

Cystic Fibrosis Center News

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Going Beyond "Good Enough": Are We There Yet?

By Stacy Vanden Branden, APN-CPNP

Striving to provide better CF care continues to be a major focus of the CF Center at Children's Memorial Hospital. We have completed a two year long commitment to the National Initiative for Children's Healthcare Quality (NICHQ) Collaborative for Cystic Fibrosis Centers that focused on improving nutritional health and reducing environmental tobacco smoke exposure. As we begin to phase in our newest QI project on diabetes and bone health screening (see article on page 8) it's a good time to ask "What have we learned? How did we do? Where are we headed? And are we there yet?".

What have we learned?

We've learned that we can change our practice habits (that is, how we deliver CF care), and those changes can be beneficial to those we care for. For example, we now systematically:

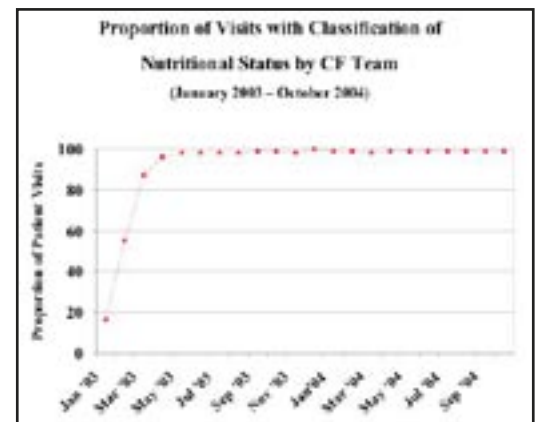


Figure A: Systematic classification of nutritional status by the team increased from <20% to 95% of visits (Jan '03-Oct '04).

- Assess nutritional status at every visit, and document it according to the CFF Nutrition Guidelines. See Figure A.
- Work with families to create a nutrition plan with set goals for every child at nutritional risk or with urgent nutritional need, and provide them with a written copy of the plan.
- Ask about household and environmental tobacco smoke exposure at every visit to identify

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Are We There Yet?

those at risk for exposure. See Figure B.

- Assist and support family members with the difficult process of tobacco cessation.

How Did Our Center Do, and Where Are We Headed?

The benefit of tracking our progress through the NICHQ project is seeing our Center patient data improve.

Each parameter shows significant improvement, which reflects the hard work and determination of the children and families within our center to carry out recommendations made by the team.

- The cumulative weight percentile of the children seen at our center has increased (see Figure C), and the number of children at nutritional risk or with urgent nutritional need has decreased.
- The number of families reporting no-smoking environments has increased (see Figure D) and about 40% of family members who smoke have quit smoking.

Are We There Yet?

Quality improvement is all about “raising the bar”, rather than completing a task.

And so it's an ongoing journey of making health and life better for individuals with CF. As new knowledge and therapies are added to the toolbox for CF care, we will adjust the bar again, and continually strive to partner with families to provide the best care possible.

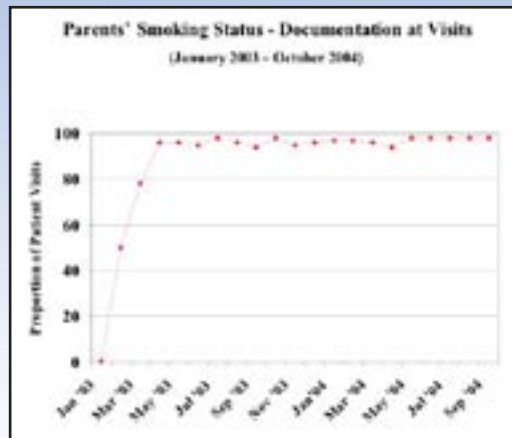


Figure B: Systematic documentation by the team of parent's smoking status increased from 0 to >95% (Jan '03-Oct'04).

