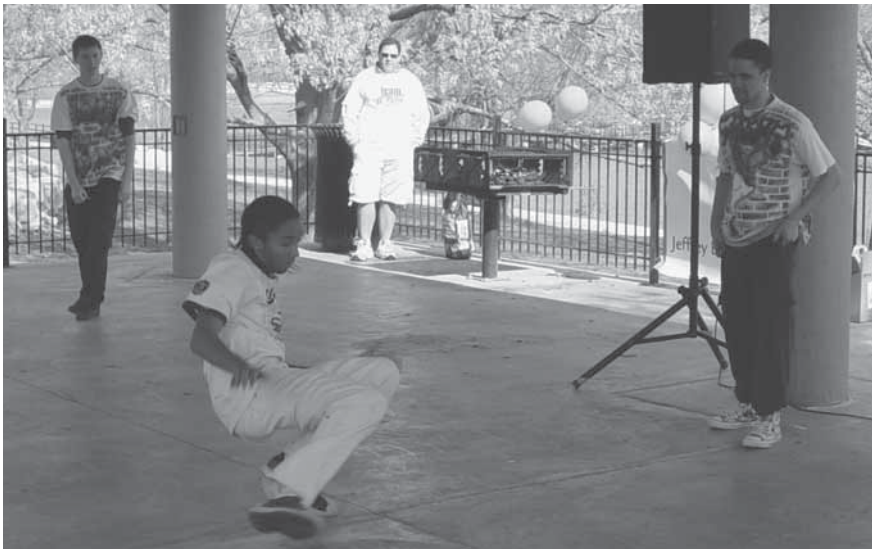
Great Strides is the primary fundraising effort by the Cystic Fibrosis Foundation and had a fundraising goal of $40 million nationally this year. Fundraising for Great Strides 2008 continues until the end of the calendar year.

Money raised by Great Strides walks is used to fund important research at the foundation. Approximately 90 cents of every dollar earned is directed to this research.

Members of the Columbia Great Strides Walk committee are already busy brainstorming ways to make next year's walk even bigger and better. The growth and success of the walk really depends on the support of CF families, friends and co-workers.

Interested people form a walk team by visiting the CF Foundation website at **www.cff.org/greatstrides** and registering. Teams are then free to fundraise throughout the year however they'd like. The walk in April is a celebration of all the teams' successes.

Committee members encourage you to start thinking now about forming a team and planning your own fundraising events. The Gateway chapter of the CF Foundation and members of the Great Strides planning committee are great resources for brainstorming new ideas!

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Upcoming CF Events

Miracles for Kids Radiothon 2008 Presented by Missouri Credit Union

The following 4 Zimmer radio group stations host the event:

The Eagle (Talk Radio) 93.9 or **www.theeagle939.com**
Kat Country (Country) 94.3 or **www.kat943.com**
The Rocker (Rock) 96.7 or **www.kcmq.com**
Y107 (pop) 106.9 or **www.Y107.com**

Radiothon will run from 6AM-6PM on September 24-26 in the lobby of the hospital (across from the Lakota kiosk). We really want to internally (at the hospital) drive home the point to listen online...externally, really drive home the point to listen to the station.

Phone number to call in and pledge (only activated 24-26): 1-866-970-GIVE

For any questions regarding radiothon prior to those 3 days please drive persons to my phone: 884-0724 or **goodma@health.missouri.edu**

Last year we made $221,000 and we would like to do a little better that that this year:)

CMN money is used for the greatest needs at Children's Hospital. In the past money has gone to support programs, patient and family assistance (such as lodging, meal tickets, etc), and equipment. We will be "shopping" for several items on this years radiothon which will be exciting to then be able to purchase equipment that is really needed.

The Great Fish Fry

Bring your appetites and come join us as Paul and Debbie Shasserre host the Great Fish Fry on Saturday October 18, 2008 at 12:00 noon at their home in Cuba, Mo. The Shasserres will be cooking up a mess of fish along with potatoes and hush puppies for us all to enjoy. Everyone is asked to bring a dish. Drinks will be provided. After we have feasted on this wonderful meal, we will gather for our CFAM meeting to learn the latest news on the CF front. This is one event you won't want to miss! Take I-44 to Cuba exit; go south on 19. They are located 1 mile outside of the city limits of Cuba. Turn on Shady Oak Lane (it only goes one way). Signs will be posted along the drive to their house. For more information (or if you get lost), their phone number is 573-885-2253.

Worldwide Candle Lighting

The Compassionate Friends Worldwide Candle Lighting, held annually the second Sunday in December, this year December 14, unites family and friends around the globe as they light candles for one hour to honor and remember children who have died at any age from any cause. As candles are lit at 7 p.m. local time, creating a virtual wave of light, hundreds of thousands of persons commemorate and honor the memories of children in a way that transcends all ethnic, cultural, religious, and political boundaries.

