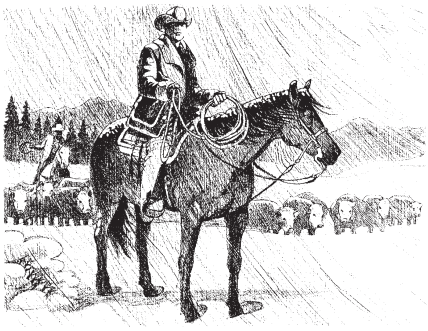
Cystic Fibrosis Association of Missouri

Courageously Fighting For A Cure



February 2010, Vol. 20, 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.

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"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; Deborah Chance, PhD, Assistant Editor; Diane Carney, CFAM Treasurer; Laura Frasher; Lois Frazier; Sally Hicks; 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

From the Director

As you probably know Dr. Guajardo moved to Texas in November, therefore our Center is even more shorthanded with doctors.

Fortunately, we succeeded in recruiting a new Division Chief and CF Center Director. Dr. James Acton is at present the CF Center Director at the Cincinnati Children's Hospital. He will join us in July 2010 and become the CF Center Director.

I will at that time step down as Center Director and Pulmonary Division Chief, but continue my CF and Pulmonary outpatient clinics. I will then no longer do inpatient care.

We are still trying to recruit another Pulmonologist and will replace Dr. Guajardo with an allergist.

Peter König, MD, PhD

University of Missouri Health Care Visiting Guidelines

- Regular visiting hours at University and Children's Hospital are between 9 a.m. to 9 p.m. seven days a week.
- Children younger than 13 must be accompanied at all times by an adult other than a hospital patient.
- To ensure the safety of our patients and visitors all of the doors lock after regular visiting hours. We have implemented additional visiting rules from 9 p.m. to 9 a.m. All overnight visitors must check in with security or a hospitality coordinator by 9 p.m. for an identification badge to show visitors are approved overnight guests.
- Overnight visitors must be 18 years old or older.
- Waiting areas on inpatient floors are designated "quiet areas" from 10:30 p.m. to 8 a.m. Television must be turned off during that time. Visitors may watch TV during quiet hours in the hospital's main lobby.
- Please see the Visiting Guidelines sheet located in visiting waiting areas for more guidelines and information.

Congratulations Dorothy Martin, LPN on your 35 years of dedication to Children's Hospital! We appreciate everything you do.

Child Life Specialist

Hello everyone! My name is Emily and I am the new Child Life Specialist on the Pediatric floor at University Hospital. I am so excited to be apart of the Children's Hospital team! It's my job to help make the hospital a fun and relaxing environment for the children, as well as, provide encouragement and support in stressful situations. Here's just a little bit about me: I'm from St. Louis, but am enjoying life in Columbia. My husband and I will be adding to our family in February! When I have some extra time, I love watching Cardinals baseball and taking my 80 pound puppy for walks.

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.

A new home for TJ is coming soon!

Children's Hospital will be moving this fall to our new location at Columbia Regional Hospital. CRH is conveniently located at the intersection of Hwy 63 & I-70. We'll let you know when we get moved and are ready to show off our new home!

Doc's Corner

Exercise Study

We all know that having a balanced life is important and that's the reason we strive to have good habits, including hygiene, nutrition, sleep, and exercise. Well, just this year the Disability and Rehabilitation journal published a review by Nancy van Doorn focusing on exercise programs for cystic fibrosis (CF). Nancy van Doorn found four studies that were rigorous enough to be further discussed and one of those studies pointed out that there was significant improvement in pulmonary function from short-term exercise interventions during hospital admissions for patients with CF. The original study was conducted by Selvadurai (Pediatr Pulmonol 2002) and in that study patients utilized the treadmill (for 30 minutes) and also did weights (5 sets of 10 reps) five times per week during their hospitalization stay. It was interesting, but not surprising, that the patients that exercised did much better than the ones that did not. On average the forced expiratory volume in the first second (FEV_1) improved by about 6.5% for the treadmill group and by 10% for the weights group. These numbers are remarkable if we think that many of our patients use chronic therapies, such as hypertonic saline and azithromycin, to get 5 to 10% improvement on their FEV_1. In addition, the increase of FEV_1 with exercise may look very attractive to hospitalized patients because it may signal an improvement in lung function with positive repercussions towards an early discharge and the overall quality of life.

In summary, more studies are needed to actually prove without doubt that exercise improves FEV_1 in patients with CF, but in view of its beneficial effects I think we should advocate for it every admission. Of consideration is that the level of exercise mentioned on the study by Selvadurai was not achieved by just having the patients 'stroll around the halls' or having them leisurely walk on the treadmill; patients were asked to perform at 70% of the maximum. So keep this in mind next time your health care provider asks you or your family member to exercise more. So far the evidence available clearly supports the beneficial effects of short-term exercise during hospitalization, and we believe that long term exercise programs will have powerful benefits too, both, in pulmonary function and airway clearance. More studies are needed to fully support this approach.

Jesus Ramon Guajardo, MD, MHPE
(contributed before his move to serve the good folks of Texas)

CF Newborn Screening: Early Detection and Prompt Intervention

Since June 2007, Missouri has implemented newborn screening for cystic fibrosis. When babies are born, blood is collected by heel stick to screen for CF and other congenital disorders. These samples are sent to the Missouri State Laboratory and an IRT (immunoreactive trypsinogen) level is measured. Elevated IRT levels are abnormal, so definitive testing by sweat chloride measurement is required.

Through this method, more than 49 babies have been diagnosed with cystic fibrosis in Missouri. Majority of these babies have difficulty gaining weight and some have respiratory symptoms like cough and wheezing. When they are followed at the four CF Centers in the state: University of Missouri, St. Louis Children's Hospital, Cardinal Glennon and Children's Mercy Hospital, they are thoroughly evaluated and appropriate therapies are started. Interventions include frequent visits, regular weight and length measurements, enzyme and vitamin supplementation, addition of extra salt and calories, and chest physiotherapy.

Although quite overwhelming for a family with a new baby, these interventions are intended to boost nutrition and delay onset of lung disease. For most babies, these treatments focus on CF disease even before obvious symptoms are present. It is like having an umbrella ready when you know it is going to rain!

Zarah Ner, MD

Nutrition Nitch

Healthy High Calorie Diets

Eating a high calorie high fat diet can be difficult especially since our society emphasizes healthy eating. Eating enough calories to gain or maintain weight can be very difficult for people with CF. Knowing that nutrition and lung health go hand in hand our CF center has been trying to improve the nutrition status of our patients.

Many people have questioned how can a high calorie high fat diet be healthy. Here are some ideas that fit into the CF diet but also promote healthy eating.

Cereals can be high calorie and contain many essential vitamins and minerals. Cereals are also high in carbohydrates which provide fuel for you body. Adding ½ cup whole milk to 1 cup of a high calorie cold cereal can provide at least 275 calories per serving. Some high calorie cereals include Frosted Mini Wheats, Raisin Bran, Honey Nut Clusters, Cracklin' Oat Bran, Banana Nut Crunch. Hot cereals also fit into a healthy high calorie diet. One packet of flavored instant oatmeal with ½ cup heavy cream can combine to provide 575 calories.

Many milk and dairy products are high in calories but also supply your body with protein and calcium. Protein is essential for building muscle in your body and calcium builds strong bones. Custard yogurts can provide 190 calories per serving. Higher calorie milk can be made with whole milk and instant nonfat milk. Combine 1 quart whole milk with 1 cup instant nonfat milk to make 4- 1 cup servings that provide 210 calories per serving. Choose cheeses that are made with whole milk over those made with

low fat milk. Instant pudding can be made with heavy cream instead of using milk; ½ cup will provide 300 calories.

