

CYSTIC FIBROSIS CENTER AT STANFORD

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- LPCH Pharmacy Refill Line..... 650-497-8289

See our website at [cysticfibrosis.lpch.edu](http://cysticfibrosis.lpch.edu) for more information about our center, CF and current topics. To subscribe to this newsletter please email or call Judy Kirby at the number listed above.

We gratefully acknowledge the leadership of friend and parent Penny Stroud in producing this publication.

*2002 CF Education Day:*  
*Saturday, March 2,*  
*from 8:30am to 3pm,*  
*in the LPCH auditorium.*

*To register, call*  
*650-723-9816.*



# Cystic Fibrosis Center News



Courtney Page (left) and Liz Nash (right) were chosen to proudly carry the Olympic Torch.

## STANFORD CF OLYMPIC TORCH BEARERS

Our CF Center has not one, but two members who carried the Olympic torch on its way to the Salt Lake City 2002 Winter Games. 20-year-old Courtney Page of San Luis Obispo carried the flame through the Cal Poly campus on January 16, and 31-year-old Liz Nash and her father carried it through San Francisco's Union Square on January 18. Each was selected from more than 210,000 nominations for everyday heroes who inspire the Olympic Spirit of courage, perseverance and strength. *(story continued on page 10)*



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**Cystic Fibrosis Center News**  
Winter 2002



## CF AND THE COMMON COLD HOW, WHEN AND WHAT TO TREAT

What is a cold and what does someone with cystic fibrosis do about it? We all get them, especially at this time of the year. Viruses cause colds. Studies have shown that we can get as many as eight infections in a year. Children at day care centers or in school, young adults in dorm rooms and adults who work in office buildings are especially vulnerable. Treatment of a cold for someone with CF is generally the same as for anyone else, however certain commonly used over-the-counter drugs should be avoided by persons with CF. Also, special care should be taken to minimize the risks of a cold turning into a CF bacterial exacerbation.

### How to Treat the Common Cold

Viral infections such as colds do not respond to antibiotics, which are only effective against bacterial infections. For persons with CF, a cold can lead to increased inflammation in the nose and lower airways that may stimulate mucous secretion in the lungs and cause chests to feel "tight," a feeling sometimes described as "the cold moved into my chest." To prevent or combat this, increasing the frequency of chest PT or other percussion is recommended. Inhaled medications such as albuterol may also provide relief of the chest tightness. In many cases, this will allow the cold to run its typical course, usually 5 to 10 days, without complications. These measures are often very helpful, however bacterial "overgrowth" in the CF lungs may still occur, necessitating treatment with appropriate antibiotics.

Drinking plenty of fluids, increasing airway clearance routines and getting lots of rest is the best advice to ease the discomforts and minimize the effects of the common cold. Chicken soup does indeed help congestion, but it probably is the hot steam that provides the benefit; tea or any hot beverage may have the same effect. Acetaminophen (Tylenol) or ibuprofen (Motrin, Nuprin, Advil) can be used to treat fevers and muscle aches. If you are on high dose ibuprofen therapy, contact the CF nurse coordinator about dosing. *If you are on anti-depressants, have evidence of liver malfunction or take blood pressure medications, please contact the CF nurse coordinator or your physician before taking any medications for congestion.*

### What to Do About Stuffy Nose and Congestion

It is important to know the difference between congestion caused by a cold and congestion caused by allergy, because treatment for one can be ineffective against the other. For cold-related congestion, the following may help:

**Nasal Wash.** For persons with CF, chronic rhinitis (inflammation in the nose) is common. Having a cold virus infection can make nasal congestion worse. A nasal wash can be helpful for removing mucus from the nose. A saline solution can be purchased at a drug store or made at home. (Recipe: add 1 teaspoon of salt and one pinch of baking soda to a pint of warm water.) The solution may be inserted into the nose using a large rubber ear syringe, available at a pharmacy. Leaning over the sink head down, the patient inserts only the tip of the syringe into one nostril. Gently squeeze the bulb several times to wash the nasal passage and then press the bulb firmly enough so that the solution passes into the mouth, then spit it out. The process should be repeated in the other nostril. A nasal wash is most effective when performed several times a day. There are also electronic devices for irrigating the nose and sinuses, as well as a magic-lamp shaped vessel, all of which are available through allergy and medical supply companies.

