

The Link

Sutter Cystic Fibrosis Center Newsletter



NOVEMBER 2006

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Children's Center
at Sutter Medical Center, Sacramento

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Clinic News:

What does your CF Center Team have to say about what's new? Kasey Pearson, PNP, Clinic Coordinator, is looking toward the future and hopes to start working on Quality Improvement in CFRD (Cystic Fibrosis Related Diabetes), Infection Control, and Pulmonary Function Testing utilizing the Cystic Fibrosis Foundation's New Quality Improvement Action Guide. Debra Scott, RD says, "Take advantage of the upcoming holidays!" Yes, enjoy all that pumpkin pie, mashed potatoes and stuffing! Laurie Decayo, RRT and David Blackney, RRT recommend paying particular attention during the winter season to any increased coughing, wheezing, or shortness of breath and to call Dr. Chipps or Dr. Perez for early treatment. As always, they say, "Clean

your nebulizers and get daily exercise." Shawn Gray, MSW, reminds you to take care of your mental health! Particularly, parents, schedule in "date night(s)" to help stay connected. Susan O'Bra, Research assistant, is completing the final details that are required for the Sibling Study and has taken on the job of mailing out reminder cards to all our patients to get their flu vaccine this year. Finally, Wendy Hubbs, CNS, is continuing to collect data for the CFF Registry and is always interested in what's going on with patients for the "Patient News" section in the newsletter. Log on to the Sutter CF Center Website at: Sutterchildrens.org (then click on Pediatric Specialty Services) to learn more about the clinic.

Influenza Prevention for the CF Community

As the flu season approaches, patients and families often request information on influenza and/or pandemic or avian influenza. In response to these questions, the CF Foundation has prepared the following article:

As the flu season approaches, we want to provide you with the latest update about influenza and how to keep yourself and your family as healthy as possible this winter.

Seasonal Influenza

Every year in the United States, influenza epidemics occur during the winter months. Influenza (the flu) is very contagious and can spread from person-to-person in droplets created by coughing and sneezing. Anyone can get influenza. Symptoms include fever, cough, sore throat, headache, chills, muscle aches, and fa-

tigue. However, some people can get much sicker from influenza. The young, the elderly, and people with chronic heart or lung conditions are particularly vulnerable to severe flu. Thus, people with CF can develop severe pneumonia from influenza which can be difficult to distinguish from a CF pulmonary exacerbation or from another respiratory viral illness. It is very important to let your CF care team know if you develop flu-like symptoms.

Preventing Influenza

The CF community and immunization experts have developed the following guidelines to reduce the impact of influenza on the CF community:

- Get vaccinated - Each year in October or

Continued on Page 3

From the Editor:



I give it a 10!

Yes, the Twentieth Annual North American CF Conference was the best ever! And what was even more special this year was that 10 members of your Sutter CF Center Healthcare team were fortunate enough to

be able to attend this great event. On behalf of your entire team, I can honestly say, we all returned to Sacramento with increased knowledge, new energy and numerous ideas for improving the care and health of our patients. When I returned yesterday, a friend said, "So what did they talk about? Just Drugs?" And my answer was an emphatic, "No!" When I reflect on the wide range of topics presented, it was truly amazing. I told my friend, that not only were there many sessions devoted to Drug Therapy, examples of other topics included Airway Clearance, Nutrition, Infection Control, Gene Therapy Research, Financial & Legal issues, CFRD, Adult CF Care, Exercise, Lung Transplantation,

Pregnancy, Quality of Life, Newborn Screening, Genetic Testing and Quality Improvement Strategies. Almost 3500 participants from all over the world congregated to share information and to challenge the world-wide CF community to continue to work toward the common goal of eventually finding a cure for Cystic Fibrosis. I specifically wanted to "pick other peoples brains" this year and learn how things are done in other centers across the country and in other countries. Let me say, I learned a lot! Some of the themes this year were to "Learn from Others," to "Examine defined techniques" and to "Standardize Care, yet Individualize Care." In closing, I will quote Dr. James R. Yankaskas (UNC at Chapel Hill) who recommended that all centers ask, "How do we individualize care?" and "How do we involve patients and their families?" So, I encourage you to get involved!!! See you at CF Education Night, November 28!