Nuts and peanut butter are great sources of protein. Trail mixes can be made at home by mixing nuts, seeds, dried fruit, pretzels and chocolate chips. Or you can choose from several varieties of trail mix from the grocery store. Peanut butter can be added to many foods like crackers, apples and celery for great snacks. Sunflower seeds or mixed nuts also make great healthy snacks; ½ cup sunflower seeds provide 375 calories.

There are a variety of snack bars on the supermarket shelves today. Some provide more calories than others. When selecting from different brands it is important to look at the food label and choose the highest calorie bar.

Eating a high calorie high fat diet can be healthy. Please talk with me in clinic if you need other ideas on ways to increase your caloric intake.

Christina Korth RD, LD

Carmel Corn

One of my family favorites, as well as easy!

2 sticks butter or margarine, melted
½ cup dark Karo syrup
2 cups packed brown sugar

Mix above ingredients in a medium saucepan and stir in ½ tsp salt. Bring to boil, turn down heat and boil for 5 minutes without stirring. Take off heat, add 1 tsp vanilla and ½ tsp baking soda.
In a brown paper bag, add two batches of popcorn (regular popcorn from a popper). Stir above mixture into bag with popcorn and stir well to coat. (Can add peanuts) Place bag in microwave and microwave for one minute. Take out bag and shake well. Return to microwave for another minute, then shake bag again and return to microwave for one additional minute and shake well. Open bag and spread out contents to cool and set. Then place in airtight container.

Chocolate Chip Dip

1 stick butter or margarine
¼ tsp vanilla
2 T brown sugar
1- 8 oz package of cream cheese
¾ cup powdered sugar
¾ cup mini chocolate chips

Beat butter or margarine, cream cheese and vanilla with mixer. Add powdered sugar, brown sugar and mini chocolate chips and stir. Serve with Honey Graham Sticks or Chocolate Sticks.

Eating Strategies to Gain Weight

- **Eat frequently!** Make time for 3 large meals and 2-3 hefty snacks every day
- **Eat larger portions,** especially foods that are higher in calories: starchy vegetables, breads, pastas, rice, nuts, cheese, dried fruit, beans
- **Add lots of "extras" to food!** Don't eat anything plain. Some ideas:

  Healthy Fats: Olive and canola oil, nuts, seeds, peanut butter, avocado, DHA enriched margarines, butter

  Healthy carbs and protein: Honey, jam, dried fruit, wheat germ, dark chocolate, syrup, cheese/dairy
- **Make beverages count!** Drink shakes, whole milk, juices, smoothies (**instead of** water, coffee, tea and diet sodas)
- **Use large plates/bowls and utensils,** such as spoons and forks, when you are eating at home
- **Snack** while watching TV or working on the computer, especially if it is at least a couple hours before a meal
- **Monitor your weight** about every 2 weeks, and keep track on a calendar

Kecia's Korner

Travel Tips

So you want to see the world… or Disneyworld. Traveling, whether for vacation or business, can be fun, but people with cystic fibrosis need to take a few extra precautions. First, you need to make sure that you are healthy enough to travel – this is especially important if you are planning to travel by air and have significantly reduced pulmonary function. You should discuss your plans with your doctor to make sure there are no exceptional concerns.

If you will be staying in a hotel, make sure that you book a non-smoking room. If you have medications that need to be refrigerated, find out in advance if your room has a refrigerator to keep meds in. You can use a cooler and ice, but that's not ideal.

Take a list of all the medications that you use regularly, as well as those that you use on occasion. Make certain that you have an adequate supply of medicines and medical supplies, both for your trip and until you can obtain refills when you return. (Don't forget prn meds – your inhaler won't do you much good sitting in your cupboard at home if you need it!).

If you will be traveling by air, the FAA requires that all medications be "properly labeled (professionally printed label identifying the medication or a manufacturer's name or pharmaceutical label)." Some people recommend having a letter from your doctor listing your diagnosis and medications; you may or may not need such a letter if you are traveling to another country. It is advisable to put all medications in a zip-lock plastic bag to make inspection easier. Given that medications and supplies can add up, it is important to know that "The limit of one carry-on bag and one personal item (e.g. purse or briefcase) for each traveler does not apply to passengers with disabilities; medical supplies, equipment, mobility aids, or assistive devices." However, you will need to identify yourself as having a disability to qualify for this, and you should check with your airline in advance to ensure that it cooperates with ADA guidelines regarding this. Additionally, when packing your meds, make sure you have a separate and ample supply in a carry-on other than what is packed away. If you have layovers, cancellations or something happens to your bags which contain your main supply, you'll need an emergency supply until you and your bags are reunited. Remember once your bags go through security and your bags are checked, you won't see them until you get off the plane.

Security is something else to think about. When going through security, give yourself and extra 20-30 more than anyone else would. Here are some important tips from the FAA:

- Notify the screener that you have a medical condition and are carrying your supplies with you.
- Make sure insulin (vials or outer box of individual doses), jet injectors, pens, infusers, and preloaded syringes are marked properly (professionally printed label identifying the medication or manufacturer's name or pharmaceutical label).
- There is no limitation on the number of empty syringes that you will be allowed to carry through the security checkpoint; however you must have insulin with you in order to carry empty syringes through the checkpoint.
- Lancets, blood glucose meters, blood glucose test strips can be carried through the security checkpoint.
- Notify screeners if you're wearing an insulin pump and ask if they will visually inspect the pump since it cannot be removed from your person.
- Insulin pumps and supplies must be accompanied by insulin with professionally printed labels described above.
- You can ask for your items to be visually screened, but nebulizers and other medical devices may be tested for chemical residues and X-rayed.
- Make sure that you are prepared to keep medications refrigerated if necessary (e.g., Tobi, Pulmozyme, insulin). Pack a quick freeze pack to keep refrigerated medicines cold and use an insulated container. If you will be traveling without access to refrigeration, you might consider buying a portable 12 volt refrigerator. Several models are available for $50.00 or so that can be plugged into the 12 volt electrical outlet in your automobile, and some have adaptors that will allow it to be plugged into a standard 120 volt outlet. If you are traveling to Europe, remember that you will need a step-down transformer (not just an adaptor) or you will overload the appliance (unfortunately, we know this from experience). We took a refrigerator with us as a carry on last summer, and plugged it into standard outlets in the airports in between flights.

Travel can often leave a lot of sedentary "down time," so make sure that you find some ways to be active and build some exercise into your trip. Just as importantly, many of us try to pack too much into our vacations. Rest and relaxation are especially important; you don't want to come home exhausted because you overdid it. Oh yeah… and have fun!

Christopher Calhoun and David Entwistle

STOP the Spread of GERMS

Germs are everywhere in our environment. People with cystic fibrosis must be extra careful to prevent the getting germs from others in order to keep healthy lungs & prevent infections. Germs can be spread in many ways including direct contact (handshaking, kissing, sharing a drink, etc) or through the air by coughing, sneezing or nose blowing.

It is important for you to help your child be aware of ways to keep healthy, by stopping the spread of germs. Good handwashing (or using gel sanitizer), cleaning nebulizers and not sharing personal items with other people who have CF or people who are known to be ill. CF patients should remember to keep at least 3 feet or arms length distance from other people with CF. When your child is hospitalized, they should wear a mask at all times when they are out of their room, and be careful not to share things with other CF patients, even game pieces or even a bag of popcorn!! Some germs can live on surfaces like countertops for up to a few days.

This is a very difficult thing to do sometimes, particularly for our teen patients, but the floor staff and CF center staff will help make accommodations so that the hospital stay can be SAFE and fun.

Looking for New Drugs....A New Collaborative Study at MU

"Orphan Drug and Animal Model Development for Cystic Fibrosis" is a collaborative basic science research project lead by Dr. Lane Clarke, DVM/PhD. Dr. Clarke and investigators T.C. Hwang, MD/PhD, and Xiaoqin Zou, PhD, at the University of Missouri along with Lara Gawenis, PhD at the University of Utah, are working on this study first initiated with a two year start-up grant from the Cystic Fibrosis Foundation. The description below is extracted from the Missouri Life Science Trust Fund Research Grant Application they submitted to support the next stage of this research for new drugs for cystic fibrosis.