*Treatment for someone with CF is generally the same as for anyone else, however certain commonly used over-the-counter drugs should be avoided by persons with CF.*

**Nasal Decongestants.** *Persons with CF should use over-the-counter decongestants sparingly, since these can lead to excessive dehydration of the nose and lung secretions which can lead to mucus plugging and poor clearance of secretions.* Use of these drugs may predispose persons with CF to increased bacterial growth in both the sinuses and the lungs. If necessary, decongestants may temporarily help dry nasal congestion and sometimes ease discomfort while getting through a cold, but they should *only be taken for two or three days*. By reducing blockage, they can sometimes decrease the risk of developing sinusitis caused by viruses or bacteria. However, **they should not be used for more than three days** because of the risk of nasal irritation, rebound effect, and dependency. Nasal decongestants become ineffective with prolonged use. All forms of nasal decongestants may dry out the sinuses and damage tissues. Keeping the nose moist, with saline drops is very important to prevent this.

**Recipe for nasal wash:** *A saline solution can be made at home by mixing 1 teaspoon of salt and one pinch of baking soda to a pint of warm water.*

Sudafed or generic equivalents) is the only over-the-counter single ingredient oral decongestant. The shorter acting preparations (4 to 6 hours between doses) are better than 12 hour preparations. "Cold medicines" are usually combinations of a decongestant, a mucus thinner, an antihistamine and sometimes a cough suppressant. Most of them contain pseudoephedrine, or phenylpropanolamine as the most active ingredient. *We do not recommend use of combination medications.*

The most common side effects of decongestants are agitation and nervousness. All nasal and oral decongestants can cause changes in heart rate and blood pressure, with oral decongestants having a greater effect. The FDA warns that anyone with heart disease, high blood pressure, thyroid disease, diabetes, or prostate enlargement problems that cause urinary difficulties should not use oral or nasal decongestants without a doctor's guidance.

Children appear to metabolize decongestants differently than adults. **Decongestants should not be used at all in infants and small children,** who are at particular risk for side effects of central nervous depression that can result in changes in blood pressure, drowsiness, deep sleep, and, rarely, coma. For all of these medications, it is important to check with the CF nurse coordinator or your doctor about dosing, particularly with children.

**Antihistamines.** Antihistamines are not generally recommended to relieve cold symptoms. Histamine is the chemical released when antibodies overreact to allergens; it is the cause of many symptoms of allergic rhinitis (nasal allergies). The antihistamines relieve itching, sneezing, and nasal discharge. People with bacterial infections in the nasal or sinus passages should use antihistamines carefully; antihistamines thicken mucus secretions and can actually worsen bacterial infections. Many prescription and non-prescription antihistamines are available in both short- and long-acting forms. They are available in tablet, nasal-inhaler, eye drop, and syrup form. Some antihistamines that have been on the market a long time may reduce cold symptoms, but their benefits are likely to be due to the drowsiness they cause which improves sleep. The newer "nonsedating" antihistamines (mostly prescription drugs) do not have these effects but also appear to have no benefits against colds.

Caption and photo to come.

While we do not recommend frequent use of decongestants, occasional, short-term (2-3 day) use of *single ingredient decongestants* may help you through a cold, especially if the cold is accompanied by increased production of mucus. Many over-the-counter oral decongestants are available, either as tablets or nasal inhalers, that are applied directly into the nose as sprays, drops, or vapors. Some of the common ingredients and brands are shown in the table on the next page. Oxymetazoline and xylometazoline are long-acting decongestants used in nasal sprays that are effective in a few minutes and remain so for six to eight hours. Any sprayers, inhalators, or devices used to deliver the decongestants *become reservoirs for bacteria* over time; discard them when the medication is no longer needed.

