



THE LINK

Sutter CF Center Newsletter



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About Our Center:

The Sutter CF Center cares for approximately 95 patients, 66 children and 29 adults. The center was nationally accredited in 2002 as a Cystic Fibrosis Foundation (CFF) Care Center. There are 115 centers in the United States and specific standards of care must be met in order to earn accreditation. Accredited Centers provide patient data anonymously to the CFF Data Base and this data is analyzed and used to improve the treatment of Cystic Fibrosis patients through research. The Sutter CF Team members are Dr. Bradley Chipps, Medical Director, Dr. Phillip McDonald, Associate Medical Director, Kasey Pearson, PNP, Dr. Yinka Davies, Gastroenterologist, Wendy Hubbs, RN, CNS, Debra Scott, Pediatric Outpatient Dietitian, Shawn Gray, Clinical Social Worker, David Blackney, Respiratory Care Practitioner, RRT and Susan O'Bra, Clinical Data/ Research Assistant. The goal of the team is to follow patients on a long-term basis and promote health in the best way possible.

2004 North American Cystic Fibrosis Conference (NAFC)

On October 14th-17th, Dr. Bradley Chipps, Kasey Pearson, PNP, David Blackney, RRT, Shawn Johnson, MSW, Dr. Phillip McDonald, and Wendy Hubbs, RN, CNS attended the 2004 North American Cystic Fibrosis Conference (NAFC) in St. Louis, Missouri. 3000 participants attended including Physicians, Nurses, Respiratory Therapists, Social Workers, Child Life Specialists, Researchers, and Scientists from North America, Europe, Japan and Australia all attended this outstanding conference. The three general session topics were: Developing CF Therapies: From the Laboratory to the Patient; How Do We

Recognize a Clinically Effective New Treatment; and Care Providers and People with CF: Together We can Make Great Things Happen. High points from the conference will be presented at the Annual Sutter CF Family Education Night, November 30th. A packet of handouts will be available that highlight the conference topics. This was a unique opportunity for the Sutter CF team to collaborate with colleagues, researchers and caregivers from around the globe and hear the latest and greatest scientific and medical updates from the worldwide CF community.

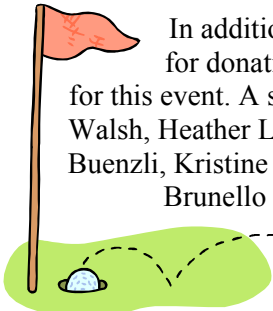
Letter from the Editor:

Over the years we've seen the Sutter CF Center grow and change. We are very proud of our patients and families and their accomplishments. We've observed that often patients and families are interested in what other patients are doing in their lives. Thus, the idea of a newsletter was born. Now that we are an accredited Cystic Fibrosis Foundation Center, one of our goals is to educate our patients with current information related to CF. We hope that you will gain support and knowledge from our publication, "The Link." Our goal is to provide a means of communication for you and from you. I would also like to say thanks to those of you that have already shared your ideas with us and have supported the concept of a Sutter CF Center Newsletter. Wendy Hubbs, RN, CNS

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Events:

1) The Golden Oaks Golf Tournament teed off in the right direction again this year. The third annual Golf Tournament and Dinner was held on October 11th, 2004 at the Serrano Golf and County Club in El Dorado Hills. Two families from the Sutter CF center, Morgan and Melissa Mahanke, and Kelly and Mario Brancoli, partnered with the Sacramento Cystic Fibrosis Foundation Chapter to host the event. Together they raised over \$49,000 for the CFF. The Mahanke's and the Brancoli's dedicated a lot of time to make this a successful event. Thank you! This event extended beyond just golf; it also included a raffle, a silent action, a live auction, wine tasting and a fabulous dinner.



In addition to the time spent by the families, a large group of volunteers spent countless hours searching for donations for the raffle, silent and live auctions. The volunteers raised over \$35,000 in donated items for this event. A special thank you to all of those who generously donate their time year after year, Christi Walsh, Heather LaMont, Kelly Leone, Vera Janecek, Teri Rodriguez, Stephani Urzi, Jana Newman, Tina Buenzli, Kristine Arrivillaga, Amy Lowe and Rae Bondura. Also, thank you to Dee McGroarty, and Tina Brunello at the CFF for all their dedication and hard work. If you are interested in volunteering for next years event, or would like to be a sponsor, or donate an item for auction or raffle, please contact the Sacramento Cystic Fibrosis Foundation at 916-979-7080.

