



The Children's Hospital

# CF News

SUPPORT • EDUCATE • EMPOWER

The Mike McMorris Cystic Fibrosis Research and Care Center

Date 4/10/09

Volume 1, Issue 1

A newsletter for CF patients, families, and communities.

## CF Outreach clinic dates for 2009

### Billings, MT

Jeff Wagener MD  
Frank Accurso, MD  
Jeri Lysinger, MD  
Jun. 24, 25  
Sep. 23, 24  
Dec. 2, 3

Call for appointment at 406-237-4280

### Great Falls, MT

Jeri Lysinger, MD  
Jerry Eichner, MD  
Jul. 27, 28  
Oct. 26, 27

Call for appointment at 406-771-3388

### Colorado Springs, CO

Edith Zemanick, MD

May 4    Sep. 2  
Jun. 1    Oct. 5  
Jul. 6    Nov. 2  
Aug. 3    Dec. 7

Call for appointment at 719-365-2244

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## Welcome!

### Dr. Frank Accurso

Greetings from the Mike McMorris Cystic Fibrosis Research and Care Center. There have never been as many exciting opportunities for improving quality of life for individuals with CF as there are now.

In this issue of the newsletter, our staff addresses several important themes in CF care and research. Dr. Sagel reports on the development of Care Guidelines for Pulmonary Treatments. We expect there will be other evidence-based guidelines like this one in the future.

We also highlight the avoidance of second hand smoke, the need for attention to nutrition, our dedicated nursing staff and the award winning CF Family Advisory Council (more about the Council in the next newsletter). We have a reminder about Great Strides, the key fund raising event of the year for the Cystic Fibrosis Foundation. With the economic downturn, Great Strides is crucially important this year.

Finally, there is a reminder that "You are the Key" to making clinical trials work. There are three treatments in clinical trial this year that go right to the heart of the problem in CF. These treatments are aimed at correcting the abnormal protein in CF. This approach was almost unimaginable even a few years ago. We at the CF center will do everything we can to make these trials a success but you are truly the key. The trials will work only to the extent that individuals and families with CF participate. Of course, your record of participating in clinical trials in the past has been nothing short of fantastic. I am, therefore, confident that the CF community will be able to meet this next and most important challenge of testing these remarkable new treatments.

Best Regards,  
Frank Accurso, MD  
Cystic Fibrosis Center Director

## CF Pulmonary Guidelines: Chronic Medications for Maintenance of Lung Health

### Dr. Scott Sagel

The Cystic Fibrosis Foundation established the Pulmonary Therapies Committee to examine the clinical evidence for therapies intended to maintain lung health and provide guidance for prescribing these therapies. The therapies include inhaled antibiotics (tobramycin or TOBI), inhaled mucolytics (dornase alpha or Pulmozyme®, hypertonic saline), oral and inhaled steroids, ibuprofen, antistaphylococcal and macrolide antibiotics.

The committee reviewed all of the available published evidence and made recommendations based on a predefined grading scheme. If an "A" grade was assigned, it means that the committee strongly recommends that clinicians routinely prescribe the medication to eligible patients. For instance, only 2 therapies received an "A", inhaled tobramycin and dornase alpha for those patients with moderate-severe lung disease. The committee published its recommendations and guidelines last year.

While these guidelines are designed for general use in most patients, they need to be adapted to meet individual needs as determined by the patient's health care provider.

The introduction and use of specific medications will depend on the individual patient, their social situation, and parental or patient preferences. In addition, because of limited data in very young children, the recommendations are only intended for individuals 6 years of age and older.

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*Lung Health Continued from page 1*

Many of you are aware that our CF Center is now providing a CF Pulmonary Action Plan to patients and their families at outpatient clinic visits. The Pulmonary Action Plan includes information and instructions regarding pulmonary specific therapies. We are using the published guidelines to prescribe these therapies in a more consistent fashion. Feel free to speak with your CF care provider about these published guidelines.

**CF pulmonary guidelines:**

Flume PA.et al. Cystic fibrosis pulmonary guidelines: chronic medications for maintenance of lung health. American Journal of Respiratory and Critical Care Medicine 2007; 176:957-969.

