Lucile Packard Children's Hospital at Stanford

SUMMER 2013

STANFORD SCHOOL OF MEDICINE
Stanford University Medical Center

CYSTIC FIBROSIS CENTER NEWS

Infection Control at the Stanford Cystic Fibrosis Center

BY CARLOS MILLA, MD

Among physicians, nurses, and medical scientists it is clearly recognized that the cystic fibrosis (CF) defect places patients at risk for the acquisition of chronic pulmonary infections with microorganisms that are difficult to treat. For the most part, these infections are commonly acquired from the environment. However, we should also recognize that health care settings provide a potential source of infection.

This is a serious issue, as acquisition of certain pathogens is often associated with more rapid decline in pulmonary function and with early mortality. Unfortunately there are many examples worldwide of incidents where patients were exposed to and acquired serious infections while receiving care at a medical facility. The recognition of the potential for patient-to-patient transmission of microorganisms, as well as the health care environment potentially providing the means for this transmission, presented a need to protect CF patients from its occurrence.

More than 10 years ago, a panel of experts in the field was convened to review the evidence available and produce a set of recommendations to prevent the risk of infection. Thanks to this effort, a consensus guideline for infection control in CF Centers was published. This led to the recognition across the network of CF Centers of the importance of developing and implementing infection control policies.

The Stanford CF Center has always considered infection control to be a critical component of safe patient care. Our stance has been fairly simple: given that we will never be able to have absolute certainty as to the infection status of a given patient, we treat ALL CF patients exactly the same way. We assume that any patient could be harboring a potentially transmissible organism. We also recognize that this is a two-way process, so we treat any health care encounter as potentially exposing a patient to an organism. With all this in mind, our practices are standardized to follow what is known as "contact/droplet" precautions at all times and for all CF patients.

If you have been at the Stanford CF center you are probably quite familiar with what "contact/droplet" precaution entails: anyone coming in direct or close contact (defined until now as three feet) with a CF patient performs hand disinfection and then dons a disposable gown, a face mask, and gloves. Once the contact is completed, the gown, mask and gloves are disposed of and hand disinfection is again performed before concluding the visit and leaving the room. Perhaps what is not apparent is that, in addition to what you see during an encounter, there are other procedures and policies in place to ensure that surfaces, utensils, equipment, and anything that could come into contact with a patient follows strict standards for cleanliness and disinfection.

Not only has there been a serious effort to educate staff and to implement the new guidelines, but we also periodically come back to our established policies and think carefully about the need for any im-

Our Center's mission is to excel in cystic fibrosis care, to be partners with those we care for, and to be leaders in the discovery process that will produce the cure for cystic fibrosis.

Infection Control story continued from page 1

provements. For this, we critically review our practices as new information becomes available and identify any aspects that might require intervention. As a result, we have harmonized infection control policies both for the outpatient and inpatient settings at Lucile Packard Children's Hospital and Stanford Hospital. Our last modification occurred a little over a year ago, in response to the ongoing major construction activity around the medical center campus. This resulted in our request for patients to wear a "turquoise" mask (officially known as an N-95 particulate filtering mask) when coming to the clinic, to minimize the exposure to mold spores.

Over the last 10 years a large body of scientific information has accumulated about infections in CF, aided by novel technology. An example of the complexities of the emerging information is in an article in our previous newsletter called "Identification of microbes in healthy lungs sheds light on cystic fibrosis in new study." Although some of the information might seem confusing and difficult to interpret, it does not change our basic understanding of CF and infections. What is becoming more apparent is that these infections are likely more complex in their onset and evolution. In addition, there is emerging evidence of their transmissibility being more likely than previously appreciated; this is particularly true for microorganisms that were not as commonly identified a decade ago.

An expert panel was recently reconvened by the CF Foundation to provide an opinion, which resulted in a revised guideline announcement. For the most part, the policies in place at Stanford are already well within what has been released for preview. Perhaps the only change under consideration is increasing the safety distance from 3 feet to 6 feet. Given recent scientific evidence pertaining to transmission of Pseudomonas, it is clear that this recommendation makes absolute sense and is one we will implement.