Please be sure to mark your calendars for next years event to be held Monday, October 3rd, 2005. If you are interested in the golf portion of this event, the cost is \$225 per person, which includes, lunch, course beverages, wine and cheese tasting, dinner, and participation in the silent and live auction. If you are interested in just coming for the evening, the cost is only \$60 per person which includes, wine and cheese tasting, dinner and participation in the silent and live auction. We would love to see you all there!

2) The first annual Masquerade Ball was held Friday, October 22nd at the Hyatt in Downtown Sacramento. Fun was had by all masked individuals! Attendees were treated to a strolling magician, juggler, and caricature artist as they signed in for the event and bid on silent auction items. Dinner entertainment included a Magic Show, the John Skinner Band, video presentation of "Child of Life" from the Lopez family and two special performances from Mikey Bay. The total amount raised is still being tabulated at this time, it is around \$20,000. We are looking forward to trying this again next year!



3) The first Sutter CF Mom's day out was held on October 16, 2004 in Folsom. The event was a lot of fun and the moms that were able to attend enjoyed socializing and having lunch. The event also included tables from 11 home consultants that included, Pampered Chef, Creative Memories, Mary Kay, Discovery Toys, The Body Shoppe, Tastefully Simple, Partylite, Cookie Lee and more. This event is tentatively planned for October 22 next year.



Mark your calendars:

1. **Annual Sutter CF Family Education Night, November 30th, 2004 at the Double Tree Hotel in Sacramento at 6:00 pm. FREE. There will be great information presented from the CF North American Conference. There will also be information from CFF, CFRI and pharmaceutical companies. Food will be served.**
2. **Sutter CF Center, Parents breakfast get-together January 8, 2005 at 9:00 am at the Bella Bru Coffee Co. at 5038 Fair Oaks Blvd. No specific cost, just purchase an item(s) directly from menu. Please RSVP to Jana Newman at (530) 644-6395 or email jbnewmans@comcast.net**

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Patient News:

- Sofia Valdez is walking now and playing on the playground equipment. The family is taking a vacation to Guanajuato, Mexico to see family and old friends in October.
- Ashley Lorenzen is 17 years old and will be graduating from High School this year. She is also very involved with the Humboldt All Star Co-Ed Cheerleading Team. The team has traveled locally and out of the State to competitions.
- Logan Coelho and family had a fabulous trip on a Disney Cruise in August; this was Logan's Make-A-Wish trip.
- Tara Telford gave birth to twins on October 1st!
- Joseph Lopez: Child of Life Video: visit www.childoflife.com and meet Joseph Lopez and his family. Joseph is 3 years old and was diagnosed with CF at the age of 5 1/2 months. "Child of Life" was written for Joseph by his Aunt Renee and two songwriters/producers in Nashville. The website includes the video as well as comments from families and friends.
- Jessica Strisower: She is now 7 months post lung transplant and is doing well. She just made the 8th grade basketball team and is very excited. Her body is having a hard time keeping up with her new lungs! She also has Diabetes but mom thinks it is starting to show improvement. She hasn't had to give herself insulin shots as much. Jessica thinks taking her medicine orally is much easier than the breathing treatments she had to do before transplant. She does have one aerosol treatment, but it is only every other month, like TOBI. Life is great for her now. No more oxygen and she is a lot more active.

General Info and Services:

1. Medical updates and information are obtained by clinic staff regularly; if you would like to receive this information please make sure Wendy Hubbs has your email address.
2. Helpful Websites:
 - a. Chiron introduces cForward.net to help provide age-appropriate information.
 - b. Cystic Fibrosis Foundation: www.cff.org
 - c. Milan Foundation: www.milanfoundation.org
 - d. Boomer Esiason Foundation: www.esiason.org
 - e. Cystic -L: www.cystic-l.com
3. Live Web Casts specific to Cystic Fibrosis can be seen on the Cystic Fibrosis Foundation website, www.cff.org. The next web cast will air on November 15 at 9:00pm ET, topic: "CF Research: What's New? What's Next?" Previous topics have been: Gold Standard of CF Care; CF Nutrition: News You Can Use; How to Avoid Germs in CF; The Patient as a Partner in Research. The archived web casts are available at: www.multicastmedia.com/cff.htm
4. New products:
 - a. CF Car Magnet: semp915@aol.com
 - b. Purple Bracelets: www.milanfoundation.org
 - c. Medical Diary: www.thelittleacorn.com