Except in special circumstances and in consultation with your CF doctor, persons with CF should **avoid combination cold remedies**. Some ingredients may produce side effects without even helping a cold. Some even contain ingredients that conflict (such as a cough expectorant and a cough suppressant). In other cases, a person may increase a dosage to improve one symptom, not realizing they are increasing ingredients that do no good and may even be harmful at higher doses. Pseudoephedrine (sold as

## Cough Remedies

**Persons with CF should not suppress coughs! It is important to expel mucus and phlegm** before it builds up in the lungs. Expectorants are medicines that help to expel mucus and phlegm, while suppressants inhibit good clearance of mucus from the lungs. To loosen phlegm, drink plenty of fluids and increase chest percussion or other airway clearance methods. Persons with CF should not use humidifiers and steamers since they can promote the growth of both mold and *Pseudomonas* within the home. For thick phlegm, cough medications that contain the mucus-thinner guaifenesin can help to loosen mucus. For those patients already taking guaifenesin (Humabid), more is unlikely to help. For a dry irritating cough that doesn't appear to have a cause such as allergies, a cough suppressant may be useful, *however their use should be limited in persons with productive coughs and they should not be used routinely.* Medications that contain *both* a cough suppressant and an expectorant *should be avoided.* Medicated cough drops that contain dextromethorphan are not useful; hard candy or lozenges are just as effective. Those that contain mild anesthetics, such as benzocaine, hexylrescorinol, phenol, and dyclonine (the most potent), may soothe a mild sore throat. If your cough worsens or persists for more than 5 days, you should contact the CF center to determine if alternate treatment is needed.

## Remedies for Sore Throat

Cough drops, throat sprays, or gargling warm salt water may help relieve sore throat and reduce coughing. A dose of ibuprofen can be beneficial in relieving scratchiness and irritation from viral infections, though if you are on high dose ibuprofen therapy you should contact the CF nurse coordinator about dosing.

## Medications for Mild Pain and Fever Reduction

Mild pain relievers, such as aspirin, ibuprofen or acetaminophen may help reduce fever and relieve mild sore throat or other aches and pains. Acetaminophen or ibuprofen are the pain-relievers of choice in children, with or without CF, and generally are recommended for fevers over 101 degrees F.

We do not recommend alternating the two agents. Aspirin and aspirin-containing products should almost never be used in children or adolescents since Reye's Syndrome, a very serious condition, has been associated with its use in children with flu symptoms or chicken pox. Ibuprofen decreases the movement of white blood cells, which may help decrease mucus secretion and swelling caused by a "cold". For persons on high dose ibuprofen therapy a 3rd dose in the middle of the day at the "normal" dose, not the high dose, can be used to reduce mild fevers.

## Natural Vitamins and Supplements

**Vitamins.** Some studies have found that large doses of Vitamin C reduce the duration of a cold by 5% to 50%. Other studies suggest that large doses of Vitamin C may have limited protective properties, and may be useful for prevention of respiratory infections in people in poor health or under heavy physical stress. However, such high doses may cause headaches, intestinal and urinary problems, including kidney stones. Furthermore, large doses of Vitamin C can interfere with the blood tests used in diabetes.

**Echinacea.** The herbal remedy echinacea is now promoted as a way to prevent the onset of colds or flu and to ease their symptoms. It is very important to note that at this time there are no standards or quality controls available for echinacea or any other herbal remedies. People who are allergic to plants in the daisy family should not take it. We strongly recommend against anyone taking untested "natural" remedies (or even unnatural ones!) without a doctor's approval. No studies have confirmed the benefits of these medications and many can cause toxic side effects in large doses.