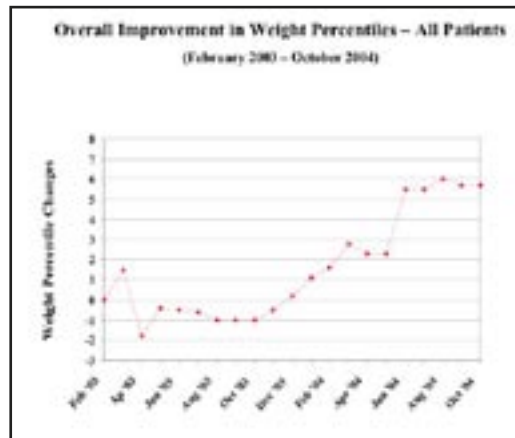


Figure C: Our Center patients' overall weight percentiles have increased since Feb '03.



Figure D: The number of families reporting a no-smoking policy at home increased to 70%.



CF Services: More Than Just A Pharmacy

The Cystic Fibrosis Services, Inc. is a wholly owned subsidiary of the Cystic Fibrosis Foundation. It was established in 1988 as a “specialty” pharmacy to help serve the specific needs of people with cystic fibrosis and continues to do so today.

CF Services provides access to medications that are CF-specific, such as nebulized medications and supplies, inhalers, pancreatic enzymes (non-generic!), diabetic medications and supplies, transplant medications, and nutritional supplements. CF Services also assists patients and families with the complicated reimbursement process. They are an advocate on the patient's behalf to get their medications covered by their insurance companies.

CF Services' highly trained staff delivers personalized service, patient education, and patient advocacy to the CF population. They consistently work with drug manufacturers to develop new Patient Assistance Programs which helps people who do not have insurance coverage obtain their medications.

If interested in registering and ordering from the CF Services pharmacy or just have a question, please call their Customer Support Department at 800-541-4959. You can also visit online at www.cfservicespharmacy.com

Cystic Fibrosis Genotyping

By Dinel Pond, MS

How is CF inherited?

Our bodies are made up of millions of cells, the “building blocks” of the body. Inside each cell are thousands of genes, which serve as the body’s instructions for our visible physical traits, such as eye color, as well as invisible traits like blood type. Genetic diseases can occur when changes (also called mutations) occur in a gene. These changes are like “typos” in the instruction. If a change occurs that causes the instruction to be unreadable, this can cause a disease.

Genes are found in pairs, meaning that there are 2 copies of every gene in the body. Everyone gets one full set of genes from each of their parents. Therefore, every person is born with 2 copies (one pair) of the cystic fibrosis (CF) gene, one which came from their father, and one which came from their mother. Both copies are normal in people who don’t have CF. The CF gene tells the body how to make a specific protein called the cystic fibrosis transmembrane conductance regulator (CFTR). The CFTR works in the cells to help sodium, chloride (salts), and water get across the cell membrane.

Cystic fibrosis (CF) is an autosomal recessive disease. This means that if an abnormal CF gene from one parent is paired with a normal CF gene from the other parent, the normal gene will make enough CFTR for the person to be healthy. In this case, the child is a CF carrier, someone who “carries” one abnormal CF gene and does not have CF. However, if an abnormal CF gene from one parent is paired with another abnormal CF gene from the other parent, the child will have CF.

How do CF mutations lead to disease?

The CF gene is very complex. There are more than 1,000 known changes that

can cause the gene to be abnormal. These changes in the CF gene, called mutations, cause the body to make defective CFTR protein which in turn causes abnormal



salt and water movement in the cells. As a result, chronic lung infections and poor digestion usually occur.

In the lungs, the mucus tends to be excessive, thick and sticky which leads to obstruction, infection, and inflammation. In the intestinal tract, mucus may block the release of digestive enzymes from the pancreas, causing poor digestion.

What is CF genotyping?

Using a test called CF genotyping, you can determine which of the CF mutations you or your child has. CF genotyping can be obtained from a blood sample or from cheek brushing.

Why do CF genotyping?