Perhaps of greater importance is that we maintain consistency in our practices and also keep you well-informed and educated about them. Our goal is to provide a safe environment for your or your child's care. It is our mission to partner with those we care for, so your involvement is key to our success. We ask you to be vigilant about what we do and when you perceive that there has been a breach, please tell us. We will also ask you to let us know when you notice any inconsistencies or when something is not clear to you. Please be reassured that we always welcome your comments and suggestions, that we will always hear any question as a good question, and that we will pay close attention to any concerns you voice.

Suggestions for Questions or Comments to your provider during an encounter*:

"Excuse me, I know you are not examining me (my child), but I would feel more comfortable if you put on a mask/gown/gloves."

"I am trying to teach my child about the importance of sanitizing his/her hands. Could you please be a model for my child and show him/her how you sanitize yours?"

"I don't mean to offend you, but I didn't see you clean your hands."

"I am unclear on the infection control policies/procedures here in clinic. Could you tell me more about them?"

**Extracted from our brochure: "Partners in Health"*

Summary of Infection Control policies for CF Patients:

While Hospitalized

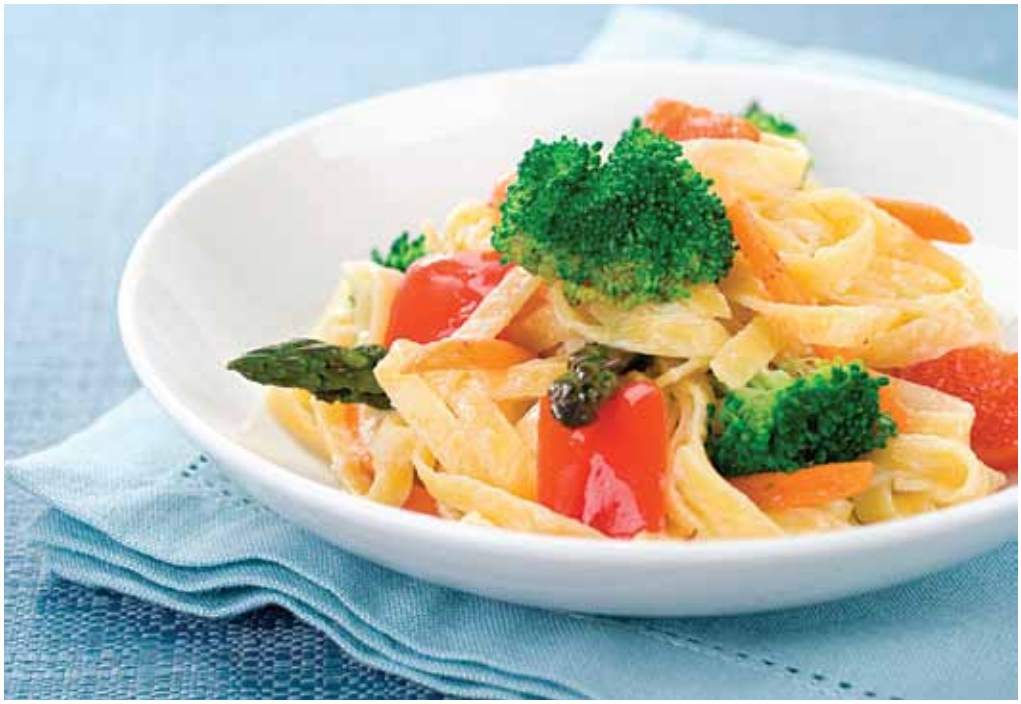
- Patients will be placed in a single room.
- Contact/Droplet isolation precautions will be followed throughout the hospitalization.
- A Contact/Droplet sign will be posted on the room's door.
- Staff will perform hand hygiene before patient contact, upon glove removal, after touching the patient or any potentially contaminated articles.
- Staff coming in direct contact or within 6 feet of a patient will perform hand disinfection and wear a gown, mask and gloves.
- The patient is to remain in the room for the length of the hospitalization, except when going to a different unit for a test or procedure.
- Patients will be visited in their rooms by Child Life specialists and the School teachers to assess and provide for patient needs while they are hospitalized.
- Housekeeping performs routine daily cleaning in accordance with the procedure for cleaning an isolation room.