Type	Recommended for CF?	When to Use	Ingredients	Sample Brands	Side Effects
Saline Nasal Sprays/Washes	Yes	Congestion and stuffy nose	Saline & baking soda	Home made solution Ocean	None
Medicated Nasal Decongestants	Not more than 2-3 days	Cold-related stuffy nose that doesn't respond to non-medicated methods	Oxylometazoline (long-lasting) Oxymetazoline (long-lasting)  Phenylephrine  Naphazoline Tetrahydrozoline	Otrivan Sinex Long-Lasting Afrin, Sinarest, Dristan 12-Hour, Neosynephrine 12-Hour Neo-synephrine, Nostril Nasal Decongestant, Sinex, NaphconForte, Privine Tyzine	Dryness Thickened mucus Poor airway clearance Ineffective if used more than 2-3 days
Oral Single Ingredient Decongestants	<i>Not OK for young children</i> Occasional use OK in adults	Cold-related congestion and stuffy nose	Pseudoephedrine• • <i>Do not take if you have evidence of abnormal liver function</i>  Phenylpropanolamine	Sudafed, Suphedrin® Children's The following are combinations of single ingredient decongestants & guaifenesin which are OK for CF use: Robitussin PE; Q-Tussin-PE; Sephred Dexatrim, Acutrim	Agitation & nervousness Increased heart rate & blood pressure Contraindications: Heart disease, high blood pressure, thyroid disease, diabetes, prostate enlargement Drowsiness
Multiple Ingredient Decongestants	No	Not recommended	Anything that says it treats a combination of "cough, fever, stuffy and itchy nose"	Tylenol Cold & Cough Vick's Nyquil Multi-symptom Cold/Flu Relief Contac 12-Hour Cold Dimetapp 12-Hour Exentabs, Actifed & Actifed Sinus; Theraflu Sudafed Cough & Cold	Multiple
Cough Expectorants	Yes	Thick mucus	Guaifenesin	Robitussin, Scot-Tussin Prescription guaifenesin (e.g. Humabid)	
Cough Suppressants	Sparingly, in consult w/CF Ctr, for dry, unproductive coughs	Dry, non-allergic cough	Dextromethorphan	Drixoral Cough, Robitussin Maximum Strength Cough Suppressant Robitussin CF	Suppression of productive cough & airway clearance
Over-the-Counter Antihistamines	Occasional with MD Approval	Allergy-caused congestion or stuffy nose	Diphenhydramine Chlorpheniramine	Benedryl Chlortrimeton	Drowsiness
Prescription Antihistamines	Yes	Allergy-caused congestion or stuffy nose	Loratidine Fexofenadine Ceterizine	Claritin Allegra Zyrtec	Drowsiness (Zyrtec)

## When Should You Call the Doctor for Persistent Cold Symptoms?

A cold or symptoms that include the following should be reported to the CF Center nurse coordinator (Monica for pediatrics and Mary for adults) for possible treatment of a bacterial complication:

- Fever of greater than 103, and lasting for more than 3 days.
- Increased sputum, especially if consistency is thicker and greener.
- Increased cough lasting for more than 5 days.
- Tenderness around the cheeks or eyes, and/or sinuses.
- Tenderness on just one side of the face.
- Chronic congestion without cold symptoms may be indications of allergies or sinus disease that should be discussed with your doctor.

To summarize, it is important to treat a cold early and aggressively to minimize the chances of it turning into a bacterial exacerbation. Maintaining good nutrition, routine airway clearance, increasing fluids and getting enough rest are important steps to prevent infections, whether colds or bacterial exacerbations. Once a viral infection such as cold or flu has begun, the most effective treatments are increasing fluids, rest and airway clearance.

# Frequently Asked Questions

In each issue we will be addressing a few frequently asked questions from our Center. Please feel free to submit questions for future issues to our nurse coordinators or Judy Kirby at 650-724-3474.

## Does it matter which nebulizer I use with different medications?

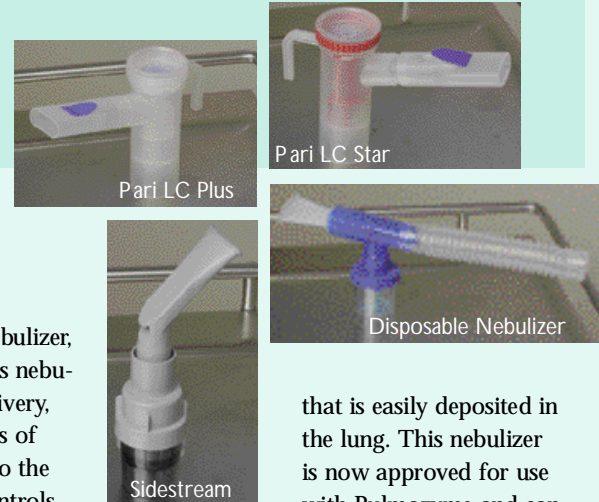
Yes, different nebulizers have different rates of drug output, efficiency of delivery and impact on particle size, which can impact the effectiveness of a treatment. All prescription medications go through extensive clinical trials with strict controls over equipment. Thus, data on the effectiveness of a medication is based on the equipment that was used during the trials. Some drugs that have been on the market for a while have been tested with multiple nebulizers, not all of which have been found to deliver the needed dose and particle size for optimal distribution in the lungs. The newer nebulizers, such as the Sidestream™, are faster, but have not been found to be as effective with antibiotics. It is also important to note that faster is not always better: particle size and amount of drug delivered to the small airways are important factors in optimizing the impact of the drug on your lungs. The following is a brief description of the most common nebulizers and a table on recommended uses.