Now believed to be the largest mass candle lighting on the globe, the Worldwide Candle Lighting, a gift from TCF to the bereavement community, creates a virtual 24-hour wave of light as it moves from time zone to time zone. Hundreds of formal candle lighting events are held and thousands of informal candle lightings are conducted in homes as families gather in quiet remembrance of children who have died, but will never be forgotten.

The Worldwide Candle Lighting started in the United States in 1997 as a small Internet observance but has since swelled in numbers as word has spread throughout the world of the remembrance.

The 2007 Worldwide Candle Lighting saw information on services received from 24 countries outside the United States. Joining TCF last year were chapters of several bereavement organizations including MISS, Twinless Twins, MADD, Parents of Murdered Children, and BPUSA and services were held in all 50 states plus Washington D.C. and Puerto Rico.

A Remembrance Book is available during the event at TCF's USA national website. In that short one day span, thousands of messages are received and posted each year from every U.S. state and Washington D.C., every territory, as well as dozens of other countries. Some are in foreign languages.

Here in the United States, publicity about the event is widespread, being featured over the years in Dear Abby, *Parade Magazine*, Ann Landers column, *Guideposts* magazine, Annie's Mailbox, and literally hundreds of U.S. newspapers, dozens of television stations, and numerous websites and personal blogs.

Please help spread the word about this tremendous event and invite anyone who is unable to attend a service to light a candle at 7 p.m. for one hour wherever they may be.

If no Worldwide Candle Lighting service was held near you in 2007, please feel free to plan one open to the public this year. As an aid in planning the service, you are welcome to use TCF's "Suggestions to Help Plan Memorial Services in Conjunction with The Compassionate Friends Worldwide Candle Lighting©."

All allied bereavement organizations, churches, funeral homes, hospices and formal and informal bereavement groups are invited to join in the remembrance.

If you are holding a formal service open to the public (whether in the United States or anywhere around the world), please provide the information on the submission link below so that we can post details for those who visit our website and are seeking a Worldwide Candle Lighting event in your area. This also allows us to post a comprehensive listing of known services, here and abroad and to track the growth of this inspiring event.

While we encourage informal services held in homes and other locations, we are sorry but we cannot include these in our listings. Nor can we include any in memory of a specific child or any that are not open to the general public.

This website will only post those candle lighting events

planned for December 14, 2008.

Please do not type your event with all capital letters as this will delay the posting!

Submit Your Worldwide Candle Lighting Service

View Worldwide Candle Lighting Services

FAQs about The Worldwide Candle Lighting

Join us in helping this phenomenal event grow even larger! We do this . . . *that their light may always shine!*

Cystic Fibrosis Association of Missouri and Friends Upcoming Events

Fall 2008

Fish Fry & Fall Meeting	Cuba, MO	October 18, 2008
22nd Annual North American Cystic Fibrosis Conference	Orlando, FL	October 23-25, 2008

Winter 2008

Compassionate Friends Worldwide Candle lighting	Worldwide	December 14, 2008

Spring 2009

CFAM Spring Meeting	West Plains, MO, Civic Center	To Be Announced
20th Annual Music Show for Cystic Fibrosis	West Plains, MO, Civic Center	To Be Announced
23rd Annual Buddy Bass Tournament	Norfork Lake, Henderson AR	To Be Announced

If you have special events coming up in your area that you would like others of our CF community to know about, in addition to letting our CF Center Staff know (office 573-882-6978), please consider posting them on the CFAM Family Support Website (a private and secure website; see article enclosed).

What Is the Cystic Fibrosis Association of Missouri?

The Cystic Fibrosis Association of Missouri (CFAM) is a support group for those afflicted with cystic fibrosis, their families and friends and provides a living community example of the problem of cystic fibrosis at the grass roots level. The purpose of CFAM (as stated in the by-laws) is to provide information to the general public regarding the disease of cystic fibrosis and related diseases through the dissemination of pamphlets, and books at no cost to the recipients; to provide, at no cost, forums and support groups for persons afflicted with cystic fibrosis and related diseases, members of their families and other interested persons; and to raise funds to support research into the alleviation, cause and cure of cystic fibrosis and related diseases. Any person who supports the CFAM's purpose may become a member. There are no membership dues. Meetings are held 3 times a year, in March, in June or July, and in October or November, at various locations around the State. Everyone is welcome to join us.