Clinic visits

- Patients will wear a "turquoise" (N-95) mask upon coming to the medical campus.
- Check in will be expedited so that the patient spends minimal time in the waiting area and is roomed promptly.
- Once the patient is roomed, the room door will be closed and patient can remove mask.
- Any staff coming in direct contact or within 6 feet of patient will perform hand disinfection and wear a gown, mask, and gloves.
- Any staff entering the room will perform hand disinfection upon entering the room and before leaving the room.
- Once the visit is completed, patient will wear "turquoise" mask and proceed to check out area. Check out will be expedited to minimize time in the waiting area.

Vitamin K

BY LARA FREET, RD



Vitamin K is one of four fat-soluble vitamins needed by the human body for different biochemical processes. Vitamin K is available from food sources, supplements, and as a byproduct of bacteria in the intestinal tract. There are three forms of vitamin K: vitamin K 1, also known as phylloquinone (natural form found in food sources) and phytonadione (synthetic form); vitamin K 2 also known as menaquinone; and vitamin K 3 also known as menaphthone.

Vitamin K 1 is the primary form available within the United States as a supplement and found in food. As one of the fat-soluble vitamins, vitamin K is stored in the liver and fat tissues. People who have cystic fibrosis and exocrine pancreatic insufficiency, in particular, have challenges absorbing fat. Fat-soluble vitamins need a fat source to effectively absorb across the gut barrier during digestion, which is why vitamin K deficiency is observed in people with cystic fibrosis.

Vitamin K is involved in a few key roles within the body. The most important and well-researched role involves helping blood clot or coagulation. Vitamin K helps to make a few of the proteins needed to improve how quickly blood clots. There is also some research highlighting the role of vitamin K in prevention and management of osteoporosis. Studies have noted that low circulating levels of vitamin K can result in lower bone density levels. Vitamin K helps calcium to be absorbed and metabolized to improve bone density. For patients with cystic fibrosis, specific clinical labs are checked routinely to assess the need for additional vitamin K supplementation. Vitamin K supplementation can interact with certain medications making them less effective, so any supplement should be reviewed by the medical team prior to starting.

Vitamin K can be found in multivitamins routinely prescribed for people with cystic fibrosis; additional supplementation can be recommended by the medical team. A variety of food sources are rich in vitamin K, the highest concentrations of which can be found in dark green produce (see the chart below for specific amounts per serving*). Freezing may destroy the vitamin K structure in foods, but heat does not impact the structure at all. If a person has a healthy gut bacterial flora, the bacteria will also produce vitamin K as a byproduct of digestion and fermentation contributing to the body's vitamin stores.

Food	Serving Size	Vitamin K (in micrograms)
Kale, raw	1 cup	472
Spinach, raw	1 cup	145
Avocado	1 each	48
Natto (Japanese dish)	1 cup	40
Broccoli, chopped	1 cup	93
Asparagus	1 cup	56
Prunes, dried, stewed, pitted, no sugar added	1 cup	65
Beet greens	1 cup	152
Brussel sprouts, raw	1 cup	156
Collards, raw	1 cup	157

Managing Big Decisions about Career and Disability

BY MEG DVORAK, LCSW

Adults with CF are living longer and more comfortable lives due to continued research and more effective medical management of the disease. According to the most recent data available through the CF Foundation, 33.9 percent of adults with CF are working full time and 11 percent are working part time. 24.5 percent of CF adults are students, most with the goal of acquiring skills and degrees for the workplace. In most cases, teens and young adults with CF are encouraged and expected to progress through the same milestones as their peers, including college, employment, and even having families. There are additional considerations, such as maintaining affordable insurance and access to care, having a stable income to live comfortably, and maintaining flexibility to accommodate for illness and disease management. Finding the perfect work/life/health balance is an ever-elusive goal for most CF adults (as it is for many adults even without the added challenge of CF). This article will address the benefits of working versus living on disability as well as some of the proposed changes in Social Security and the Affordable Care Act (ACA).

Most emerging adults desire to have some experience in the workplace, if not a full career. The basic human need for accomplishment, success and recognition that usually come with a job are strong factors in one's decision to seek employment. One's identity can be influenced through career choice and work experience. For those with CF, work can be a healthy distraction from the tedious and time consuming treatments. Having a job helps one to feel "normal" and in sync with non-CF peers. Work also acts as a financial, social, and emotional anchor to balance out the emotional impact of the disease. Finally and most importantly, work provides income and in some cases insurance to meet the most basic needs for food, clothing, shelter, and healthcare.