The **Pari LC Plus** is a reusable nebulizer, which lasts 6-12 months. The LC Plus is advertised as increasing drug delivery. The patient's breathing controls the out-

put rate of the nebulizer by use of a valve system; therefore little medication is lost during expiration. This nebulizer has been shown in studies to be an efficient way to deliver TOBI® and most other medications.

The **Pari LC Star** is a reusable nebulizer, which will last 6-12 months. This nebulizer promises increased drug delivery, and a high percentage of particles of optimum size for good delivery to the lungs. The patient's breathing controls the output rate of the nebulizer by the use of a valve system and there is less medication lost during expiration than with the Pari LC Plus. The Pari LC Star has been shown to be the best way to deliver Colistin (an antibiotic prescribed to some CF patients), because it can nebulize the medication efficiently without developing foam. This nebulizer can also be used to deliver other medications.

The **Invacare Sidestream™** is a reusable nebulizer, which will last 12 months. This nebulizer is advertised as a faster way to deliver medications. It provides a high number of particles in a size range



that is easily deposited in the lung. This nebulizer is now approved for use with Pulmozyme and can

also be used with bronchodilators such as albuterol, ipratropium (Atrovent™), and cromolyn (Intal™). However, *it should not be used with antibiotics*, like TOBI® or amphotericin, a drug used to treat fungal infections. One disadvantage of this nebulizer is its continuous operation. Since it has no valve, the nebulizer continues to pump during exhalation and an estimated 25-50% of the medication is wasted.

Disposable or standard nebulizers available in hospitals and home care companies come in many shapes and sizes, but generally have the same features. They are designed for one-time, one patient use, but can be washed and re-used for a limited amount of time (usually one month or so). They are inexpensive and are designed to nebulize common medications like albuterol, Intal™ and Atrovent™. One disadvantage of this type of nebulizer is the continuous operation; because the nebulizer continues to put out mist during exhalation (instead of only during inspiration), 25-50% of the medication is wasted.

### Recommended Nebulizers for Common CF Medications

Medication	Pari LC Plus	Pari LC Star	Sidestream	Disposable
Albuterol	Yes	Yes	Yes	Yes
Atrovent	Yes	Yes	Yes	Yes
Intal	Yes	Yes	Yes	Yes
Pulmozyme	Yes	Yes	Yes	Yes
TOBI	Yes	Yes	No	No
Colistin	Yes	Yes	No	No
Amphotericin	Yes	Yes	No	No

## NORTH AMERICAN CFF CONFERENCE HIGHLIGHTS

Stanford had record attendance at the CFF annual conference, the world's largest meeting of clinicians and researchers focused on CF. The Annual Education Day on March 2 will provide more in-depth information on the latest research and new clinical guidelines. Here are some of the highlights our staff noted from the proceedings:

- The basic biology, different strains and patterns of resistance of Pseudomonas Aeruginosa (PA) were major topics of research. These advances should ultimately lead to more effective treatments for chronic management and acute exacerbations.
- Advances in genetic identification of organisms are leading to new ways of looking at infections. Patterns of drug resistance appear to be more important than general type of organism. Scientists have found more than ten strains (genomovars) of what was formerly called Burkholderia cepacia, only one of which is positively linked to more rapid decline in health.
- Infection control was a major topic and is the subject of new clinical guidelines that will be discussed at the annual Education Day on March 2 at LPCH.
- New pediatric nutrition guidelines will be introduced this year that focus on the benefits of earlier identification and intervention for poor nutritional status. The guidelines set higher goals for ideal body weight and increased monitoring of basic nutritional measures, such as skin fold measurements.
- Nutritional research is showing the benefits of earlier monitoring of bone density and use of additional vitamin supplementation.
- New lung imaging of infants, children and adults with CF are more precisely defining the progression of disease and correlations with lung function tests and infections. Later this year, Stanford will open one of only eight infant pulmonary function units in the nation as part of the CFF Therapeutics Development Network. More precise measurements during infancy and early childhood will advance our understanding of CF as well as improve outcomes measures for new and old treatments.