Wendy Hubbs, RN, MSN, CNS
Hubbsw@sutterhealth.org

Interview with Dr. Myrza Perez

In September, Dr. Myrza Perez joined Dr. Bradley Chipps' practice and the Sutter CF Center Team. She shared the following information about herself in an informal interview with Wendy Hubbs, RN, CNS.

1. Tell us something about your background and experience? I was raised just outside of New Orleans but moved around a fair amount for my training. I went to college at Harvard University in Cambridge, Massachusetts and medical school at Louisiana State University School of Medicine in New Orleans. From there I went on to Montefiore Medical Center in the Bronx, NY for residency in Pediatrics and then to the Children's Hospital of Philadelphia for my Pediatric Pulmonology fellowship.

2. What do you like most about working with CF patients and their families?

The motivation and interest on the part of patients and their entire families in many situations. There are no other illnesses that I know of where medical knowledge, advancements and advocacy have been driven to such a degree by patients and their families.

3. What are some of your interests and what do you like to do for fun?

In college my major was art history and this is still an interest of mine. I love going to galleries and museums. To maintain my sanity I like to run.

4. What would you like to see at our center in the future?

I would like to see an exercise and

physical therapy program as part of a greater pulmonary rehabilitation program. Exercise and physical activity are known to be important for an individual's well-being yet this is a component often overlooked when patients are ill.



Influenza Prevention for the CF Community (Cont.)

November, influenza vaccination (the ‘flu shot’) is given to people with CF, their family members, and their healthcare providers to prevent the flu by boosting immunity to circulating strains of the virus.

- If the close contacts of people with CF receive vaccine, they will not get the flu and this will help to protect people with CF from getting influenza!
- You may have heard about the “flu vaccine spray”. This vaccine is sprayed in the nose, but is only approved for healthy people 5 to 49 years of age. People with CF cannot get this type of flu vaccine, but their family members without CF or other health conditions can.
- October or November is the best time to get vaccinated, but getting vaccinated in December, or even later, is still beneficial as flu season can last until the Spring.
- Have Good Health Habits - Infection control measures can reduce the spread of flu in healthcare settings such as the CF clinic and in community settings such as school and work. These Good Health Habits include:

Avoid close contact.

Avoid close contact (*stay at least 3 feet or an arm’s length*) with people who are sick. When you are sick, keep your distance from others to protect them from getting sick too.

Stay home when sick.

If possible, stay home from

work, school, and errands when sick. You will help prevent others from becoming sick.

Cover mouth and nose.

Cover your mouth and nose with a tissue when coughing or sneezing. Discard the tissue into a receptacle. You will help prevent others from becoming sick.

Clean hands.

Cleaning your hands (*especially after coughing, sneezing or respiratory therapy*) often with soap and water or with alcohol hand rub will help protect you and others around you from germs.

Avoid touching eyes, nose or mouth.

Germs are often spread when a person touches something that is contaminated with germs and then touches his or her eyes, nose, or mouth.

Practice other good health habits.

Get plenty of sleep, be physically active, manage your stress, drink plenty of fluids, and eat nutritious food.

Antibiotics - Anti-viral antibiotics are available to treat people when they get the flu. They are most effective if taken within 24 hours of the start of symptoms.

Pandemic Influenza and Avian Influenza

A pandemic is a disease outbreak that occurs globally. A flu pandemic occurs if a new influenza strain emerges for which people have little or no immunity, and for which there is no available vaccine. Thus, a flu pandemic would spread

easily person-to-person, cause serious illness, and sweep across the country and around the world in a very short time.

It is difficult to predict when the next influenza pandemic will occur or how severe it will be. There is concern that avian influenza H5N1 virus could spark a flu pandemic if it evolved into a virus capable of human-to-human transmission. Public health authorities are carefully tracking the activity of avian influenza and your care center and the CF Foundation will keep you apprised if the risk of a pandemic increases.

More information

We hope that you have found this information useful. To learn more, you can read “Respiratory: What You Should Know About Germs” available from your care center or the CF Foundation’s Web site (www.cff.org). Should you have specific questions, please feel free to contact your care center or contact the CF Foundation at 800-FIGHT CF or info@cff.org. For comprehensive information on influenza, visit the CDC’s web site www.cdc.gov/flu or the World Health Organization’s web site at: www.who.org.

MEDELA MAKES A QUICK CLEAN MICRO-STEAM BAG FOR STERILIZING EQUIPMENT IN THE MICROWAVE. CAUTION: FOLLOW MANUFACTURE’S INSTRUCTIONS. USE ENOUGH WATER WHEN STERILIZING PEDIATRIC MASKS (THEY CAN MELT).