This project will involve a team of interdisciplinary scientists from MU and the University of Utah in a drug discovery effort for treatment of the underlying defect in the human disease cystic fibrosis (CF). Although CF is a major genetic disease, the patient population is relatively small (25-35,000 patients) so large drug companies do not find it profitable to engage in research and development for this disease. Specific drugs used in treating CF are considered "orphan drugs" because it is very unlikely that they will eventually be used on large patient populations.

In 2006, the Cystic Fibrosis Foundation provided funding to form teams of researchers to search for potential drugs and the MU team was selected. However, the trust fund of the CF Foundation has been devalued by current economic conditions and will not be able to continue to support this important effort after December 2009. In the first two years of development, the team has become operational through the development of assays and through the coordination of different laboratories. If the next three-years of research are funded, the team will not only engage a fully operational program in the search for CF drugs, but also, the search process that is developed can be utilized to search for other orphan drugs to treat diseases with small patient populations. Thus, there is both the potential to find a cure for CF, as well as, develop an orphan drug search paradigm to benefit other diseases.

CF is a major genetic disease that affects the lungs, pancreas, liver and intestine resulting in organ failure and a severely shortened life span. The major mutation in the CF gene (ΔF508) allows the protein to be synthesized in affected organs but destroys the protein before it can become functional. Remarkably, it has been discovered that ΔF508 can be rescued from destruction by certain compounds that were discovered by high-throughput screening (supported by the CF Foundation). However, these compounds were identified under very non-physiological conditions.

The purpose of the MU team and this project is to take the potential drugs from high-throughput screening and determine whether the drugs affect ΔF508 selectively and have desirable pharmaceutical properties. The first step involves one laboratory (Dr. Zou's) that has created software that will search large databases for similar compounds which can be tested. The second step involves a laboratory (Dr. Hwang's) that determines whether the drug is specifically acting on ΔF508. The third step involves a laboratory (Dr. Clarke's) that determines whether the drug is nontoxic and works in a mouse model of CF. In addition, our collaborator at the University of Utah (Dr. Gawenis) will make new mouse models where the human ΔF508 has been inserted and the normal mouse gene is deleted, which will be better models for CF drug testing.

Early success with some compounds suggest that a drug can be found and it is anticipated that the recognition that results from such a discovery will provide a strong impetus for formalizing future orphan drug searches.

Lane Clarke, DVM/PhD

Xiaoqin Zou, PhD
Assistant Professor, Physics & Biochemistry Depts

Lane Clarke, DVM/PhD
Professor, Biomedical Sciences Dept

T.C. Hwang, MD/PhD
Professor, Medical Pharmacology & Physiology Dept
Photo taken during sabbatical leave in Taiwan

Drs. Clarke, Hwang, and Zou are part of the Cardiovascular Research Center. For more information see the Center website: ***http://dalton.missouri.edu/****. The Center, known as "Dalton", "seeks understanding and information about some of the most prevalent health issues of the day - hypertension; heart disease; adult-onset (Type II) diabetes; obesity; muscular dystrophy; cystic fibrosis; and breast, uterine and prostate cancer. Teams of investigators from medicine, engineering, biomedical sciences, veterinary medicine, physiology and other disciplines work together to find answers to questions that will directly affect the understanding of disease prevention and treatment."*

Using the Lab to Understand What's Going on in the Lungs in CF and Test New Ideas as to What to do About it …

Part I: Exhaled Breath

With the advancement of technology new methods for assessing disease have surfaced. Now-a-days there is equipment capable of detecting and measure very small concentrations of substances in fluids and it is this type of equipment that is starting to be utilized to analyze breath. Yes, breath, the very air we breathe out. Dogs have had it right for long time to the point that currently some researchers are utilizing the very sensitive noses of dogs to detect cancer just by the smell it produces. Well, hopefully with time and the development of new technologies we will be able to surpass that canine ability and be capable of detecting changes in health much earlier than we are able to today. Just imagine having a whole medical evaluation by breathing out into a machine!

Dr. Guajardo testing an early prototype exhaled breath condensate (EBC) collecting device.

Currently at the University of Missouri we are working with the now available, very sensitive technologies to analyze exhaled breath condensate (EBC). EBC is obtained by having patients breathe through a mouth piece into a condenser for 10-20 minutes which results in the collection of one to two milliliters of liquid (~ 1/15th of an ounce). The breath goes into a cold chamber and condenses into a liquid that accumulates in the sample holder. The sample is then frozen and taken to the biochemistry labs where state-of-the-art analyzers will check for different substances in the fluid. Studies conducted so far are starting to shed some light regarding the chemical nature of EBC. It seems that infections, such as those found in cystic fibrosis (CF) lungs, make the EBC more acidic (low pH) and that inflammation itself can be detected by specific patterns of small molecules and by the concentration of specific cellular products (cytokines). At MU projects are being developed in many areas including: detection of lung cancer, assessment of asthma and CF, evaluation of chronic obstructive pulmonary disease, and others.

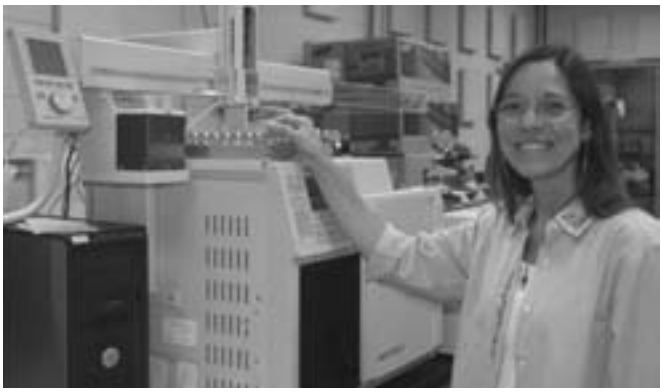
We are excited about the new CF exhaled breath research now going on at the University of Missouri. Be on the lookout, as we will be requesting volunteers for our study. Those who volunteer will have the hard or difficult job of sitting on a chair for 10 or 20 minutes while breathing through a mouth piece. Dr. Guajardo has done this multiple times with the major side effect being a severe attack of boredom. We may need to integrate games such as solitaire or sudoko to make sure none of the volunteers get hit with a boredom attack. Joke aside, we hope this study will contribute to the development of new techniques to non-invasively evaluate what's going on in the lungs!

Jesus Guajardo, MD/MHPE

Though Dr. Guajardo is now practicing medicine in Texas, he will be collaborating with Drs. Tom Mawhinney and Deborah Chance at the University of Missouri as they continue pioneering in this new area with the help of Dr. Peter König and research nurse Donna Smith.

Part II: Studying and Treating CF Pathogens "As They Live"

Everyone familiar with cystic fibrosis knows that airway infections are a major problem in this disease. Folks with CF, and those who treat CF infections, know all too well that bacterial infections are often very difficult, and sometimes impossible, to eradicate. While there are antibiotics that test very well in the laboratories on bacteria that come from CF sputum, these don't always work well within the CF airway. To tackle the question of how to help improve clearance of these infections, basic scientists such as Drs. Chance and Mawhinney have teamed up with physicians and patients to try to study CF pathogens "as they live" in the CF airway.



Deborah L. Chance, PhD
Molecular Microbiology & Immunology/Child Health Depts

At MU, some of our simple findings about the bacteria that come from CF sputum include: that they can live for long periods of time under conditions which we would not have thought possible (such as at very high pH or without fresh nutrient supplies); and that when an individual has an infection with two or more bacteria at the same time

(polymicrobial infection), these bacteria can "co-colonize" a space and appear to look as if they are happily living together in a mixed bacterial community. Laboratory observations suggest that bacteria can physically change themselves in order to adapt to environmental conditions. In addition to the physiological conditions that the CF airway provides related to the CF airway cell problems of CF, these conditions may include long term exposure to drugs and to other organisms.