CF genotyping can be used to diagnose CF. This is especially important for people who have an inconclusive sweat chloride test. If CF genotyping discovers two CF mutations, then the CF diagnosis is confirmed. For the adult with CF who is considering having a family, genotyping is recommended for his or her significant other. Each pregnancy between an individual with CF and a CF carrier represents a 1 in 2 chance that the baby will have CF, and a 1 in 2 chance that the baby will be a carrier. If CF genotyping confirms that the significant other carries no CF gene mutations, the baby will be a carrier.

CF genotyping can also help with family planning for the extended family. Having a close relative with CF increases one’s chance of being a CF carrier. Because 1

in 30 Caucasians in North America carries the abnormal CF gene, and about 1 in 400 marriages involves 2 carriers¹, the likelihood of having a child with another CF carrier may be significant. The probability of 2 CF carriers having a child with CF is 1 in 4 with each pregnancy. When a person with CF knows what mutations they have, the testing of close family members can be done more accurately.

An additional benefit of genotyping relates to CF research. There are several current studies looking at the relationships between specific CF mutations, the degree of symptoms a patient has, and the effect of other non-CF genes on the disease. In the future, there may be studies to determine if specific treatments work better in people who have certain mutations.

Does it matter where I have it done?

Although most people with CF have at least one copy of one of the common mutations, the majority of CF mutations are very rare. The first CF genetic tests in the 1990’s looked for just a handful (6-12) of mutations, and thus many test results done then were inconclusive. Now there are tests that can identify most of the known CF mutations. However, laboratories differ in the number of mutations they test for, depending on whether the test is for carrier testing or diagnosis. Any patient or family member considering testing should consult a genetic counselor or doctor to determine which test is best for them.

Will my insurance cover the cost? Insurance coverage for CF genotyping tends to be good, even for those who have had inconclusive testing in the past. Call your insurance company to inquire whether CF genotyping is a covered benefit.

Genetic counseling is available. Your or your child’s CF genotype is an

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Is Balance Possible?

By Mary Ellen Withers, LCSW

As some of you know we have re-established the multi family group meetings for families of newly diagnosed children. It is just another effort on the CF Center's part to help families who have children seen at our center. Lots of things are discussed in these group meetings such as new CF research, how to manage airway clearance for a 2 year old, insurance for now and the future, sibling care, etc. I have come to understand that my main concern for these families and the other families coming to our center is this: I want families to learn to manage their child's CF with out losing all the other important things that make having children and being a family enjoyable and important. So I decided to write about balance for this newsletter.

Of course, at first we all wonder... Is balance even possible for families who have a child with CF? It is a good question, really. Even families who do not have children with any chronic illness struggle with this.

We live in a society that has a high value on being busy and getting a lot done. Children are taught to achieve very early in life so they can be successful. Many people have so much to do that they do not provide for themselves and their family the basics of life like enough sleep and proper nutrition. Some are so busy they do not spend time making friends and having good relationships. So if non-affected families struggle with balance, then how much more do families in which there is a child with CF struggle? I believe that balance is possible for families who have a child with CF, but I think it is harder to achieve, and sometimes it requires families to be more thoughtful and deliberate.

The things that CF families must manage each day are enormous in number. There is the simple emotional response

that all parents have when their child is diagnosed with CF. These feelings can range from worry and guilt to anger and frustration. Added to these are the treatments, which can take a lot of time. Parents become overwhelmed and suddenly life is about CF. Life is not about being a family.

How does a family find balance, then? In order to manage, families have to decide that CF is not going to take over. I think that is the first step. Because providing excellent care to their child with CF is a priority, this can be hard to do. It may feel uncomfortable to parents to make this decision. Yet balance is essential to the well being of ALL family members, including the child with CF.

The next step for families is to figure out the nitty gritty of how to take care of CF while allowing all family members to do the things that are important to them. This may mean finding a child care provider who is comfortable in caring for a chronically ill child so that a mother can return to work or so parents can have a weekend away. It may mean sacrificing a perfect treatment schedule for an okay one so the family may attend a sibling's ball game. It might mean learning not to favor you child with CF so the other children in your family can feel important. The list could go on and on. For every family there is a different list of things that would help them achieve more balance.