## CF Family Advisory Council (FAC)

The CF Family Advisory Council (FAC) is a group comprised of volunteer parents and members of The Children's Hospital CF care team. The CF FAC was established in 2007 to work as partners with the CF clinical care team to ensure excellence in providing comprehensive and compassionate medical care for those with CF and their families in the Rocky Mountain region. The FAC is actively involved in several self-initiated projects (ex. education forums, clinic binders) and serves as a sounding board for ideas and quality improvement projects being considered by the CF clinical care team. The FAC is seeking interested parent representatives. If you are interested in becoming a member of this energetic group, or learning more, please contact Jennifer Levine at [jsl72@comcast.net](mailto:jsl72@comcast.net).

## Second-hand smoke exposure and CF

**Lisa Monchil, RRT-NPS CCRC**

Do you or anyone who cares for your child smoke? I am sure you have been hearing this question when you come for your clinic appointments. Let me share with you why this information is so important to your CF Healthcare Team.

For CF patients there is NO risk-free level of secondhand smoke exposure. A study published last year determined CF patients exposed to secondhand smoke in their homes had a substantial reduction in lung function. There may be an interaction with the genes that cause lung damage in CF and the smoke exposure. We know that even children without CF, who are exposed to secondhand smoke, have an increase risk for asthma, ear infections, lower lung function, and even SIDS (Sudden Infant Death Syndrome). More research needs to be done to determine the exact genetic link.

In the meantime, if you smoke and are interested in quitting, talk to your healthcare provider or call Colorado Quit Line at 800-639-QUIT.

## How much food do you need?

**Janice Fordyce, MS, RD**

People with CF have to eat a lot of calories to stay in good health—see below for how many calories you need in a day and **don't forget the enzymes!**

These numbers are **only estimates** of how many calories you need. Your CF dietitian can give you a tailor-made food plan based upon your weight, growth, and activity level. Along with extra high calorie recipes that they have on hand, they also have information about the nutritional supplement program. If you have not signed up for one, please talk with them by phone or the next time you are in the clinic.

	Age (Years)	Calories per Day
Infants	Birth-3 mo.	400-700
	3 mo-6 mo	700-1000
	6 mo-1 yr	1000-1500
Children	1-3	1500-1600
	4-6	2000-2200
	7-10	2200-2400
Males	11-14	2800-3000
	15-18	3000-3400
	19-24	3400-3500
Females	11-14	2400-2700
	15-18	2400-2700
	19-24	2400-2700

### Nutrition Tidbits

#### Super-Duper High Calorie Peanut Butter Popcorn

2 TBS of each: Sugar, Peanut butter, Light corn syrup

- Combine in saucepan, heat over low-medium until well mixed.
  - Add 1 tsp vanilla (optional)
  - Drizzle over 2-3 cups popped popcorn
- Yum, yum, yum—500 calories for the tummy!



We can provide you with information on cessation. We can also provide you with steps you can take immediately to decrease your child's level of secondhand smoke exposure.

We have made great progress in CF research over the past several years. We received funding from the National Institutes of Health, private industry, and the Cystic Fibrosis Foundation to work on CF research. The CFF has dedicated a multimillion dollar budget of your contributions to find new treatments and ultimately, to find a cure. However, your contribution to CF does not stop there. We are coming back to you to ask for your help once again. You are the key to CF research and its success. Your participation in the CF research studies will help us find treatment and the cure that much faster.



Study	Purpose	Age	Time in the study
Assenting process	To study if children would have more understanding of medical procedure when watching a video	11-14 years	1.5 hours
Denufosal	To study new inhaled treatment.	6 years and older	1 year
Hypertonic saline	To study if hypertonic saline inhalation can benefit infant and young children	4 months-6 years	1 year
Pulmozyme	To study how the drug works in younger children	3-6 years	2 months
Sildenafil	To study if this drug can help with exercise tolerance and cardiac function.	16 years and older	3 months
Vertex 809	To study if the new drug can correct the abnormal protein in CF	18 years and older	1 year

If you are interested in participating in CF research, we are here for you. Both Adult center at National Jewish and our center at the Children's Hospital would love to talk to you.

We are working on these studies and more. If you are interested in participating in CF research studies, please contact us any time.

Pediatric center: Churee Pardee at (720)-777-6162, or [pardee.churee@tchden.org](mailto:pardee.churee@tchden.org)  
 Adult center: Marion Jones at (303) 398-1265, or [ionesm@nihealth.org](mailto:ionesm@nihealth.org)

## Great Strides is here!

Great Strides is a wonderful opportunity for you to help raise money for the CF Foundation. Your efforts have helped bring CF research to where it is today. Almost 90 cents of every dollar raised goes directly to CF research and programs.

It is a lot of fun! Form your team and come join us all for a great time outdoors. Call your local CF Foundation or go online for help.