Current studies in our laboratories are focused on understanding how bacteria such as *Pseudomonas aeruginosa* and *Staphylococcus aureus* adapt to survive in their environment. Specifically, we are looking at the way the bacteria adapt their metabolism and their cell membranes in both CF and CF-like growth conditions. With the state-of-the-art instrumentation and technologies which we are now using to look at small molecules in the exhaled breath of people (as EBC), as described above by Dr. Guajardo, new research has also begun to determine what molecules the bacteria place into their airspace that may describe how they are living (under stress, under low oxygen conditions, in biofilms, *etc*). These same compounds in the body may be affecting nearby human cells or bacteria. Through the development of new, sensitive techniques using tools like a gas chromatograph-mass spectrometer, an ion chromatograph, and a liquid chromatograph-high resolution mass spectrometer, we will search for such biomarkers that can be detected in the vapors above the bacteria. Once identified, these signature molecules may also be detectible in the human breath (EBC). As a result, these data may give us a clearer indicator of infection, and potentially yield more information on how, in the patient, the bacteria are thriving (*i.e.* growing rapidly under good oxygenation and nutrient conditions), or surviving (*i.e* simply maintaining viability or growing slowly in biofilms or under anaerobic conditions). Ultimately, achievement of this goal would help enable physicians to choose drugs which best attack the bacteria "as they grow".

In addition to chemical signatures of metabolism and adaptation in the airspace above the bacteria, our laboratories are also investigating changes that occur in the chemistry of bacterial membranes. Such changes in the membrane of *Pseudomonas aeruginosa* (PA), for example, may alter the effectiveness of drugs against it and/or enable it survive with other bacteria. Currently we are focusing on one particular type of molecule found within the Pseudomonas membrane, that is "lipid A". Lipid A is a complex molecule of different fats and sugars that is part of a larger structure found in most types of gram negative bacteria called lipopolysaccharide (commonly referred to as LPS). Lipid A serves to hold the LPS in the bacterial cell membrane. Lipid A is an important bacterial molecule for the human to detect, as it triggers a number of immunological responses to rid the body of the microorganisms. PA in CF appears to be able to alter its lipid A composition, possibly helping it persist in the CF airway. Dr. Mawhinney is currently chemically synthesizing different versions of lipid A. These rare "laboratory standards" will then be used to help in our studies of what the lipid A of CF PA looks like directly from the patient. Additionally,

Thomas P. Mawhinney, PhD
Biochemistry & Child Health Depts

possessing these standards will aid significantly in our investigations on *Pseudomonas aeruginosa* and how lipid A may be altered in its composition in the laboratory when challenged with different growth conditions, such as with limited oxygen supply; in co-colonization studies (*i.e.* while living in mixed species communities); and when exposed to subinhibitory levels of antibiotics. PA has been observed to alter its "phenotype" (how it looks) under different growth conditions, and in ongoing studies we will see whether some of that "look" may reflect changes in the membrane composition and its ability to survive the new environmental conditions.

The newest important CF project in our laboratories, lead by Dr. Chance, is the screening of essential oils (the oily steam-volatile extracts from plants) for antimicrobial activity against CF pathogens. Many of them you may know of as being used in "aromatherapy". Extracts of plants have long been known to provide a variety of health benefits, and so the possibility that some of the volatile components of some essential oils might be useful as inhaled antimicrobials, or in combination with other antibiotics in CF, is under investigation. While this project is still very young, we have found several oils which may be potentially useful. These, and the individual chemicals within the oils, will be studied in more detail when the initial screening of the large collection of oils is complete.

So stay tuned folks. There is a lot of good CF research going on at MU. Thank you to all of you who volunteer for studies, who contribute samples, and who support and encourage CF research. Whether your support is through local, state, and national means, you do make a significant difference. Great strides have been, and continue to be made, by basic science research along-side clinical studies around the world to improve our understanding and treatment of cystic fibrosis.

Deborah Chance, PhD and Thomas Mawhinney, PhD

Sharing Spot

Cystic Fibrosis Lifestyle Foundation- Promoting Healthy Lifestyles

Physical exersize and activity is healthy for everyone, particularly for people living with cystic fibrosis. Evidence suggests that people with CF who participate in aerobic & strength training can improve lung function and overall strength.

CFLF assists in providing avenues toward healthy and active lifestyles through recreation, thereby educating adolescents and young adults with cystic fibrosis on the critical psychological, social and emotional connections between their lifestyle and their health. They provide $500 recreational grants to help people with CF pursue their goals of leading a physically active lifestyle. They provide "recreation" grants directly to the agency, not the patient. Whether you enjoy swimming, kickboxing, hiking or biking, CFLF wants to help you reach your goals. For more information or to download an application, go to their website **www.cflf.org**

2009 Scholarship Winner

Cystic Fibrosis of Missouri, West Plains Chapter is proud to announce this year's winner of the 2009 Dr. Giulio Barbero Memorial Scholarship. This year we have one renewal cystic fibrosis patient 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. König's office for assisting us with this process. We are so very grateful to our special donors this year, Mrs. Marj Barbero and Mrs. Lea König.

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 her fifth year at the St. Louis College of Pharmacy, St. Louis, Missouri.

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 states "I have been blessed with good health for the past few years, for which I am very grateful as my classes at STLCOP have become progressively more challenging... I am excited to say that the end is in sight at this point."

Backes is awarded a $1,000 scholarship to be used at the college of her choice. She is a wonderful example to all of us. She set her goals high and has worked very hard to reach them. We look forward to her graduating in May, 2010 from St. Louis College of Pharmacy and also look forward to her career as a pharmacist. Just think, some day she may be passing out the medication that cures cystic fibrosis!

Dr. Barbero would be so very proud Sophie Backes. 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 Backes and her family, you know Dr. B. must have be right.

If you would like to be a scholarship winner for the school year 2010-2011, please contact Tony in Dr. König's office and he will be glad to send you an application. The scholarship committee would like to encourage all cystic fibrosis patients, parents and siblings to please apply for these scholarships. Even though it is not a lot of money, it is very helpful and the scholarship is renewable each year. Deadline is March 1, 2010.

Lois Frazier

CF-Related Scholarship Opportunities 2010

Giulio Barbero Memorial Scholarship
2010-2011 deadline March1, 2010. For an application as a CF patient or family member, call CF Center in Columbia MO, 573-882-6978.

Cystic Fibrosis Scholarship Foundation
2010-2011 deadline March 21, 2010. www.cfscholarship.org

Boomer Esiason Foundation CF Ambassador Scholarship
Awarded quarterly. www.cfambassador.com

Elizabeth Nash Foundation Scholarship Program
2010-2011 postmark deadline April 5th, 2010. www.elizabethnashfoundation.org

SolvayCARES Scholarship
Applications will be posted late January. www.solvaycares.com

Jessica's Story

This link will get you to a short video of Jessica Joyce's story, as she and her Mom were interviewed by the transplant folks at Children's Hospital in St. Louis. As one friend affected by CF wrote "Jessica's story is great and definitely one that gives hope to so many of us!".
http://www.youtube.com/watch?v=QqNC5-roSRM

Health Benefits of Owning a Dog

As we all know, diet and exercise are important ways to keep our bodies healthy. But there's one more thing that helps you stay healthy….owning a pet. Most people consider getting a pet and think they are too much work. That's true. But, the positive aspects of owning a pet far outweigh the negative ones. Owning a pet can lower blood pressure, increase immunity, and keep you from becoming depressed. Studies have shown that pet owners have an increased life span versus people who do not own pets.

Perhaps one of the greatest benefits of owning a dog is that they demand exercise. Taking your dog for a walk means that you are walking too. Exercise is so important to staying healthy and your dog will not allow you to miss a day of exercise. Having other animals that do not require exercise are still beneficial. Developing a relationship with a pet provides people with a reason for enjoying life and connecting with others.