CFRI Conference: August 4-6, 2006

This year's conference presented by Cystic Fibrosis Research Incorporated Titled: "The Cystic Fibrosis Journey: All Ages, All Stages" was wonderful. This conference was a great opportunity to meet others with CF, parents, friends, spouses, care providers, and pharmaceutical representatives. As usual the information presented was priceless, the topics ranged from Disaster Preparedness to current research to the keynote speaker's moving speech, which focused on "Being the best parent you can be."

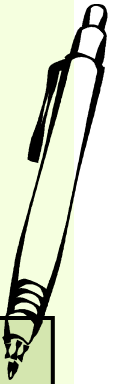
Two vendors at the conference had products that are new to the CF market. The first was a software program that helps manage medical data. This software (Your Data Keeper) was designed specifically for CF and you can find out more by going to: www.yourdatakeeper.com. There is a fee for this program and I am not sure what the exact costs are. The second was a mechanical clearance product called The Frequencer, which was developed in Canada and is in the process of obtaining FDA approval. This is an interesting product that may work well for those that don't like the Vest. More informa-

tion can be found on The Frequencer at: www.dymedso.com. Both of these products were designed by someone with CF.

Don't be left out, purchase the conference DVD's: www.cfri.org or call the CFRI office: (650) 404-9975.

The conference facilities are amazing and even though the days and nights are packed with activities, the conference is a nice change from day to day activities. Next year's conference is already in the planning phases. I hope you are able to attend next year.

Jana Newman, Parent



Mark your calendars
CFRI is hosting a workshop:
"Parenting Children with Health Issues"
presented by Foster Cline and Lisa Greene
January 27, 2007 from 9-3:30
More details to come!

Sacramento CFF Newsletter Excerpts

New Board Members: ...Kasey Pearson from Sutter Cystic Fibrosis Care Center has joined the Board of Directors. Kasey has been with the Sutter CF Clinic for many years and a long time volunteer with the local CF Chapter.

CureFinders: *CureFinders* is the Cystic Fibrosis Foundation's new school and youth fund-raising program for grades K-12. Students compete to raise the most money to win a free pizza lunch delivered to their classroom by BJ's restaurant. A fund-raising kit has been developed for school event coordinators that include examples of fun ways for students to raise money that will help the young people with cystic fibrosis (CF). The kit makes it easy to choose from a variety of fund-raising activities including: one-day

events to weeklong campaigns, and from classroom activities to school wide activities. School coordinators are encouraged to select the best method for raising money at their schools.

As an added incentive, CF Foundation's national partner BJ's Restaurants, will donate \$1,000 to each school that raises at least \$1,000 for the CF Foundation while also matching that \$1,000 donation for the CF Foundation. If you know a school that may be interested in this program please contact the chapter office at 916-979-7080.

Search the web and raise funds for CF: www.Goodsearch.com

Did you know that you can earn money for the Cystic Fibrosis Foundation every time you search the Internet? We are pleased to

announce that the CF Foundation is now affiliated with GoodSearch.com! When you need to look something up, just go to www.GoodSearch.com and select the Cystic Fibrosis Foundation as your charity of choice!

The site is powered by Yahoo!, so you'll get the same quality search results that you're used to. What's unique about GoodSearch is that it will direct approximately \$0.01 to the CF Foundation with every click.

Think about how many times we search the Internet each day-those pennies will add up quickly!

Make CF stand for Cure Found!



General Information

- Hi, I am writing you to tell you about a Cystic Fibrosis **support group** that is starting to thrive on a new website, www.DailyStrength.org. Cystic Fibrosis Group: [www.dailystrength.org/support/Lungs Respiration/Cystic Fibrosis/](http://www.dailystrength.org/support/Lungs%20Respiration/Cystic%20Fibrosis/) DailyStrength brings together people with similar life challenges to share their experiences, treatment information, stories and support each other through the hard times. We have over 500 groups ranging from brain cancer to parenting a toddler and everything in between.

Our **Cystic Fibrosis Community** is growing and we're excited to share it with everyone who has Cystic Fibrosis and who might benefit from an online support community. Please join! You really can help us shape the way this site works and what it offers. We're just getting started.