I am sure there will be times when this task will seem just too overwhelming for a family. I believe to struggle with this is normal. Other times a family will be pleased that they took on the "fight for balance", especially when something happens and they realize the children raised in their family are just the most wonderful people... something all parents love to experience.

These are some of my thoughts on balance. I think it is a worthwhile issue for all families to tackle. Good luck!



Flu Season Reminder!

Don't forget that washing your hands is the number one protective measure against acquiring an infection. This is especially helpful for everyone during flu season!

Your Vest Options

By Cathy O'Malley, RRT

High frequency chest wall oscillation (HFCWO) is an airway clearance option that uses a machine to deliver consistent and effective airway clearance therapy. The machine is an air-pulse generator which delivers high frequency oscillations to the chest wall. The patient puts on a vest and the air-pulse generator inflates and deflates the vest rapidly, gently compressing the chest wall many times per second. This action loosens and mobilizes mucus from the small airways to the large airways where they can be more easily cleared with a cough.

There are two systems on the market today that deliver HFCWO, The Vest™ system and the MedPulse® SmartVest™. As compared to other forms of airway clearance, the vest option is an expensive one. However, it is a medical device that has proven its value in patient efficacy, safety, and satisfaction. Therefore, insurance coverage has been very good.

The original HFCWO, the ABI® Vest, was approved by the Food and Drug Administration (FDA) in 1988. It was the first “vest” on the market. Since then, the device has made practical improvements



The Vest™
Airway Clearance System

in design and function. In 1997,

it was remodeled and named the ThAIRapy® Vest, Model 103. Many patients from our center are familiar with and use this particular model. The latest model is called The Vest™ system, Model 104, and it was approved by the FDA in 2003. It is a smaller and more portable machine. It weighs 17 pounds, and compared to the previous model, is half the weight and one third the size. Patients who are newly prescribed The Vest™ system will receive this newest model.

The cost of The Vest™ system is currently \$16,425. Patients who use an older model and are

interested in an upgrade can trade in their older model for a new one. The upgrade costs \$6,000. For more information, contact Hill-Rom (formerly Advanced Respiratory, Inc) at 1-800-426-4224, or visit www.thevest.com.

The other HFCWO on the market, designed and manufactured by Electromed, Inc., is called the MedPulse® SmartVest™ airway clearance system. The FDA approved their original device in 1999, and their newest model, Model 2000ez™, in 2004. The MedPulse™ device is similar in function and purpose to The Vest™ system; however, the two differ in style and price. It weighs 30 pounds, has one hose, and looks like a small suitcase.

The MedPulse® airway clearance system currently costs \$13,998, and the cost for an upgrade is \$1,000. For more information contact SourceCF at 256-704-4880, or visit www.sourcecf.com and www.electromed-usa.com.



MedPulse®

The Nutrition Bonus Program at CMH

Teaching children and teenagers how to choose foods wisely is one of our goals. Our CF Center offers a program which puts a positive spin on nutrition education for those who need to gain weight. The “Nutrition Bonus” is a \$25 gift card to a grocery store. After learning about nutrient dense, high caloric eating and food labels, our dietitians send them to the grocery store with their parent for some thoughtful shopping. What have they bought? Here are some favorites: chocolate covered peanuts, cashews, fettucine alfredo TV dinner, Pasta Sides Butter and Herbs®, Ben & Jerry's® Peanut Butter Cup ice cream, Hot Pockets® and cheesecake! This program is made possible by an educational grant from Nestle (makers of Nutren®).



Add One More Treatment To Your List: Wish Therapy!



Every child has a dream. The Make-A-Wish Foundation® is an organization dedicated to making dreams come true. Many people know about Make-A-Wish®, but most of our CF families don't realize that any child with CF who is between the age of 2½ and 18 is eligible for one heartfelt wish! Despite the remarkable advances in treatments, we currently can't cure CF. Those who live with CF work hard every day to stay healthy. A wish acknowledges that CF care is hard work, and this hard work deserves recognition in a memorable and special way.