How to Contact Us

CFAM

Mrs. Ruth, Elliston, President CFAM, 29412 Hunter Road, Carl Junction, MO 64834, (417) 649 7567, **rie_cj@yahoo.com**
Mrs. Sandra Conner, Vice President CFAM, 1805 Meadowview Drive, Kirksville, MO 63501,(660) 665-6603, **jandsconner@sbcglobal.net**
Mrs. Sally Hicks, Secretary CFAM, Rt. 1 Box 450, Ava, MO 65608, (417) 683 2195, **rhicks@dishmail.ne**t
Mrs. Diane Carney, Treasurer & Board Chair CFAM, 2684 County Road 4028, Holts Summit, MO 65043, (573) 896 4737, **ldcarney2684@earthlink.net**
Mr. Mike Pratt, Historian CFAM, 3602B West State, Springfield, MO 65802, (417) 862 7553, **pratts343@yahoo.com or danapratt@sbcglobal.net**

Cystic Fibrosis on the Trail

To get on the mailing list, or change your mailing address, or to contribute questions, suggestions, stories, photos, poems, etc. to the newsletter, please call us at, or send correspondence to:

CFAM Newsletter, Department of Child Health, DCO58.00,Univ. of MO, Columbia, MO 65212, (573) 882-6978
Mrs. Diane Carney, 2684 County Road 4028, Holts Summit, MO 65043, (573) 896-4737
Mrs. Sally Hicks, Rt. 1 Box 450, Ava, MO 65608, (417) 683-2195

CFAM Family Web Site

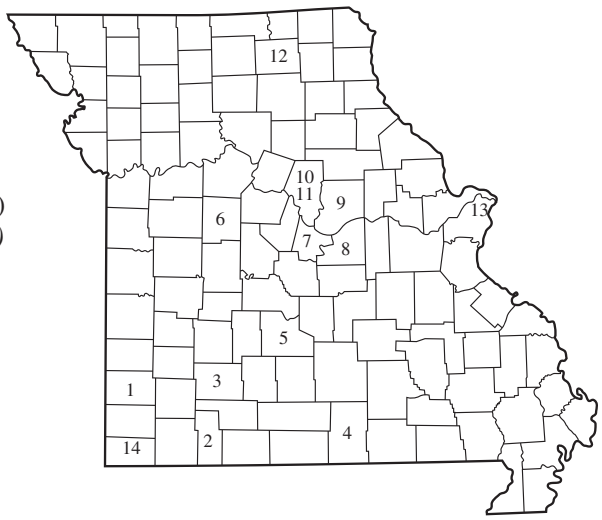
Lois Frazier, **special_loe@yahoo.com** Sally Hicks, **rhicks@getgoin.net**

Local CF Contacts

You or your child has CF. Have you ever felt frightened? Alone? Angry? Scared? Helpless . . . maybe even hopeless? Do you ever feel like no one understands what your family is going through? And for the child with CF, does he ever feel like he is the only person who has to deal with the problems of CF? It's tough to deal with a serious illness without a good support system, and when you deal with a chronic illness, it can really wear you down over time. The good thing about coping with CF here in Missouri is the wonderful support system available. The CFAM "family" is here to help all of us. Your friends and relatives may not understand what you are dealing with, but another CF family does!!! Just having someone to talk to who has "been there" can ease some of the stress when CF gets you down.

Check out the numbers on the map below . . . close to home or far away, feel free to give any of us a call. North or South, there are lots of people to talk to . . . and we are just a phone call away.

1.	Lynette Rowe	Carthage	417-782-7569
	Ruth Elliston	Joplin	417-649-7567
2.	Marty May	Galena	417-357-6797
3.	Mike, Dana, Rhonda & Megan Pratt	Springfield	417-862-7553
4.	Rick & Lois Frazier	West Plains	417-256-5388
5.	Sabrina & Trentin Smart	Lebanon	417-288-9487
6.	Debbie Douglas	Sedalia	660-826-8674
7.	Laura Frasher	Jefferson City	573-636-9934 *(h)*
			573-353-5865 *(c)*
	Mark & Jeannine Toomey	Jefferson City	573-893-4851
8.	Gary & Mary Backes	Linn	573-897-3287
9.	Larry & Diane Carney	Holts Summit	573-896-4737
10.	John and Julie Klein	Columbia	573-446-9650
11.	Debbie Hess	Higbee	660-676-7164
	Eric Hess	Higbee	660-998-2300
12.	Jim & Sandy Conner	Kirksville	660-665-6603
13.	Sophie Backes	St. Louis	573-690-2446(c)
14.	Bernie & Karen Almeter	Anderson	417-845-6855



CF Center
Department of Child Health
N601, School of Medicine
One Hospital Dr.
Columbia, MO 65212

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