Once a person with CF begins to experience health problems, there can be difficult and confusing decisions to make. Because each person's disease characteristics and workplace situation are vastly different, there is no single solution in how to balance the need to work with the need to care for health. Options to consider include creating a more flexible schedule, applying for short term disability, finding a new job where one can work from home, or working part-time. Transitioning from work to disability requires careful planning of finances, insurance coverage, and the emotional considerations of such a significant life change. These decisions should be made with the careful guidance of the CF care team and significant others in your life.

Many individuals with CF are unaware of the Social Security Administration (SSA) eligibility criteria for disability and thus continue to work long after they meet disability criteria. Others who are aware of their eligibility status choose to continue working either because they have to or they want to. The CF Program social worker is the best resource to discuss any questions, concerns, or issues related to the workplace and/or disability. Additionally, the

For those with CF, work can be a healthy distraction from the tedious and time consuming treatments.

CF Foundation funds a CF Legal Information Hotline (1-800-622-0385, cflegal@cff.org) which provides free and confidential information about health insurance, Social Security benefits, employment rights, and education rights. The CF Social Security Project, a case-management service, may be able to provide legal representation for people with CF applying for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits (1-800-622-0385).

You may have heard that the SSA is currently reviewing and updating the eligibility criteria for CF. The rationale behind this review is to "clear up confusing rules and keep up with modern medicine" (per SSA webinar 5/9/13). Under the proposed rules, an individual with CF will have to meet stricter criteria for FEV1 (for males 45 percent, for females 35 percent; ages 18-20 50 percent or lower) as well as the number of hospitalizations in the year one is applying for benefits. These new rules are likely to be implemented between May and July 2014. For those who are already receiving benefits, a continuing disability review (CDR) will be conducted using the old eligibility criteria (per webinar 5/9/13). If you are considering applying for benefits now, you must complete your application no later than March 2014 to be considered under the old rules (which consider FEV1 at 50 percent and use of home IVs). For more detailed information and updates, you can contact the CF legal information hotline or visit www.socialsecurity.gov/disability.

Another big change on the horizon is the implementation of the Affordable Care Act (ACA) in January 2014. The ACA will be a big breakthrough for people living with CF who have been unable to get insurance because of a "pre-existing condition" or unable to afford insurance. Starting in 2014, the Medicaid program will be expanded and all Americans will be able to buy private insurance through an online "marketplace." With one application, you can see all your options and enroll. When you use the Health Insurance Marketplace, you'll fill out an application and find out if you can get lower costs on your monthly premiums for private insurance plans or lower out of pocket costs. The Marketplace will also tell you if you qualify for free or low-cost coverage available through Medicaid or the Children's Health Insurance Program (CHIP). Open enrollment starts October 1, 2013 and coverage starts as soon as January 1, 2014. The Health Insurance Marketplace is sometimes known as the health insurance "exchange." For more information and to enroll, go to www.healthcare.gov.

Adolescence and Cystic Fibrosis

BY SIRI VAETH, MSW

"The teen years can be difficult to navigate regardless of health status, but for teens with CF, there are additional challenges."

The Cystic Fibrosis Parent Advisory Council's recent activities have been focused on addressing issues faced by teenagers with cystic fibrosis (CF). A new transition brochure has been created, which will be distributed in clinic and posted on the CF Center website. To help prepare students with CF for college, a workshop was provided and filmed for posting online as an enduring resource. The Council continues to explore ways for teens to connect with one another, especially in light of cross-infection precautions. The website has been updated with teen-specific content, addressing issues of sleep, nutrition, college and reproductive and emotional health. In the coming year, the Council hopes to address the needs of parents with newly diagnosed children. The input of parents is vital to our planning process. Parents are encouraged to email Siri Vaeth, Lead Parent, with any unaddressed issues and/or suggestions, at svaeth@lpch.org.

The following is an excerpt from the Teen Section of the CF Center Website, *Teens, CF and Body Image*: "The teen years can be difficult to navigate regardless of health status, but for teens with CF, there are additional challenges. Key among these is a positive body image. While most young people with CF look "normal," many teens with CF struggle to maintain a positive body image. Whether it is low body weight, a steroid-induced "moon face," a gastronomy-tube, clubbed fingertips, urinary incontinence, or an ever-present cough, the manifestations of CF can deeply affect the self-perception and self-esteem of those who live with the disease.