Many young individuals with CF have received the gift of a wish. Whether it's a dream family vacation, an opportunity unattainable with everyday resources, or a wish that helps others (a “selfless wish”), wishes bring smiles, memories and balance. A simple phone call from a family member or CF caregiver starts the wish process. Experienced wish volunteers will meet with your child to explore ideas because it's often difficult to know exactly where to start!

Make-A-Wish® serves families of all races, religions, ethnic and financial backgrounds. For more information, please call the CF Center or the Make-A-Wish Foundation® at 312-602-WISH, or email Dina Kapani at Kapani@wishes.org.

NACF CONFERENCE – Learning and Sharing

The 18th Annual North American Cystic Fibrosis Conference (NACFC) was held in St. Louis in October. This 4 day program gave 3,000 medical professionals and researchers the



opportunity to hear the latest in all areas of CF care and share their ideas. Dr. McColley was a member of the conference planning committee. Twenty members of our pediatric and adult CF team attended NACFC this year; 12 staff members were invited to present research or clinical information.

Quality Improvement

Susanna McColley, MD presented our successful NICHQ experience which focused on improving nutrition and helping smoking parents to quit to other CF Center Directors at a special meeting for Center Directors, Affiliate Program Directors and Adult Program Directors. **Stacy VandenBranden, APN** presented our NICHQ experience and outcomes at a symposium session entitled “Improving Our Center Systems”, open to all conference attendees. Stacy and

Tony Talley, RRT participated in a panel discussion at the short course on “Smoking Cessation”. We were very proud to share our Center’s successes, and are grateful to all of the families who worked with us every day to achieve our goals!

Multidisciplinary Care

Joanne Cullina, MSN, RN moderated a workshop on Transition in CF Care, and highlighted our Center’s adult program development in a talk, “Transition to Adult Care: Progress from 1999”. **Cathy O’Malley, RRT** moderated a round table discussion on “Aerosol Therapy”. **Rich Carroll, PharmD**, presented “Putting It All Together: Beyond Antibiotics – The Pharmacist’s Role” at the Pharmacists’ Discussion Group.

Educational Material Development

A Nurses’ Network Session was devoted to selected patient education materials developed at CF Centers. **Emily Griffith, RD** presented “Nutrition in Bite-Sized Pieces”, our CF nutrition newsletter; **Eileen Potter, MS, RD** presented “Supporting Nutrition: Understanding Tube Feeding”; **Stacy VandenBranden, APN** presented “Health Maintenance Guidelines: A Patient’s Guide to the Clinical Practice Guidelines for Individuals with CF”.

Educational Materials

Several families from the CMH CF Center and members of our CF Care team are featured in a new CF Foundation video, “An Introduction to Cystic Fibrosis for Patients and Families”. The video was played continuously on the exhibit floor. Our brochure entitled “Supporting Nutrition: Understanding Tube Feeding” was distributed by Digestive Care, Inc., who sponsored its publication. All 2,500 printed copies were distributed, with orders taken for 1,000 more. The brochure has been approved by the CF Foundation’s Education Committee. Thanks to all the families who participated in the video and brochure!

Research

Alan Hauser, MD (Northwestern University) presented “Pseudomonas Aeruginosa Isolates Change Their Type III Secretion Phenotypes During Infection”. This study is currently being conducted at CMH and NMH, with over 150 of our patients participating. **Cathy Powers, RD, CCRC** was co-author for the project “Randomized, Controlled Study Examining Bioavailability and Safety of DHA in CF”, presented by John Lloyd-Still, MD.

Clinical Case Presentation

Kimberly Watts, MD presented a case study during the Clinical Fellows’ Session.