*"Our family has participated in the Great Strides walk for the last 6 years. In the beginning, it was really about seeing our friends and family as they supported our cause and our little girl. As each walk came, we started to see the same families as the year before. Now, not only do we look forward to seeing those on our team, but it is also a time to chat with the other CF families that we have connected with over the years. Last year to spent quite a bit of time on the walk chatting with a CF friend (we had both gotten separated from our teams ☺) It was nice to share not only our CF stories, but spend time getting to know each other. We look forward to the walk each year, knowing that it will be a day spent raising money for a great cause, being with family and friends, and getting the chance to see our new CF friends."*

*Jen Levine, parent of child with CF.*

### Save the Date GREAT STRIDES

**Colorado:**  
 Ft. Collins.....5/9/09  
 Denver.....5/16/09  
 Co. Springs.....5/16/09  
 Longmont.....6/6/09  
 Dillon.....7/11/09

**Montana:**  
 Missoula.....6/27/09  
 Helena.....7/18/09

**Register today at**  
[www.cff.org/great\\_strides](http://www.cff.org/great_strides)

**CF Foundation National Office:**  
 (800) FIGHT CF  
 (800) 344-4823  
 E-mail: [info@cff.org](mailto:info@cff.org)

**Denver Office:**  
 (303) 296-6610  
 Email: [colorado@cff.org](mailto:colorado@cff.org)

**Co. Springs Office:**  
 (719) 444-8966  
 Email: [pikes-peak@cff.org](mailto:pikes-peak@cff.org)

## Get to know the pulmonary nurses

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We have expanded our nursing team to provide you with the best service possible. Each nurse brings diverse strengths to our team. The next time you need us, one of our nurses will be here to take care of you.

**Rosalie Bush:** Rosalie has been a nurse for 37 years. She worked in neonatal care for 20 years, ICU for 6 years. She has worked in the CF field for over 10 years. She is a clinic nurse specialist and also covers our outreach clinics in Great Falls and Billings, MT.

**Ruth DeVoogd:** Ruth has been a nurse for 32 years. Her previous works include inpatient care for infants and toddlers, ICU, and clinical nurse specialist in tracheostomy and ventilated children in the special care unit. She joined the CF team 14 years ago. She is a certified pediatric nurse practitioner.

**Alicia Hanes:** Alicia has been a nurse for over 5 years. She came to us from Michigan where she worked in pediatric clinic and ICU. She joined our team since October of 2008. She specializes in interstitial lung diseases.

**Shelley Mann:** Shelley has been a nurse at Children's for over 22 years. She joined the CF team 7 years ago. She covers our Co. Springs outreach clinic monthly and enjoys working in CF research the rest of the time.

**Sally Mescher-Allen:** Sally has been a nurse at Children's for 20 years and on the pulmonary 4 years. Prior to that, she worked in the ICU for 16 years. She specializes in Sleep Disorders.

**Julia Micalizzi:** Julie has been a nurse for 6 years. She is Asthma-Educator certified. Prior to coming to us, she worked in Jacksonville, FL, working in an inpatient respiratory and infectious disease unit.

**Laura Muenstermann:** Laura has been a nurse for over 20 years-all at Children's. She came to us from the ICU and has been with our CF team for almost 2 years.



**Phone: 720-777-6181**

**Churee Pardee:** Churee has been a nurse at Children's for 19 years. She worked in the medical and surgical unit at Children's prior to joining the CF team 10 years ago. She is a clinical nurse specialist and spends most of her time working on CF research.

**Kathy Spomer:** Kathy specializes in Asthma and Allergy. Before coming to Children's she spent 8 years working in asthma and allergy at National Jewish. She has been a nurse for over 25 years. Prior to joining our pulmonary team 8 years ago, she took care of medical and surgical patients here at Children's.

**Gina Urbine:** Gina has been a nurse for 6 years. She worked in the ICU for 5 years. She joined the Allergy clinic at the beginning of the year.

**Erin Wells:** Erin has been a nurse for 6 years. She came to us from Louisiana via San Diego where she has worked in both inpatient and outpatient pediatric pulmonary. She joined our team in July of 2008 and works with CF, general pulmonary, and asthma.

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The Children's Hospital

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Access the newsletter by web:

<http://www.thechildrenshospital.org/conditions/lung/conditions/cf/cystic-fibrosis.aspx>

This newsletter is published by the department of Pulmonary and Allergy Medicine at The Children's Hospital.