If you have CF or have had a transplant, there are special considerations to think about when owning a pet.

- Make sure your pets eat high quality food and drink only clean water. Keeping your pet healthy can help you stay healthy.
- Never allow your pet to kiss you on the face.

- You should not permit your pet to sleep with you.
- Cats are ok, but someone else in the household should be responsible for changing the kitty litter as there is a risk for toxoplasmosis.
- Birds can carry parasites so it is not recommended to clean the birdcage or handle the bird.
- Wash your hands after petting or playing with your pet, especially before eating.
- Develop a close relationship with your veterinarian and make sure your pet is current on all vaccinations.

My home is taken over by two dogs and a cat. They run my home and they provide me with much joy. When I am sad, they cheer me up. When I am lonely, they give me company. When I am sick, they lay with me. When I am excited, they are excited with me. They are always happy to see me. They keep me happy and healthy.

All of my pets are rescue animals and I encourage you to visit your local animal shelter to rescue a dog or cat that needs a good home. Often adult pets are a better choice for immunocompromised persons as puppies and kittens are at an increased risk for shedding bacteria in their feces. They will be forever grateful to you and provide you with many years of love and laughter.

Jill Roberts, (Jenks, OK)

CF Events 2009

Spring CFAM Meeting 2009: Learning to Breathe Away Stress

The Spring CFAM meeting was held in West Plains, MO, on March 21, 2009. Billie Hutchings, a local West Plains Therapist, was the guest speaker. She went over a packet of information about how stress affects the body and how to reduce stress levels. Illustrations involved getting the group to actively participate in some deep breathing exercises and breathing through straws, which at least got the group laughing and cajoling, whether or not any stress was lifted!

2009 CFAM Officers, front row: Sally Hicks (left), Secretary; Jennifer Wharton (right), Treasurer; back row: Mary Backes (left), Vice President; Mary McCutcheon (right), President. (not pictured: Mike Pratt, Historian)

The regular business portion of the meeting included discussing the Music Show, Bass Tournament, and the election of officers. Mary McCutcheon and Sophie Backes, who were both scholarship winners in 2008, updated everyone on their progress. Tim Stanfill spoke about the generous donation of a handmade angel for our auction,

made and donated by a man who lost loved ones to CF, also in memory of Chris Douglas.

After the meeting concluded, we all had a good time drawing for door prizes. Everyone got something to take home. Joe Diffey came in to sign autographs and pose for pictures, and get us psyched up for the show, and the firemen and stage hands who help out with the Music Show came in to relieve us of some of the abundance of leftover food. Yes, I couldn't write this without mentioning the food . . .

And for those of you who didn't make the meeting or left early, you missed an excellent presentation by Tom and Deborah about research with essential oils, which seems to have the possibility of opening all kinds of new doors to treatments in the future. Thanks to our researchers and all our members who support the effort by attending our meetings!

Sally Hicks, Secretary CFAM

21st Annual Cystic Fibrosis Music Show

For 21 years a group of local and loyal friends, Brenda Land, Julia Sheldon, Joe & Gayla Auffert, K-Kountry 95 Radio Station, Jess & Patsy Atkinson, Brenda Guilliams, Linda Cates, Libby Grisham, Sara Manville, Crystal Cantrell, Stacy Auffert and others band together, dedicated to work hard to find a cure for cystic fibrosis. They are still working as hard today as they did in the beginning. We appreciate your love and support.

Once again our many sponsors answered the call, to make donations to help our effects. This year was great because of you. We appreciate your support especially through these tough times of our economy. Bob Eckman and Lynn Hobbs and K-Kountry 95, Harlen Hutchinson and The Ozark Radio Network, Ed Martin and KHOM, Carol Bruce and the West Plains Daily Quill, Sunie Pace and the Horse Trader all did an out standing job promoting our Show. Steve Stewart and Vicki Smith at ColorTech Printing did a wonderful job on our posters, tickets and programs. Thank you Myles Smith for doing a fabulous job at being our MC. Thank you to all the businesses and individuals that took their time and effort to sell our tickets, what a wonderful job you did.

We appreciate Becky Lott and the West Plains Elementary School for helping with our practices each Sunday. The Front Show has been made up of Jessica's Friends since the beginning. Thank you for caring enough to be willing to put in the extra effort and dedication to perform. Under the direction of Diane Reed and her assistants Audrey Ann and Julie Ann Reed, the children and teenagers did an unbelievable job. The crowd loved those cowboy hats and each one of you did a great job entertaining them.

We feel very fortunate to have a place like the Civic Center to have our Music Show each year. Carl Johnson and all of the staff are so helpful and easy to work with. Thank you for always going the extra mile for us.

The Howell County Rural Fire Department volunteers do so much more than fight fire. They are always there when they are needed, willing to volunteer to help out no matter what the task is. Thank you so very much.

At a time of great loss of their loved ones, many families continued to remember cystic fibrosis victims. Thank you for your unselfish love and conviction in helping us find a cure.

Billy Sexton, Brenda Guilliams, Bo Pace, Robbie Crites, Russ Gant, Bill Cates, Glen Johnson, and Mark Collins did a wonderful job with our auction. Also, Linda Cates, Carol Johnson, Diane Adams, Libby Grisham, Kelly McGinnis and the CF families did an awesome job running the silent auction. Thank you for donating and purchasing our items. Cheryl Thompson by selling tickets on the bicycle and Julie Miller by helping sell roses added something very special to the evening's events. These four extra events raise a lot of money each year.

To each and every one of you that purchased tickets, thank you for making this a huge success. We appreciate

you all standing in line to get in and waiting for the Show to get started. There is no greater joy to everyone that works so hard on the Show to look up and see so many of our old and new friends there supporting our efforts. Many of you come every year and this may be the only concert you will attend. Many are friends of our families and some have become our friends through this effort. Thank you for coming and showing your support.

Thank each and every one of you for the part you played in our 21st Annual Music Show. Because of your love, we raised $33,500 in an effort to find a cure for cystic fibrosis. With your help, this gives victims and their families hope.

Our family feels that God has blessed us very richly by surrounding us with such loving and caring people from all walks of life. You took us into your hearts and for all these years, never gave up on us and our dream of finding a cure

Silent auction volunteers

for cystic fibrosis in Jessica's lifetime. THANK YOU!

If you were unable to attend this year's event, please mark your calendar for March 20, 2010 for the 22nd Annual Cystic Fibrosis Music Show. It is sure to be a weekend packed full of fun.

Cystic Fibrosis Association of West Plains
Victims & Families of Cystic Fibrosis
Rick & Lois Frazier and Jessica

24th Annual Buddy Bass Tournament Another Success Story

What a wonderful day it was on Saturday, April 25, 2009. Even though the Tournament did not start until Saturday morning, the fun began on Friday night with the celebration of getting to see all of the cystic fibrosis families and friends and getting another chance to eat at Fred's Fish House in Mtn. Home, Arkansas.

We all gather in the atrium waiting for assignment for the upcoming day's events. Some chose to get to bed early, while others hung around to see who could stay up the latest. Paul Shasserre is giving Ruth Ellison and Lois Frazier a run of their money these days in this area.

The weather was a little windy, but the temperature was wonderful. It had been a long time since everyone was not freezing that morning. We had 295 boats in the tournament. With 154 of them returning to weigh in fish. There was a total of 601 fish weighed in with a total weight of 1,314 lbs.

First place winners were Kyle Pressley and Justin Yarbrough, Harrison, Arkansas with 15.50 lbs. They won a 17' Bass Cat Phelix Boat and Trailer and a Mercy Motor

donated by Bass Cat Boasts of Mountain Home, Arkansas and $2,000.

Second place winners were Fred Hale and Waco Johnson, both of West Plains, Missouri with 15.15 lbs. They won $1,000.

Big Bass winner was Danny Holmes and Jared Hambelton, Gainesville, Missouri weighing in a 5.44 largemouth bass. They won $1,085.