Cystic Fibrosis Genotyping (continued from page 3)

important piece of information, and it may lead to other questions. CF genotyping should be done with your doctor and a genetic counselor who can guide you through the information and answer all of your questions. Our CMH genetic counselor, Dinell Pond, MS, is available at (773) 880-3709. For information on genetic testing and counseling

at Northwestern Memorial Hospital, call (312) 926-6622 (Reproductive Genetics Department), or contact Joanne Cullina at (312) 695-2003.

1. An Introduction to Cystic Fibrosis for Patients and Families, 5th Edition, Cystic Fibrosis Foundation, 2003.

PFT's Under Three!

(for children under 3 years)



Lung function tests (or pulmonary function tests, PFTs) evaluate how much air your lungs can hold and how quickly air can move in and out of your lungs. In children over the age of five years, PFTs are done at every CF visit. They provide you and your doctor with an actual number value to see how healthy your lungs are at that time. When you have a cold, increased cough or other breathing trouble, your PFTs can be decreased, indicating that more treatments may be necessary

to improve lung function. Most children under the age of five find the PFT maneuvers too difficult to perform, however.

CMH is now able to do these tests in children under the age of three (actually they need to be under a height of about 39 inches). Infant Pulmonary Function Tests can be done safely with the child sedated and takes a few hours. It is recommended that Infant PFTs be done approximately every six months for routine care, and more often if necessary.

When you bring your child in for an Infant PFT, he/she will not be allowed to eat anything for six hours prior to the test. We also ask that your child be sleep deprived, in other words has stayed up late the night before and awakened early the day of the test. Sleep deprivation helps the child sleep better for the test. Once you arrive, Dr. Adrienne Prestridge and a nurse will assess your child. A sleeping medicine called chloral hydrate will be given by mouth. Chloral hydrate is very safe and has been used for many years without problems. Shortly after drinking the medicine, your child will be asleep. During the entire procedure, your child will be watched by a nurse, a respiratory therapist (Tony Talley or Liz Vacca) and Dr. Prestridge. Heart rate, oxygen level and breathing are continuously monitored.

The test is performed with the child sleeping in a bed that looks like an isolette used by newborns. During the test, your child will have a face mask on that is connected to tubes which allow him/her to breath fresh air and exhale air into the room. There is also a vest placed around the chest and stomach with a balloon inside the vest. During part of the test, the balloon will give your child a hug to help get all the air out of the lungs. In order to see how large the lungs are, a clear plastic box cover will be closed around your child for a brief period of time. A medicine (albuterol) may be given into the lungs to see if we can open them up more. The whole test takes about two hours after your child falls asleep.

Your child will wake up a bit groggy and usually silly happy. He/she will be monitored until he/she has had something to drink and is ready to go home. While your child is waking up, Dr. Prestridge will interpret the test and then discuss the results with you and give you a copy. A copy also goes to your primary CF doctor.

If you are interested in having Infant PFTs done on your child or have more questions, please call the CF center or talk with the CF team at your next clinic appointment.

Meet Our Staff



John Barbaza, BS, joins our team as an exercise physiologist who writes: "Before joining CMH, I was with NMH for almost 6 years. During that time, I was an Exercise Physiologist for Cardiology, Pulmonary, Nuclear Medicine,

and Cardiac Rehab departments. My position there involved nuclear and echo testing, pulmonary research protocols for adults with congestive heart failure and all phases of cardiac rehabilitation. Before coming to Chicago, I resided in Florida and attended the University of Florida. During college, I did extensive exercise research (including cardiopulmonary testing) with college and elite athletes. I also studied dance choreography and dance therapy which I hope to incorporate in future pulmonary rehabilitation programs at CMH. During high school and college, I also worked for Disney where I choreographed their parades and stage shows. I am currently taking a small break from formal dancing; however, I teach aerobics, funk, kickboxing and personal training at local fitness clubs. I just started training for a triathlon, which will take a lot of work!

At CMH, I hope to become involved in CF research once I'm completely settled in. I am currently devising a "revamped" pulmonary rehab program, and will be providing exercise prescriptions/programs for both inpatients and outpatients. In collaboration with a nutritionist, I hope to provide fitness education to patients and their families. In the Cardiology department, I will be performing cardiopulmonary and cardiac stress tests. This June, I will be graduating from the University of Phoenix with an MBA specializing in health care management."