The issue of weight is key. For those with cystic fibrosis, a low body mass index (BMI) can lead to a correlating drop in lung function, with frightening outcomes. It is not uncommon for girls to overestimate their BMI, even when they are significantly underweight. In a Scottish survey of 160 people with CF, nearly 25 percent of females said they had skipped enzymes in order to lose weight, and many noted that they had also omitted insulin and supplements to do so. Conversely, for many with CF, the extreme effort required to keep one's weight up can take away the joy of eating. When efforts to gain weight are unsuccessful, a gastrostomy tube (G-tube) may be placed, leading to another body image challenge.

Delayed puberty is common for teens with CF, likely caused by low body weight, which postpones hormonal activity. While this is temporary, it can cause anxiety and depression. The body image of some young men with CF may be impacted by a lower BMI than their healthy peers. The knowledge that they may be unable to father children without medical intervention can impact boys' self-esteem. Girls with CF may experience chronic yeast infections due to antibiotic use, and suffer in silence due to the embarrassment they feel. Many teens with CF have a chronic cough, which may place stress on the pelvic floor muscles of young women, leading to urinary incontinence and shame.

The physical and emotional challenges of cystic fibrosis are closely intertwined for teens with the disease. The CF care team, as well as the parents of CF patients, must explore and address these issues with their adolescent patients, as having a positive body image can impact health outcomes while improving the quality of life of teens with cystic fibrosis.

New Pediatric Staff Member, Dr. Michael Tracy

Although Dr. Tracy grew up in Brooklyn, and attended college and medical school on the East Coast, he headed out West to LPCH/Stanford for residency, and now considers the Bay Area home. He felt fortunate to have completed his residency training at LPCH, so much so that he stayed on for an additional year as a Chief Resident. During his chief year, he confirmed that pulmonology was a great fit, and was lucky enough to match at Stanford again, this time for a Pulmonology Fellowship. When he does make it outside of LPCH, he enjoys running, hiking, and cooking. He looks forward to meeting everyone in the CF Center!

Adult CF Center Update

BY KATHY GESLEY, RN

• The Genetic Handicap Persons Program (GHPP), which provides health coverage to specific conditions including Cystic Fibrosis, is increasing the support personnel to better service current clients and more quickly process applications and authorizations. It is important to process your renewals as soon as receive your reapplications. Check with the Adult Coordinator if you are unsure of your renewal month. Kathy Gesley, Adult Coordinator, and Meg Dvorak, MSW, provide advocacy for adult patients for new applications and renewals. Contact us as soon as you realize you have a renewal problem to avoid delays in returning to clinic or in renewing medications.

• The Adult Cystic Fibrosis program processes pharmacy refills through the electronic medical record daily. If your pharmacy continues to use a fax refill request you may experience a delay in receiving medications. Please use My Health online to request refills, or leave a message on the patient line at (650)736-1358. Please ask your pharmacies to send refill requests electronically.

• Based on a recent FDA advisory, adult cystic fibrosis patients on maintenance Zithromax will have a surveillance EKG done annually to monitor for possible side effects of the regular use of this medication. At Stanford Hospital and Clinics, the EKG is a walk-in procedure so you may complete this requirement before or after a regular clinic appointment.

• Each adult cystic fibrosis patient needs to have an active relationship with a primary care physician in addition to your Adult CF Team. Primary Care physicians may be a Family Medicine physician or an Internal Medicine physician. Female patients may also have a Gynecology physician for well woman care.

If you:

- Live in Santa Clara and San Mateo county, you may be seen at SUH Internal Medicine Clinic or Ravenswood Clinic
- Live outside these counties, your own county health department operates public health clinics for your care
- Have private health insurance, your insurance company website will provide a physician list with open practices based on where you live
- Want a physician affiliated with a specific hospital in your area, call the medical staff office of that institution and ask for physicians with open practices
- Live in a remote rural area, the county medical society in that county can provide you with physicians with open practices

• When you check in for Adult Cystic Fibrosis Clinic, tell the registration personnel the name and contact number for your selected primary care physician. The clinic visit note is then forwarded to that physician so that your primary care physician remains informed of your health status. We recommend seeing your primary care physician at least yearly. Pediatric patients moving to the Adult CF Clinic will select a primary care physician prior to moving to the adult clinic as part of the Transition Program.