Many people like Dan & Rhonda Singletary, Bo Pace, Jason Willard, Waco Johnson, Robert Burtrum and Fred Hale work several months to pull this event off each year. We also appreciate our partnership and friendship with Rick Pierce and Bass Cat Boats. Each year their donation of a Bass Cat Boat and Trailer with a Mercy Motor helps to make our Tournament what it is today.

We would also like to think Falcon Rod and Ardent Reel for the donation of a rod and reel for us to auction off. Thank you also to everyone that helped out by selling the raffle tickets for us. We raised $1,509

on the raffle. Rick Callahan was the winner this year of the rod and reel.

We would also like to thank Ozark Awards, West Plains for their donation of our trophies again this year.

We would also like to thank everyone that worked at the Cook Shack. Marvin Ball and Jim Conner did an excellent job cooking the burgers while Irene Frazier, Marie Hensley, Sally Hicks and Naomi did a great selling them. They sold them faster than they could cook them this year. While Duane Hensley and Jessica Joice were busy selling them something to drink and adding a raffle ticket on the side.

Others helping at the weigh in was Larry Carney and Debbie Shasserre on the dock with Austin Ball, Kyle Armor, Paul Shasserre, Otis & Ricky Hostettler all at the fish tanks with Jennifer Wharton, Brenda Guilliams, Mary Kay Ball, Maizy Hicks, Deborah Chance and Rhonda Singletary helping out. Jason Willard and Robert Burtrum weighing the fish in and Roy Hicks, Jim Bax, Jess Atkinson, Jake Shasserre, and Bill Manville carrying the fish. If you don't think fish are heavy, just ask one of them after carrying 154 baskets of fish. We are very grateful to the ladies in the van, Diane Carney, Jeannie Bax, Ruth Ellison, and Sandy Connor. They are the ones that have to keep all the figures straight for us and the fishermen.

Hope you enjoy all the wonderful pictures that Tom Mawhinney and Maizy Hicks took. They really got some great shots, (for more photos, see website www.hope4cf.com).

Before sunrise and after the sunset, people were busy talking, laughing, and having fun while they worked hard in an effort to take another step into trying to find a cure for cystic fibrosis. They did an excellent job at it too. We raised $14,200 this year adding to our total raise in the 24 years to $275,000. Thank you to each and every one of you that took a part in making this happen. We all have to do what we can no matter how little or big that part is. Together we can find a cure.

If you are reading this article and wish you could do something like this, please come and join in on the fun in 2010. New people are always welcome and remember each of us were new at one time or another. Before you know

it, you will be like Roy, Sally and Maizy Hicks. They just realized this year that they have been coming for five years now and had to give up the new comer award. Trust me, this is a wonderful time and God has always blessed our efforts and kept us safe.

Lois Frazier

CF Walk '09

On May 2, 2009, CF families and friends came together for the 4th Annual Columbia Great Strides Walk. The walk, coordinated by a local steering committee in conjunction with the Gateway Chapter of the Cystic Fibrosis Foundation, raises money to support research and other functions of the Cystic Fibrosis Foundation. This year's walk featured a barbecue, raffles, educational booths and entertainment by the Boone High Steppers.

The beautiful weather and great location at Stephens Lake Park brought out approximately 250 walkers and raised over $25,000 for the foundation. We also welcomed 7 new walk teams. Combined with returning teams, there were 25 walk teams participating.

The Great Strides Walk is a great way to meet other families impacted by Cystic Fibrosis and to help support the fund-raising efforts of the foundation.

CFAM Summer meeting 2009

The summer meeting of CFAM was held June 27, 2009 in Springfield, MO at the Doling Park and Family Center, and was hosted by Mary McCutcheon. We had about 16 people in attendance for some good discussions and good time to share in the events of each other lives.

Rick Frazier gave updates on the 2009 Music Show with Joe Diffie & the Fishing Tournament. Dr. Jesus Guajardo talked about the new breath research study with the research lab. Dr. Tom Mawhinney and Dr. Deborah Chance gave slide presentation updates on their research studying the chemistry of Pseudomonas and on essential oils as possible antimicrobial agents for CF bacteria. Tammy Wilson sent posters and information on the Fast Lanes Motorcycle Rally to be held on July 18th in Chillicothe, MO. (See article to follow). We were reminded that the CF Awareness Day in Columbia was set for November 14, 2009.

Thanks to all who came and shared. Looking forward to seeing our CF friends again in West Plains at the Spring 2010 meeting.

Mary McCutcheon, President CFAM

Motorcycle Rally for CF

A Fast Lanes Motorcycle Rally for CF was held in Chillicothe, MO on July 18, 2009. The event was hosted by Tammy Wilson & family along with Fast Lanes Fun Family Entertainment Center, Chillicothe. There were 27 bikes with 32 riders. They rode about 90 miles round trip. We sold

raffle tickets, 50/50 tickets, and t-shirts. There were vendors set up for different biking apparel and such. You could even go indoors to bowl a few games if you wanted to get out of the heat. There were a few bands, one which was an all-teen group, along with a DJ. "Angels in Waiting" performer Tammy Cochran who sang for an hour. The rally was a new

and fun experience. I met three CF families during the day and a bunch of soft hearted, generous bikers too.

Mary McCutcheon

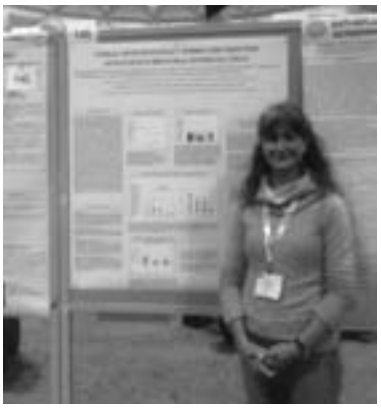
Highlights from the North American CF Conference 2009

Downtown Minneapolis

Sponsored by the Cystic Fibrosis Foundation, the Annual North American Cystic Fibrosis Conference (NACFC) was once again a bit hit in October '09. The Conference was held in Minneapolis, MN and had a great turnout (~ 3500 people) even with the economic difficulties and the flu scares. It's amazing to see how people from all over the world are working so hard in the CF field as caregivers, researchers and volunteers. What a great chance to share what has been learned at the conference.

Ashley Gage and Kecia Nelson

Attending from our University of Missouri Health Care and CF Center were Dr. König, Dr. Ner, Connie Fenton, Kecia Nelson, Christina Korth, Jennifer Andert , and Ashley Gage. Ashley Gage, MSW, and former CF social work intern, presented a case study in motivational interviewing & problem solving for a lively panel discussion with other CF social workers. Researchers from MU included Lane Clarke, DVM/PhD from the Dalton Cardiovascular Research Center, and Deborah Chance, PhD from the School of Medicine.



NACFC - not just for North Americans. Poster session photo of new acquaintance from Italy, studying similar types of compounds as we are at MU.

Among the highlights of the Conference were plenary session presentations on hopeful new treatments that are already in the drug development pipelines of clinical trials. These include inhaled antibiotics, and compounds that may ultimately help the body with certain CFTR mutations to get a larger quantity of functional CFTR protein to the cell surface to do its job.

On the basic science side, as each year, so very many labs are contributing small pieces toward the still puzzling parts of this CF story. The CF pig model is now a reality.

Yes scientists and physicians now have pigs with "CF", that is with mutant CFTR genes and showing the gastrointestinal and pulmonary difficulties of very severe CF. Though early on in the research, already the animals are showing investigators much about how "CF pathology" occurs at the cellular and organ level. While a lot of work for the physicians and scientists caring for the pigs, the CF pig model represents a major advance in the ability to study CF and progress keenly focused toward the development of new therapeutic strategies and agents.