### 2002 LPCH ANNUAL CF EDUCATION DAY

#### INVITED SPEAKERS:

Keynote Speaker—Jane Burns, M.D., Associate Professor, Pediatric Infectious Disease, Specialist CF Microbiology, University of Washington  
 CF Sinusitis—Winston Vaughn, M.D., Stanford Sinus Center  
 Bone Health and CF—Laura Bachrach, M.D., LPCH Endocrinologist  
 Technology and Disease Management—David Bergman, M.D., LPCH Pediatrician

#### CENTER TEAM SPEAKERS:

Nutritional Back to Basics—Julie Matel, Nutritionist  
 Reproductive Issues in CF—Noreen Henig, M.D., Adult Center Director

#### INFECTION CONTROL CONFERENCE PROTOCOLS

For protection of yourself and others, infection control protocols for the conference will require persons with CF to wear a mask. Persons who have cultured *Methicillin Resistant Staph Aureus (MRSA)*, *Burkholderia Cepacia* or who are currently culturing a bacteria resistant to all antibiotics **should not attend**. If you have any questions about your status, please ask for this to be checked when you call to register.

#### REGISTRATION

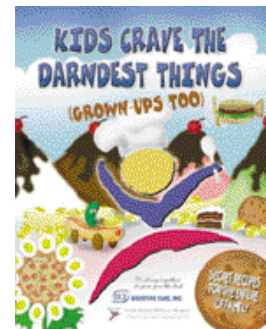
To register for the conference call 650-723-9816. There is no fee, however registration is required. Continental breakfast will be served from 8:30—9:00am, and a box lunch will be provided to registered attendees.

**Saturday, March 2,**  
**from 8:30 am to 3pm,**  
**we will be hosting the**  
**second annual CF**  
**Education Day**  
**at LPCH. Here are**  
**this year's featured**  
**speakers and topics.**

## STANFORD CF IN THE NEWS

Over the past few months, members of the Stanford CF team have been involved in the following efforts to advance the knowledge of CF and clinical care:

- **Dr. Noreen R. Henig** published a chapter in a new online textbook called **Best Practices in Medicine**. Dr. Henig also presented findings at the 2001 NACFC on risk factors for death while awaiting lung transplantation in patients with CF.
- **Dr. Rick Moss** reviewed and summarized clinical experience with TOBI® in the journal CHEST (9/01) and has written another article in CHEST (1/02) on the striking effectiveness of TOBI® in adolescent patients.
- **Dr. Carol Conrad** and pulmonary function technologists **Glenn Hodg e** and **Colleen Dunn** spent three days at Children's Hospital of Columbus training for the start-up of the new infant pulmonary function laboratory later this spring. LPCH received the equipment, one of only 8 units in use in the country, as part of the CFF Therapeutic Development Network.



### LAST CALL FOR COOKBOOK SUBMISSIONS

OUR UPCOMING CF COOKBOOK PUBLICATION \*KIDS CRAVE THE DARNDEST THINGS (GROWN-UPS, TOO)\* HAS RECEIVED WIDE-SPREAD ENTHUSIASM AND

RECIPES FROM CF PATIENTS AROUND THE COUNTRY. IT'S NOT TOO LATE TO SEND IN YOUR FAVORITE RECIPE AND RECEIVE A FREE COOKBOOK! WE ARE IN THE FINAL STAGES OF RECIPE EVALUATION AND TESTING, AND HOPE TO HAVE THE BOOK IN PRODUCTION LATER THIS YEAR. RECIPE FORMS ARE IN CLINIC E, ON THE CF CENTER WEBSITE, OR YOU MAY CALL OR EMAIL JULIE MATEL OR JUDY KIRBY.