CF Center Website Update

Our CF Center website is expanding!
Visit www.childrensmemorial.org/cysticfibrosis to see the first of several phases. We welcome your suggestions and comments!

Adult CF Clinic Has Moved!

Starting this fall, our Adult CF Program will conduct CF Clinic at Children's Memorial Hospital (Lincoln Park, 1st floor). Only the location has changed! The Adult CF Team will continue to see their patients every other Thursday morning, and appointments are made by calling (312) 695-2003. Valet parking is available for \$5. Sick visits are available at Northwestern Memorial Hospital Pulmonary Clinic. Please contact Joanne Cullina at (312) 695-2003 with any questions.

Introducing Our Newest QI Project

Diabetes And Bone Health Screening And Management

Quality Improvement (QI) in CF care is a priority of the Cystic Fibrosis Foundation and our CF Center. Individuals with CF can reap a measurable health benefit from the use of proven therapies and current research. QI tools can help caregivers apply these therapies efficiently and effectively. The CF Center at Children's Memorial Hospital and Northwestern University is expanding its quality improvement work with a new initiative: screening and management of CF-related diabetes (CFRD) and osteoporosis (bone thinning) in adults and children.

The evidence is strong that early diagnosis and treatment of CFRD can improve lung health and nutrition. It is therefore important to regularly screen for any abnormal fluctuations in blood sugar. Also, as people with CF are routinely living to adulthood, there is an increased risk of bone-thinning and fractures, especially spine fractures. Fractures have a detrimental effect on lung health. Strong bones are formed in childhood, so identifying and treating bone loss should begin early, and continue into adulthood.

We are pleased to be one of 12 CF Centers in the Learning and Leadership Collaborative II, a CFF-sponsored QI initiative. Through this interactive framework, our LLC team will fine-tune the way we do things. Ideally, we want to blend the findings from recent research with the CFF Consensus Guidelines for CF Care, and apply/individualize patient care accordingly. The LLC team members are Carolyn Heyman, RN, Emily Griffith, RD, Adrienne Prestridge, MD, Susanna McColley, MD, Manu Jain, MD, Joanne Cullina, MSN, and Alisa Kirsche, MS, RD. More detailed information about CFRD and bone health will be available in future newsletters and visits.

Special Thanks To Our Sponsors!

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Staff News:

Good luck to **Ann O'Connor, MS**, exercise physiologist, who recently joined Advocate Christ Medical Center's cardiac rehabilitation team. **John Barbaza, BS**, our new exercise physiologist, is featured in "Meet Our Staff" (see page 7).

Welcome to **Adrienne Prestridge, MD** and **Mary Nevin, MD**, pulmonary attending physicians. Dr. Prestridge completed her pulmonology fellowship at the Children's Hospital Medical Center in Cincinnati where she gained extensive experience in CF care and quality improvement. She is our Associate CF Center Director and Director of the Pulmonary Function Laboratory; she has recently launched our Infant PFT program (see article on page 7). Dr. Nevin completed her residency training at Duke University Medical Center and her pulmonary fellowship at CMH. Her special interests include Impulse Oscillimetry (a technique that assesses lung function in young children) and the care of complex chronic illness. **Dr. Kimberly Watts** begins her 1st year of pediatric pulmonology fellowship at CMH, having completed her pediatric residency at Advocate Lutheran General Children's Hospital. She has a special interest in CF and is the recipient of a CFF Clinical Fellowship Grant.

We are very fortunate to have **Margaret (Callan) Delany, RN, APN** join our CF Center as a research coordinator. Many families know Margaret from 9West, where she was a staff nurse. She is familiar with CF and is excited to work with our patients and families again. The future brings relaxation for **Kiki Richman, LCSW**, who is retiring from her position with the Adult CF Program. We wish Kiki and her husband Bob many happy travels!