Newborn Screening Update

BY JACQUELINE ZIRBES, DNP, CCRC

The diagnosis of cystic fibrosis due to symptoms is associated with short and long term complications such as growth failure, malnutrition, vitamin/mineral deficiencies and pulmonary infections which are associated with decreased lung function. The impact of these complications becomes increasingly evident as infants age. In July 2007, the initiation of the CF newborn screening program (NBS) in California provided an opportunity to delay and potentially prevent many of these complications through early intervention and preventive care. The infant program continues to be active drawing patients from north of Sacramento to as far south as Los Angles with nine new referrals since January.

With the unique approach of DNA analysis, CF Centers are now referred infants through NBS with 2 CFTR gene mutations/variants. The question now is: How important is the sweat test? Sweat chloride has been the standard diagnostic test to confirm a diagnosis of cystic fibrosis. Research is still ongoing at Stanford and four other California CF centers following infants identified through NBS over a period of five years studying phenotype/genotype and sweat chloride relationships. Stanford is the lead investigative site for this project observing the genotypic determinants of sweat chloride concentration and its longitudinal changes, and the effect of fluid and electrolyte balance on sweat chloride results. Forty subjects are currently enrolled in this project with enrollment ongoing with funding from the Cystic Fibrosis Foundation.

Stanford Adult Cystic Fibrosis Advisory Council

BY LAURA STEUER

What sounds like a sesame cracker or that duck in the insurance commercial but is neither of those?

It's ACFAC (pronounce Ack-Fack), also known as the Stanford Adult Cystic Fibrosis Advisory Council. And we don't sit around eating crackers (or even crackers and cheese), rather we figure out active ways to support our fellow CF patients, in partnership with the adult CF clinic. So here's what we're doing these days:

• Leading a mentorship program where CF patients can be matched with other CF patients on any issues for which they want support. Want to become a mentor or be assigned to a mentor? Talk to Meg Dvorak, your adult CF social worker.

• Helping other CF patients get to clinic appointments. Again, talk to Meg about travel vouchers, gas cards, and transportation info. There's no excuse not to come to clinic and we want to help you get here!

• Supporting newly diagnosed adult Cystic Fibrosis-related diabetes patients. We're developing some resources for you including a confidential Facebook site. Stay tuned to hear more, or check in with Meg or our nutritionist/dietician, Lara Freet.

For more info about ACFAC, go to http://cfcenter.stanford.edu/acfac/ or contact chairperson Laura Steuer at laurafs@juno.com.

WORD SEARCH: Test Your Research Knowledge

BY COLLEEN DUNN, RRT, & ZOE DAVIES, RN

A	K	P	H	F	I	B	M	P	Y	F	K	D	J	B
M	H	D	Q	R	N	L	O	M	T	T	H	R	E	E
V	P	T	Y	N	F	B	J	H	K	R	D	V	J	D
Z	Y	C	F	S	O	L	O	C	X	T	R	J	D	I
P	L	M	O	P	R	I	N	C	I	P	A	L	I	J
U	H	B	V	G	M	F	D	O	W	T	R	D	M	K
L	P	U	G	C	E	S	T	O	L	H	G	F	T	P
K	N	H	U	T	D	K	N	R	C	F	T	N	K	P
P	O	U	Y	T	R	E	W	D	A	S	E	D	F	G
P	L	A	C	E	B	O	H	I	K	S	H	J	K	L
M	N	B	V	C	X	Z	A	N	S	K	N	O	Y	T
A	S	D	T	T	Y	E	K	A	R	I	Y	E	I	P
L	K	H	R	I	S	K	S	T	P	O	O	N	R	V
V	F	R	B	G	M	U	H	O	L	Z	M	V	B	P
Q	E	R	Y	U	R	E	P	R	T	V	H	J	P	Z

Answers can be found on the bottom of page.