### CF PATIENT BULLETIN BOARD ON 3 NORTH

17-year old Angel Mammino was an inpatient at LPCH three times this year, most recently on the new nursing unit. She also participates in clinical trials that keep her a frequent visitor to Clinic E. Now she will be

making those frequent trips to Stanford more productive with a new project that she hopes will serve as a "virtual meeting place" for the Stanford CF community. Angel realized there was not a place for Stanford CF patients to learn from the experiences of other persons with CF, communicate with other CF patients and families, or learn about CF events and the lives of her extended "CF family" of children and adults living with the disease, and the people who care for and about them. She also wanted to recognize and honor the life of her best friend, Adam Oneto, who died from CF in April. Angel decided that a CF patient-sponsored bulletin board on the inpatient unit would serve both functions. The Bulletin Board honors Adam, who worked with his friend Thayer, to get the "green ribbon" designated as a symbol for CF, similar to the pink breast cancer and red HIV ribbons. Monica Smith, pediatric CF nurse coordinator, helped get approval for the board, and LPCH engineers quickly had one mounted. Now Angel plans to change the board once a month and encourage others with CF to post information or their thoughts and pictures—from outside the hospital setting—so that other inpatients can know more about each other. Angel hopes the board will reduce the feeling of isolation CF patients often have when in the hospital, since they are frequently asked not to attend school, craft and group activities due to infection concerns. Persons with CF may post things by or about themselves, however permission may be required to post something about another person with CF. She already plans to start a board in the adult CF unit at Stanford Hospital in February when she turns 18.



### LPCH CF INPATIENT UNIT MOVES TO 3 NORTH

In November 2001 LPCH nursing unit 3 North became the home away from home for most LPCH CF inpatients. The move helped make room for the expanded heart surgery program while also allowing improved separation of patients at risk for cross infection. The unit is smaller than 3 West, with only 16 beds, and no 4-bed rooms! There are 10 single rooms and 3 double rooms. CF patients are assigned private rooms whenever possible. There is also a treatment room on the unit, making it easier to do minor procedures such as insert IV lines. Most of the nurses remain the same, including unit manager's Andy Brittan and Rita Robinson. Many of the nurses are working 12-hour shifts, thus patients will have only two nurses assigned for their care on any one day. Most nurses rotate between 3

North and 3 South. The staff has begun decorating the unit to make patients and families feel more at home. Nurse Patti Smith created a series of warm and inspiring quotations that are posted outside the doors of each room.

Charge Nurse Andy Brittan said the move has gone smoothly, with many nurses and patients working to make the unit a comfortable place for patients and staff. Bulletin boards in the hall have staff pictures and names, and a new CF patient Bulletin Board has been mounted.

*"The world belongs to those who dream boldly, care deeply and work diligently."*

—unknown



From top clockwise: Happy nurse caption; Volunteer Natasha Deganallo shares a moment with young patient Caley Camarillo; two nurses caption.

## STANFORD OLYMPIC TORCH BEARERS (continued from front page)

For Courtney Page, the event comes just twenty months after her “personal Independence Day”—May 5, 2000 when she received a double lung transplant at Stanford. She resumed life as a college student just four months later, following two pre-transplant years on oxygen. Family and friends from her hometown of Cambria, and doctors and nurses at Stanford, nominated Courtney for the Olympic honor. Courtney reports that her adrenaline was rushing and it was an awesome experience. When not attending classes at Cal Poly, her favorite pastimes are wakeboarding and jet skiing.

Liz Nash was nominated by her father, who was invited to join her as an “inspirational pair” for the event. The Olympics always excited Liz, who grew up near Lake Placid New York, and later earned a Ph.D. in Molecular Genetics in Salt Lake City. She works for a biotech company now, and in addition to daily CF treatments, she competes in sprint triathlons—a shorter version of the swimming-biking-running endurance race. She also finds time to chair the Research Advisory Committee of Cystic Fibrosis Research, Inc. When he received the torch from her, Jim Nash, Liz’s father, said, “I thought about all the goals she set for herself, goals you would have thought she couldn’t have achieved, but then she did. That’s the Olympic spirit to me.”