Infection Control Guideline Reminder

Please use disinfectant hand gel after entering the exam room during your clinic visits. Then please use gel again before leaving the exam room. This is the recommendation of the Cystic Fibrosis Foundation Infection Control Guidelines.

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Question and Answers:

1) Q. What do the numbers mean on the Pulmonary Function Test (**PFT**)? Why is this important for me?

A. The **PFT** is a gold standard of lung wellness. The goal is to maintain stable lung function as we grow. However lung function normally declines as one grows older.

The **FVC** is a test that can be used to display airflow abnormalities (ie. Obstructive and air trapping)

The **FEV1** is a measurement of airway resistance showing how long it takes the lung to empty in 1 second. It looks at the large and medium airways.

The **FEV 25%-75%** represents airflow in the smaller airways.

Be sure to obtain a copy of your PFT for your records and discuss it with your clinic team.

2) Q. I would like advice on handling school issues for CF children of all grades, especially when there is more than one CF child in the same grade at a school.

A. Here are some good resources:

1. The pamphlet, Day-to-Day: School and CF – Call 1-800-Chiron8 or 1-800-244- 7668. (these pamphlets are also available at the Sutter CF Center)
2. 1-800-Fight CF (The Cystic Fibrosis Foundation)



3) Q. If I'm not feeling sick why do I need a sputum sample or throat culture?

A. Bacterial organisms and their antibiotic sensitivity can change, sometimes dramatically, over relatively short periods of time. It also helps us maintain good infection control in the clinic setting and allows us to inform you when you need to be more careful about cross infection.

The Iron Women of Cystic Fibrosis:

An excerpt from the Internet CFF article (www.cff.org)

Two women, Tracy Richardson of New Zealand and Lisa Bentley from Canada will connect the world with Cystic Fibrosis as they complete in the Ironman World Championship in Kona, Hawaii this year. The triathlon includes a 2.4 mile swim, 112 mile bike ride, and a 26.2 mile run. The competition occurred on October 16, however it will be broadcast on NBC on November 20th. Both women have been asked to share their experiences with CF as part of the programming. Both Tracy and Lisa are using their races to raise awareness and funds for Cystic Fibrosis.

Tracey Richardson is a mom to four children, two of which have CF. She began training in 2002 to help ease her depression and lose some weight; the inspiration for competing in a triathlon came from reading an article on a cereal box.



Lisa Bentley was diagnosed with CF as an adult in her early 20's. She has been training hard and must take extra precautions to regulate her sodium levels and remain hydrated. Bentley has competed in over 20 Ironman Triathlons so she is prepared for this competition.

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Recipe: (by Jana Newman, parent)

Chicken and White Bean Soup:

Measurements can vary, make it as mild or spicy as you prefer!!! Serves 8

- 1) 2 lbs white beans
- 2) 1 roasted chicken
- 3) 20 cups chicken broth or water
- 4) 2 yellow onions
- 5) 20 crushed garlic

- 6) 1 can of chopped Ortega chilies
- 7) ½ tbs cumin, white pepper and cayenne
- 8) When ready to serve mix in:
 - a. 3 cups of mozzarella cheese
 - b. 3 cups of pepper jack cheese
- 9) Garnish with cilantro and sour cream

Soak White Beans over night and remove those that float. Bring beans to a boil using chicken broth or water, boil for 1 hour or until beans are soft. Add roasted chicken to beans. In a separate pot sauté 2 large yellow onions in olive oil, when browned add the crushed garlic, Ortega chilies, and spices. Add sautéed mixture to beans, cook for approx. 30 minutes. Stir in cheese and garnish.



Front Row:

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Susan O’Bra, BS
Shawn Gray, MSW

Back Row:

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Wendy Hubbs, RN
Yinka Davies, MD
Kasey Pearson, PNP
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