Our online support groups are a great compliment to the real-world support groups you may be involved in now. In the near future we are planning to offer support groups and other organizations great tools that will help them communicate with their members and stay organized. And we have a host of other projects planned which will make our site much more useful and effective than it already is.

I work with DailyStrength, which was started by three partners who met at Yahoo!, where they helped create some of the biggest online communities on the web. We know how to make successful online communities that are safe and anonymous. We're really excited to offer www.DailyStrength.org

to the world.

I would be eternally grateful if you'd come check out the site, let us know your thoughts, and share this resource with others who it might help.

I can be reached at Nicholas@DailyStrength.org with any thoughts your might have.

Warm Regards, Nicholas Jarrett

The above e-mail was sent to Patrick Dunlap at the Sacramento Chapter CFF. It may be of interest to some of you that have asked about on-line support groups.

- The Boomer Esiason Foundation, BEF, offers an opportunity to support the power of daily physical exercise through Team Boomer! Read about a new effort that will help fund their Exercise for Life scholarship program for people with CF. This scholarship will acknowledge their commitment to physical activity and also help them pursue their academic dreams.

Participants in Team Boomer can raise monies through their involvement with many different athletic pursuits: from jogging to swimming, whether they have CF or not. Sponsors support these athletic accomplishments and at the same time, they are helping Team Boomer.

For more information, visit:

www.jerrycahill.com

www.esiason.org (under events)

www.cysticfibrosis.com

Flu Vaccine by Nancy Lewis, MD

Taken from the cForward website:

Get a flu vaccine! Acquiring a Pseudomonas infection is more common in winter than in summer, suggesting that viral infections may be a predisposing factor for Pseudomonas. Viruses can injure the cells lining the bronchial tubes and set the stage for Pseudomonas to bind to the bronchial tube wall.

Animal studies show increased binding of Pseudomonas after influenza infection, so the Influenza vaccine is recommended for all people with CF and their families. It is usually available in October, so aim to get it by Halloween (It is not too late in November, if you were unable to get it in October)!

**CF Education Night
Tuesday
November 28, 2006
5:30pm Vendor
Displays and
Appetizers
6:30pm Program**

5th Annual Golden Oaks Charity Golf Tournament

Once again, this annual event was a huge success. Organized by Melissa and Morgan Mahanke with the support of their volunteers, \$ 76,000 was raised to benefit The Cystic Fibrosis Foundation. In addition to the golf tournament, participants also enjoyed a wonderful dinner and a silent and live auction.



Assistance Programs:

- 1) Bayer Indigent Patient Program:** Provides Cipro to assist patients who are not eligible for, or covered by insurance and whose household income is below federal poverty level guidelines. Contact info: Bayer Indigent Patient Program; PO Box 29209, Phoenix, AZ 85038-9209; 1-800-998-9180
- 2) King Care:** Provides Colymycin to assist patients who are not eligible for public assistance and who are financially unable to afford the cost of medication. Contact info: King Pharmaceuticals; 118th Street, Bristol, TN 37620; 1-877-546-5332
- 3) Solvay Patient Assistance Program:** Provides Creon to patients who cannot afford to pay for prescriptions, who are not eligible for Medicaid and who do not have insurance or other third party support. Eligibility determined on a case by case basis. Contact info: Solvay Pharmaceuticals, Inc: Patient Assistance Program: PO Box 66550, St. Louis, MO 63166; 1-800-256-8918
- 4) Wee Care for CF Nutrition:** Provides a free supply of creon minimicrospheres pancreatic enzymes and vitamax pediatric drops through a patients second birthday. Contact info: Wee Care for CF Nutrition; CF Services, Inc.; Attn: Wee Care Program; 6931 Arlington Rd, 2nd Floor, Bethesda, MD 20814; 1-800-541-4959
- 5) Extra Helpings Program:** Provides a free 60 tablet bottle of vitamax multivitamin (pediatric drops or tablets) with every purchase of at least a 30 day supply of creon minimicrospheres. Contact info: Extra Helpings Program; CF Services, Inc.; Attn: Extra Helpings Program, 6931 Arlington Rd, 2nd Floor, Bethesda, MD 20814; 1-800-541-4959

Information on other assistance programs will be included in future newsletters.

Nebulizer Maintenance

1. Nebulizer Drive line (line between the air compressor and nebulizer). The manufacture does not recommend washing the tubing as it is very difficult to dry completely. The inside of the tubing usually remains dry and clean because of the air blowing through the tubing.