The future is looking so bright for making CF an even better managed disease than it is now. Speaking at one of the plenary sessions was Dr. Francis Collins, who is now the Director of the NIH. Dr. Collins shared much enthusiasm about the progress that has already been made in CF, and spoke about how the CF world - its patients, care teams, researchers, volunteers, drug development network, corporate collaborations, international cooperation, etc.- is so far advanced and is pointing the way for others to be successful in battling other diseases, with so many benefitting from the CF groundwork and role model.

More information on the conference including videos of the 3 plenary sessions and Dr. Collins' now famous musical performance "Dare to Dream", can be found at the CFF website link http://www.cff.org/research/NACFC/. Happy viewing.

Deborah L. Chance, PhD

Cystic Fibrosis Awareness Day 2009

What an educational day we had in Columbia, MO November 14th at the Garden Hilton Convention Center. Special thanks to all of our excellent speakers and representatives from CF drug, vest, and specialty treatment companies, and for all the behind the scenes efforts of Connie Fenton, Kecia Nelson, and the rest of the CF Team, and for the support of many funding sources.

We had two great nationally known speakers, Dr. James Yankaskas, Co-Director of the Adult Cystic Fibrosis Center of the University of North Carolina-Chapel Hill and Kathy Sabadosa, MPH of Dartmouth-Hitchcock Medical Center on behalf of Clinical Affairs at the Cystic Fibrosis Foundation. Among other things, they shared with us about the great progress in CF care across the country and how the CF Foundation and CF care have developed over the years to include a large care center network, the very valuable CF registry tool, and the CF Therapeutics Development Network (TDN). The CF Foundation is now pioneering a very successful quality improvement initiative. For more information see website with seven worthy goals for CF care quality improvement: http://www.cff.org/LivingWithCF/QualityImprovement/.

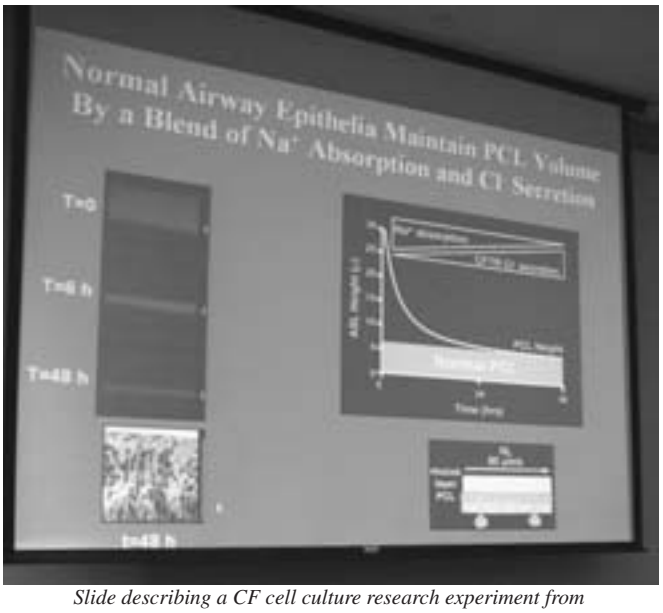
Along with Dr. König, our CF Center Director, we heard from Michelle Kemp from the Parent's Advisory Committee and Lois Frazier from of the Cystic Fibrosis Association of Missouri. Local speakers in their areas of expertise included respiratory therapist Natalie Harris, pediatric endocrinology nurse specialist in diabetes Janeth Todd, dietician Christina Korth, social worker Kecia Nelson, and researcher Deborah Chance.

Dr. Peter König

Connie Fenton

Kathy Sabadosa

Dr. James Yankaskas



Slide describing a CF cell culture research experiment from one of Dr. Yankaskas' talks.

Michelle Kemp

Lois Frazier

Christina Korth

Janeth Todd

Natalie Harris

"The Scoop": the lead into Christina's presentation.

Kecia Nelson

Deborah Chance

Thank you all you could make the trip to Columbia. We know it is a long distance for many of you. For those of you who were unable to come, we are hoping to develop educational materials, in one form or another, from the speakers' presentations that can be made available to patients upon request.

Please consider this as the initial view of the day, and look for an article to come from "a mother's perspective".

Deborah L. Chance, PhD

Upcoming CF Events

The Pascale's Pals 12th Annual Benefit Auction, Dinner & Dance!

This year's event will be held at the Holiday Inn Executive Center in Colulmbia, MO on Friday, March 12, 2010, starting at 5:30 p.m. For more information please view the website www.pascalespals.org. Proceeds of the event benefit our Children's Hospital patients and their families.

22nd Annual Cystic Fibrosis Music Show & 2010 Spring CFAM Meeting

With Spring just around the corner, it is time to start making plans for the annual events and happenings in the West Plains area. On Saturday, March 20th, 2010 the Spring CFAM Meeting and the 22nd Annual Cystic Fibrosis Music Show are two events we hope you will not want to miss. The day will be packed full of fun for all that attend. If you have not been to these events before, we invite you to give them a try. If you have been before, we hope you had a wonderful time and will come back again this year.

The 2010 Spring CFAM Meeting will begin with food and fellowship starting at noon at the West Plains Civic Center, West Plains, MO. Then about 1:00 p.m will start a very informal meeting with lots of information. This will be a wonderful opportunity to meet families from different parts of the state and to share with one another who know about what it's like to have or live with cystic fibrosis. Guest speakers will be Danny Hobbs, members of the Cystic Fibrosis Care Team, and Researchers from the University of Missouri, Columbia, MO. The meeting usually lasts until about 4:00 p.m.

The 22nd Annual Cystic Fibrosis Music Show's doors will open at 6:00 p.m. starting off with a silent auction. Then at about 6:45 p.m. a live auction will begin. Both auctions are packed full of donated items that everyone is sure to enjoy. If you have something you would like to donate, please bring it with you.

Next up will be the wonderful Jessica's Friends singers. This group, made up of local talent, has been performing each year and they are always a crowd pleaser. This year's group will be under the direction of Diane Reed. If you have a child that would like to be a part of Jessica's Friends, please let us know. Everyone is welcome to come and be a part.

Then when you think the evening couldn't get any better, Aaron Tippin will take the stage. He will be singing some of his all-time favorites like, "You've Got to Stand for Something", "There Ain't Nothin' Wrong With the Radio", and in wake of 9/11, his patriotic anthem "Where the Stars and Stripes and the Eagles Fly", plus many, many more. This is a Show that everyone is sure to enjoy. Ticket prices are $15 for adults and $5 for children 12 and under.

There will be an after-the-Show get together at the Best Western Hotel in West Plains. We will have rooms reserved in case you would like to spend the night. We do not have the room rate as of yet. Also, we will meet (optional of course) for breakfast the next morning before everyone leaves that stayed the night.

We are sure you have figured out by now that this weekend is packed full of fun and laughter. Please mark your calendar for Saturday, March 20, 2010. If you have any questions, please contact Rick or Lois Frazier at 417-256-5388 in the evening. Look forward to hearing from you!!

Lois Frazier

Calling All Walkers!

Come join us for our annual Great Strides walk where taking steps to cure cystic fibrosis goes a long way toward making a difference in the lives of those with CF. There are a few different sites where you can join in the fun.

Columbia, Stephens Lake Park, Saturday, May 1, 9 AM
Jefferson City, Memorial Park, Saturday, May 15, 10 AM
Kirksville, Brashear Park, Saturday, May 22, 10:30 AM
Springfield, Rutledge-Wilson Farm Community Park, Saturday, October 2, 9 AM

This will be the 6th Annual walk in Columbia and the 2nd walk for Jefferson City.

Pre-registration is not required but preferred. You can register a team online at www.cff.org or by contacting Anna Kusnierkiewicz at 1(800)727-1464 for more information. Come help us celebrate the new CF medical advances. Enjoy fun family activities. Lunch will be provided following the walk.

25th Annual Cystic Fibrosis Buddy Bass Tournament

Have you ever thought about fishing in or attending a Bass Tournament before? If not, why not?