1. What you sign before you start a study? _____ consent
2. The MD in charge of the study is designated as the _____ Investigator.
3. The person you will see most often during study visits is the research _____.
4. All studies are approved by the Institutional Review Board or more commonly known as the _____ before you can enroll into a study.
5. When you receive compensation for participation in a research study, you are compensated for _____ and effort.
6. What is the special form designed just for children to read and sign when participating in a research study? _____
7. The "sugar pill" used in a study is also called a _____.
8. Which research coordinator has worked in CF research at Stanford the longest? _____
9. When enrolling in a study all of the known _____ are explained to you.
10. Which phase of research enrolled the most patients? _____

ANSWERS: 1) Informed 2) Principle 3) Coordinator 4) IRB 5) Time 6) Assent 7) Placebo 8) Zoe 9) Risks 10) Three

CF Center at Stanford
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Pediatric CF Center Update

BY MARY HELMERS, RN

We are continuing our Quality Improvement Project (aka: the CF Binder project), which addresses the educational needs of our patients and families. Once again the CF Team would like to say thank you to all our families and patients who have filled out the questionnaires. These questionnaires help us to assess the areas we need to focus our teaching for all our patients and families. We appreciate all your efforts and value your input! The current topics for teaching are on hemoptysis, pulmonary function tests (PFTs), and salt supplements. Handouts and/or Internet links of teaching materials will be provided to assist our patients with their learning.

News Update: The Pediatric CF Clinic has moved. The new clinic location is 770 Welch Rd on the third floor. The specific details of the move has been mailed out by letter to the families that are seen at our CF Center.

Reminder: We have turquoise-colored masks that we provide at the front desk and ask all CF patients to wear during clinic and hospital visits. These masks have smaller filters, which allow for more protection when walking outside during the construction of our hospital expansion. We would like all patients to wear them to and from all clinics/hospital and when you walk outside the medical center. They should fit snug around your nose and mouth. If you have not received the new mask, ask the front desk staff or anyone from the CF Team.

CYSTIC FIBROSIS CENTER AT STANFORD

Pediatric Providers at Packard Children's: Carlos Milla, MD, Pediatric CF Center Director; Sumit Bhargava, MD; My My Buu, MD; Carol Conrad, MD; David Cornfield, MD; Richard Moss, MD; Terry Robinson, MD; Nanci Yuan, MD; and Jacquelyn Zirbes, DNP, RN, CPNP.

Clinic Scheduling	(650) 724-4788
Clinic and Prescription Refill	FAX (650) 497-8791
Erica Oliva, Patient Services Coordinator	(650) 498-2655
Mary Helmers, Nurse Coordinator	(650) 736-1359
Kristin Shelton, Respiratory Therapist	(650) 724-0206
Julie Matel, Nutritionist, Dietitian	(650) 736-2128
Lindsey Martins, Social Work	(650) 736-1905
Jacquelyn Zirbes, Newborn Screening Coordinator	(650) 721-1132

For Urgent Issues:
Monday-Friday, 8 am to 4 pm, contact RN Coordinator (650) 736-1359
All other times, for children's needs, call (650) 497-8000 (Packard Children's main number)

Adult providers at Stanford: Paul Mohabir, MD, Adult CF Center Director; David Weill, MD; Gundeep Dhillon, MD; Camille Washowich, MSN, ACNP; Elika Rad, RN, MSN, NP, Kelly Johnson RN MSN NP, Susan Cassidy RN, MSN, NP, Laura Starr RN, MSN, NP

Clinic Scheduling	(650) 725-7061
Kathy Gesley, Nurse Coordinator Office	(650) 498-6840
Patient Line	(650) 736-1358
Carol Power, Respiratory Therapist (	650) 736-8892
Lara Freet, Registered Dietitian	(650) 721-6666
Meg Dvorak, Social Work	(650) 723-6273

For Urgent Issues:
Monday-Friday, 9 am to 4 pm; after hours call Stanford Hospital, (650) 723-4000,
and ask for Pulmonary Fellow on-call.

Research:
Colleen Dunn, Zoe Davies, Cassie Everson (650) 736-0388

Visit our website at http://cfcenter.stanford.edu for more information about our center and CF.

To subscribe to this newsletter, please contact Cathy Hernandez by phone at (650) 724-3474 or by email at cathyh1@stanford.edu
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