## LANDMARK LUCILE PACKARD CHILDREN’S HEALTH INITIATIVE CAMPAIGN TO BENEFIT CF CENTER

November 15 marked the kick-off of the Lucile Packard Foundation for Children’s Health (LPFCH) \$500 million campaign to support Packard Children’s Hospital and the Stanford University School of Medicine. The goals of the campaign are to foster development of preeminent programs that will impact children’s health here and at medical facilities throughout the world. The Pediatric Pulmonary & Cystic Fibrosis Center at Stanford is one of six Centers of Excellence that will receive focused development. The David & Lucile Packard Foundation donated \$100 million as a lead gift, and have committed to matching all gifts up to an additional \$200 million! As a Center of Excellence, up to \$20 million will be devoted to enhancing the clinical and research programs for CF and pediatric pulmonary at LPCH and SUSOM over the next ten years. The CF Center’s efforts to meet the \$10 million challenge grant are off to a good start with an anonymous donation to endow a new professorship in pediatric pulmonology in honor of Ann and Richard Bass. Dr. Harvey Cohen, Chairman of Pediatrics, noted, “I firmly believe we have begun a journey towards developing a preeminent center for research and discovery across the span of complex pediatric conditions and disease. These funds hold the key to making this groundbreaking concept a reality that promises to hugely impact pediatric healthcare.” The campaign presents great challenges and an opportunity to build on the vision and legacy of Lucile Packard as the hospital enters its second decade of caring for children and their families. We are honored to have been designated as a Center of Excellence and invite you to join us in building a preeminent CF Center.

Janie Perez, P.N.P., Research Coordinator for the Stanford CFF Therapeutic Development Center.

## Research News

### CF.DOC INTERNET PILOT PROJECT

A new Stanford CF Center pilot study will test an interactive personal web page for LPCH CF patients. Up to 50 individuals will be enrolled in this study to test use of the internet for improving communications with the Center and participating in management of one’s own health. We are especially excited to enroll people who have not participated in other studies because they live too far away, adults with busy lives, and families whose children have not met the criteria for other studies. “CF.DOC” will establish a secure private medical web page that will allow you access to personal medical information such as lab or PFT results. You will be able to send and receive secure emails from your clinician, schedule appointments and refill prescriptions online. Study commitments will include:

- A brief training session on the program
- Weekly (or more) contact with the website
- A 6-month commitment to participate
- Commitment to set and monitor progress on individual treatment goals

Participants will need a computer, internet access and a willingness to try new ideas. Please contact Judy Kirby at 650-724-3474 or jkirby@leland.stanford.edu, or Lynn Nepomuceno at 650-723-9816 or llynn@stanford.edu.

### NEW STUDY ON UNDERSTANDING DIFFERENCES

The Stanford University Center for Biomedical Ethics is seeking adults with CF for a study to investigate how CF impacts the way you live and what having CF means. Participation will involve completing a 60-90 minute anonymous interview. Participants will be compensated for their time. If interested, please call 1-800-716-2614 Extension 3. There are also flyers in the CF clinic with more information.



### JANIE PEREZ JOINS CF RESEARCH TEAM

Join us in welcoming Janie Perez, P.N.P., the new Research Coordinator for the Stanford CFF Therapeutic Development Center. Janie joins Zoe Davies and Colleen Dunn in the clinical trials and research program. She is a pediatric nurse practitioner in her fifth year at Packard. Previously she held positions in the Packard health van and high risk infant development follow-up programs. After only a week on the job she observed a gene therapy trial, and is excited to join a team working on the forefront of CF research. Janie has already been impressed by the warmth and support of the research team and volunteer research participants and looks forward to participating in all aspects of clinical research.

### ACTIVE RESEARCH RECRUITMENTS

We are actively recruiting subjects for the following trials:

- Cystic Fibrosis Once Daily Aminoglycoside Collaborative Trial (CFODACT). Please consider this study if you are being admitted for an exacerbation.
- A Multicenter, Double-Blind, Placebo-Controlled Phase II Study of Aerosolized tgAAVCF in Cystic Fibrosis Patients with Mild Lung Disease
- Standardization of the Measurement of the Nasal Membrane Transepithelial Potential Difference
- Diabetes Therapy to Improve Body Mass Index and Pulmonary Function
- Validation of Sputum Induction as an Outcome Measure for Lower Airway Sampling in Patients with CF
- A Phase I/II Study of Interferon Gamma-1b by Inhalation for the Treatment of Patients with Cystic Fibrosis
- Sweat Rate Procedure Standardization for CF Research Centers for patients who have had genotype testing
- Health Buddy telephonic/web-based home monitoring system for persons with CF
- Hi-D FACS with CF Blood & Lung Leukocytes study of chronic oxidative stress in CF (cell samples needed from blood/sputum/bronchoalveolar lavage)

Please consider participating in our research efforts. It is through the efforts of all of us that better treatments will become available. Ask your physician or call our research staff if you are interested in learning more about participation. Some of our teen patients have received community service credit for their participation in trials and studies.