On occasion, there may be moisture in the tubing as a result of condensation. If the tubing does become wet, it should be washed with the other part of the nebulizer. After the tubing has been washed, wipe off the outside of the tubing with a cloth.

You can usually dry the inside of the tubing by attaching it to the compressor, turn it on and allow the air to blow through it . If moisture in the tubing continue to be a problem, consult the company it came and from and request a new tubing.

2. Like the nebulizer, the compressor is subject to bacteria and debris, which can cause infection. To clean the compressor, wipe down the outside of the unit with a clean damp cloth on a daily basis, as required by the manufacturer and change any filters found on the machine.

Note that different manufacturers recommend changing the filters at different time and follow there recommendations. Home made filters is not a good idea since the filtering capabilities may not be as effective.

Replacement filters are usually available through the manufacturer or through the company where you purchased the compressor.

Please contact me if you have any questions, concerns and/or comments.

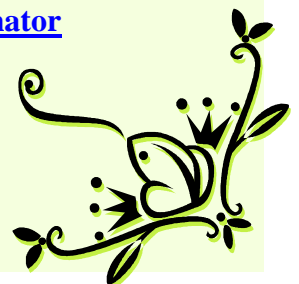
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Patient News

- Rachel Bolen recently graduated from UCSB and majored in Art. She plans to get her teaching credential.
- Madyson Ysasga had fun competing on Swim Team this past summer.
- Randi Sanford spoke at the Emigh's Hardware

Golf Tournament that benefited Cystic Fibrosis. She spoke about the Newborn Screening Law. Randi had a Lung Transplant on February 2, 2006 and she said she is doing great and has had "no complications."

Patient Photos

Karina and Guillermo Vazquez, and their father, participating in the John Hopkins Sibling Study here at our center.



Aimee Braddock, age 16, goes to Natomas Charter School and is interested in Marine biology and Manga (Japanese comic books). She enjoys the visual arts and has been taking Art Lessons for the past few years. She is excited about starting a new job at Anchor Blue Clothing.



Neri Vilafan excitedly showing his new backpack, donated by Axcen, and Kasey Pearson, RN, PNP during a clinic visit.

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Front Row: Kasey Pearson, PNP, Myrza Perez, MD, Susan O'Bra, BS
 Back Row: Phillip McDonald, MD, Debra Scott, RD, Lori Dacayo, RRT, Shaun Gray, MSW, Wendy Hubbs, RN, Bradley Chipps, MD, David Blackney, RRT

Recipe: Shepherd's Pie (www.kidshealth.com)

Prep Time: 45 Minutes

Ingredients:

1 c. mashed potatoes, prepared

1/3 c. sliced mushrooms

8 oz. ground beef

1/3 c. onion, diced

2 tsp. Worcestershire sauce

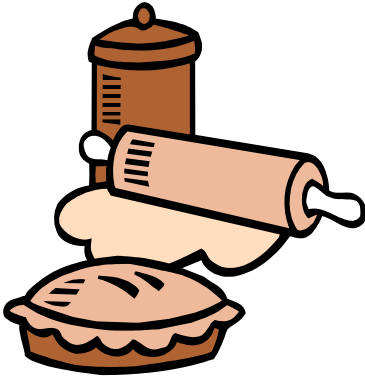
2 cloves of garlic, minced

1 tbsp. flour

1/2 c. beef gravy

1 carrot, shredded

1/4 tsp. marjoram



Directions:

1. Preheat oven to 350 degrees Fahrenheit
2. Sauté mushrooms, garlic, and onions until tender, approximately 7 minutes
3. Transfer mixture to bowl

4. Cook beef until brown in skillet over medium heat, approximately 8 minutes
5. Add flour and stir for 2 minutes
6. Add mushrooms, onion, garlic, gravy, carrot, Worcestershire, and marjoram
7. Simmer for 4 minutes, stirring occasionally
8. Spoon beef mixture into a small baking dish or two oven safe bowls
9. Spoon mashed potatoes over top of beef mixture
10. Bake until heated through and golden brown, approximately 25 minutes
11. Let stand for 5 minutes before serving

Serves: 2

Serving size: 1 1/4 cups

Nutritional analysis: 922 calories, 34g protein, 72 g fat, 931 mg sodium, 111 mg calcium



**Sutter Medical Center
Sacramento**

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