If you always wanted to but really never had a good reason to go to one, we would like to give you a reason to attend the 25th Annual Cystic Fibrosis Buddy Bass Tournament. By being a part of this event, you are helping to save lives.

If you like to fish for bass, we have the perfect place to fish - the beautiful Lake Norfork, Henderson, Arkansas. This year's tournament will take place on Saturday, May 8th, 2010. The boat dock will be full of cystic fibrosis families and friends by 5:00 a.m. just waiting to greet you. The first flight will launch at 7:00 a.m. Dan Singletary, Bo Pace, Rick Frazier and the others that help with the tournament will make you feel right at home and will be there to answer any questions you may have before or after the tournament. You will have the opportunity to either fish in Missouri or Arkansas, or both if you choose to.

If you do not receive an entry form in the mail, you can go to hope4cf.com and print it off and mail it in or call Dan Singletary at 417-256-0055 or Rick Frazier at 417-256-5388 and they will be glad to mail you a form.

If you want your money to go for a great cause, this is it. The entry fee is $65 per boat. The first 40 places will win either money or prizes. 295 boats were in last year's tournament. These fishermen and women and friends raised $15,000 for research for cystic fibrosis. Boy, did they do an excellent job and had loads of fun doing it. At the end of the tournament last year, everyone went home a winner. You can too if you will attend this year.

If you really don't want to fish but would like to see what it is all about and help out, there is a job for everyone and if you are lucky, there may even be two or three. We are always needing help getting set up for the tournament, helping with the weigh in, carrying the beautiful fish, writing out thank you cards, cooking hamburgers and selling drinks and raffle tickets. The list of fun things to do can go on and on.

There will be a block of rooms reserved at the Lake Norfork Hotel. If you would like a room, please contact Rick or Lois Frazier at 417-256-5388 and they will reserve a room for you.

So what are you waiting for? The fun can't start until you get there, so come on and make your plans to attend the 25th Annual Cystic Fibrosis Buddy Bass Tournament on Saturday, May 8th, 2010.

Lois Frazier

Quote

"The things that make you strong, and make you feel as though you've accomplished something, are not the easy ones; it's the things you had to work and struggle through. Those are what give us our depth -- that make us not gray and plain and nothing, but give us depth and texture and longing."

-Dr. Jerri Nielsen
(she is the doctor that had cancer that was rescued from Antarctica in 1999.)

hope4cf.com Web Page

The new hope4cf.com web page is up and running. At the present time, we have had over 900 hits on the site. Which is wonderful news. We are still very busy changing and adding things. If you have not had the opportunity to look at it or if you haven't visited it in a while, we invite you to look at it again. Also, please tell your friends and family members about it.

We would love to add any information you would like to share about yourself or an event you will be hosting in your area. We can add pictures too. We will not be making any doctors appointments on this site. This is just an informational web page. If you have any ideas that you would like to see posted on this site, please let us know. You can contact us at **special_loe@yahoo.com**. In the subject line make sure you list **hope4cf.com**.

The web page is being hosted by Jaggar Technologies and designed by Crider Publishing. We would like to thank them both for all their help in making this possible for us to enjoy. We would also like to thank Sandy Morgan for taking the Music Show pictures and also Dr. Deborah Chance and Dr. Tom Mawhinney for taking the Fishing Tournament pictures. We hope you will enjoying them as much as we have.

Cystic Fibrosis Association of Missouri and Friends Upcoming Events

SPRING 2010

Giulio Barbero Memorial Scholarship	Application Deadline	March 1, 2010
CFAM Spring Meeting & Music Show	West Plains Civic Center, West Plains, MO	March 20, 2010
Great Strides CF Walk - Columbia	Stephens Lake Park Columbia, MO	May 1, 2010
CF Buddy Bass Tournament	Lake Norfork Henderson, AR	May 8, 2010
Great Strides CF Walk - Jefferson City	Memorial Park Jefferson City, MO	May 15, 2010
Great Strides CF Walk - Kirksville	Brashear Park Kirksville, MO	May 22, 2010

SUMMER 2010

CFAM Summer Meeting	location to be determined	date to be determined

FALL 2010

Great Strides CF Walk - Springfield	Rutledge-Wilson Farm Community Park Springfield, MO	October 2, 2010
CFAM Fall Meeting & Fish Fry	Cuba, MO	date to be determined (probably Oct or Nov)

For more details on scholarship application, please see the scholarships article in the section Sharing Spot.
For more details on meetings and walks, please see the section Upcoming Events.

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 at www.myfamily.com).

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

Ms. Mary McCutcheon, President CFAM, 3428 W. Sexton, Springfield, MO 65810, (417) 894-7637, **jolucmar4@gmail.com**
Mrs. Mary Backes, Vice President CFAM, 157 Country Rd. 420, Linn, MO 65051, (573) 897-3287, **m3backes@gmail.com**
Mrs. Sally Hicks, Secretary CFAM, Rt. 1 Box 450, Ava, MO 65608, (417) 683-2195, **rhicks@dishmail.net**
Mrs. Jennifer Wharton, Treasurer CFAM, 1143 Farm Rd. 48, Pleasant Hope, MO 65725, (417) 839-5034; **mojospark@aol.com**
Mr. Mike Pratt, Historian CFAM, 3602B West State, Springfield, MO 65802, (417) 862-7553, **pratts343@yahoo.com or danapratt@sbcglobal.net**
Mrs. Diane Carney, Chair CFAM Executive Board, 2684 County Rd. 4028, Holts Summit, MO 65043, (573) 896-4737, **ldcarney@embarqmail.com**

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, **ldcarney@embarqmail.com**
Mrs. Sally Hicks, Rt. 1 Box 450, Ava, MO 65608, (417) 683-2195, **rhicks@dishmail.net**
Mrs. Lois Frazier and Mr. Rick Frazier, 1619 Webster, West Plains, MO 65775, (417) 256-5388, **special_loe@yahoo.com**
Dr. Deborah Chance, Molecular Microbiology & Immunology/Child Health, M616 Medical Sciences Building, Univ. of MO, Columbia, 65212, (573) 268-8102, **chanced@health.missouri.edu**

CFAM Family Web Site

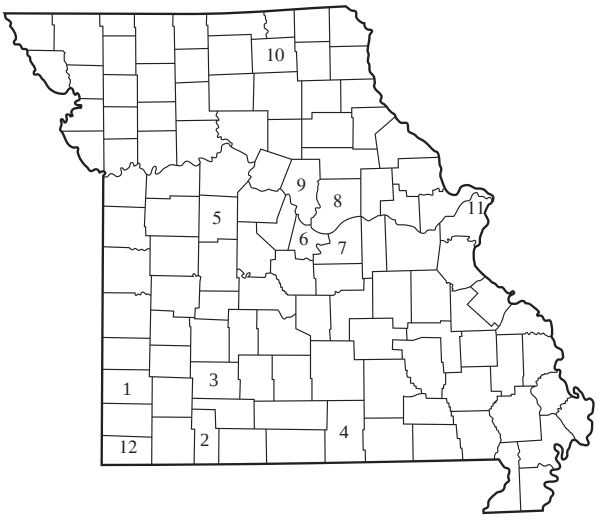
Lois Frazier, **special_loe@yahoo.com**

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.	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.	Debbie Douglas	Sedalia	660-826-8674
6.	Laura Frasher	Jefferson City	573-636-9934 *(h)*
			573-353-5865 *(c)*
	Mark & Jeannine Toomey	Jefferson City	573-893-4851
7.	Gary & Mary Backes	Linn	573-897-3287
8.	Larry & Diane Carney	Holts Summit	573-896-4737
9.	John and Julie Klein	Columbia	573-446-9650
10.	Jim & Sandy Conner	Kirksville	660-665-6603
11.	Sophie Backes	St. Louis	573-690-2446(c)
12.	Bernie & Karen Almeter	Anderson	417-845-6855



Children's Hospital
University of Missouri Health Care

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

RETURN SERVICE REQUESTED