

CYSTIC FIBROSIS CENTER NEWS

Reproductive Health in Cystic Fibrosis, Part II: Contraception

BY JENNIFER CANON, NP

Overview

This article is dedicated to the topic of contraception in cystic fibrosis (CF) patients. As a disclaimer, this is an enormous topic and it would be impossible to cover with just one article. As always, it is best to discuss any questions you may have with your health care team. It is also important to note that this topic includes sensitive information. Please know that the intent is to serve as an educational tool so that our patients can make the best decisions for themselves and their families.

The importance of contraceptive education

As an increasing number of CF patients are living into their reproductive years, the importance of safe and effective contraception cannot be underestimated. Women with CF are sexually active at rates similar to the national average and — as was discussed in the first part of this series — concerns regarding increased rates of infertility in CF women have typically been discounted. Pregnancy outcomes for CF women are improving. However, the decision to start a family is complex and requires significant health care planning. The goal of contraceptive education and utilization is that it allows for our female patients to take ownership of their reproductive path and optimize their health prior to pregnancy.

Current research: Contraception in cystic fibrosis patients

Unfortunately, although there is a large need for expanded information regarding CF and contraception, the data is not yet established. Upon extensive review, there is limited information regarding:

1. Safety of contraception in CF patients
2. Efficacy of contraception in CF patients
3. Noncontraceptive benefits in CF patients
4. Contraceptive use in CF patient populations

Although there is limited information directly pertaining to CF patients, there are established contraceptive guidelines that do apply to many of the medical conditions commonly associated with CF patients (such as liver disease, diabetes, anemia, etc.), and these guidelines can be used to help providers and patients find the best contraceptive fit.

Forms of contraception

As you will notice, the available options for contraception are vast and seemingly endless. The benefit of this is that it makes it easier to find the right option for you.

Duration of action

The first major distinction is the duration of action. This can range from taking a pill once a day to having an IUD implanted for up to 10 years. The most important factor to consider is that there are higher rates of contraceptive failure with the shorter-acting contraceptive methods in comparison to the longer-acting methods. The reasoning for this is simple: It is difficult to take medications correctly on a consistent basis. Using a long-term method such as an IUD or implant prevents patients from “missing a dose.”

TABLE 1:
Contraceptive methods: short-term vs. long-term action

Short-term action (daily to monthly)	Long-term action (3 months to 10 years)
Oral contraceptive pills (OCPs): daily	Injection: 3 months
Contraceptive patch: weekly	Contraceptive implant: 3 years
Contraceptive ring: monthly	Intrauterine device (IUD): 3–10 years

Hormones or not?

The vast majority of contraceptive methods utilize hormones to prevent pregnancy. They do this by inhibiting ovulation, thickening cervical mucus at the entrance of the uterus and thinning the lining of the uterus. In a small subset of patients, it may not be safe to use hormonal methods; however, for the vast majority of CF patients, there is no reason to believe that hormones are unsafe.

Combined hormonal methods versus progestin-only hormonal methods:

What's the difference?

The major difference between combined hormonal methods

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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.

(estrogen and progestin) and progestin-only methods from a clinical perspective is that estrogen (which is a component of combined methods) has a larger number of medical contraindications than progestin. From a patient perspective, the major difference is cycle regularity. With combined methods, the menstrual cycle is predictable; however, with progestin-only methods, bleeding can be a bit more irregular during the first 6 months. The good news is that after the 6-month window, most patients using progestin-only contraceptives do not experience a menses at all.

TABLE 2:
Hormonal methods versus non-hormonal methods

Hormonal		Non-hormonal
<i>Combined estrogen and progestin</i>	<i>Progestin-only</i>	Copper intrauterine device
Combined oral contraceptive pills (COCs)	Progestin-only oral contraceptive pills (POPs)	Barrier methods: condoms, spermicide, diaphragm, etc.
Contraceptive patch	Injection	
Contraceptive ring	Contraceptive implant	
	Progestin intrauterine device	

TABLE 4:
Past medical history and appropriate contraceptive methods

Past medical history	Consideration
History of a deep vein thrombus (DVT) or pulmonary embolism (PE)	Estrogen-containing products are UNSAFE to use
Anemia	A hormonal method may be more appropriate as this will decrease the amount of blood loss from menstrual bleeding A copper IUD may be inappropriate depending on how low your blood counts are
Liver disease	Hormonal birth control may be UNSAFE to use
Osteoporosis	Contraceptive injection (Depo-Provera) may not be appropriate for long-term use as it can reduce bone density
High blood pressure	Hormone-containing contraception may be UNSAFE to use
Cancer history, specifically breast cancer	Hormone-containing contraception may be UNSAFE to use
Migraine with aura	Estrogen-containing contraception is UNSAFE to use.

TABLE 3:
The pros and cons of hormonal versus non-hormonal contraceptive methods (STI = sexually transmitted infection)

Hormonal: Combined		Hormonal: Progestin-only		Non-hormonal	
Pros	Cons	Pros	Cons	Pros	Cons
Several contraceptive options	Possible side effects: nausea, breast tenderness, headache	Several contraceptive options	Irregular menses	Copper IUD: Less medical contraindications, highly effective	Copper IUD: Heavier menses for approximately 6 months, and no protection against STIs
Reduction in iron-deficiency anemia	Increased number of medical contraindications	Many long-acting options	Possible side effects: nausea, breast tenderness, headache	Condoms: Protection against STIs	Condoms: User dependent
Regulates menses	More frequent dosing schedules	Reduces anemia	No protection against STIs		
Cancer risk reduction: ovarian and endometrial	No protection against STIs				

What’s best for me?

Choosing the birth control option that makes the most sense for you can be quite a challenge. The most important consideration in deciding upon a contraceptive method is weighing the risk of a particular contraceptive method versus the risk of unintended pregnancy. Or, put another way, is the risk of a patient experiencing an adverse event with a particular birth control method greater than the risk of an unplanned pregnancy? What helps us determine the risk of a contraceptive method? Many factors are considered, including a patient’s past medical history, a patient’s current medication list, the inherent safety of a contraceptive method and its side-effect profile. Another important factor is the idea of personalization or “best fit.” You should ask yourself “What is most practical for me?” This includes considering the sort of dosing schedule you are able to commit to, what type of side effects you are willing to work with and when you are planning a family (or the length of time that you will be using contraception).

Reproductive Health in CF story continued from page 2

TABLE 5:
Choosing a contraceptive method: What to consider

Consideration	Sample questions
Dosing: Each method has a different dosing schedule. The rate of user error is much lower for a long-acting method versus a pill that must be taken on a schedule.	Can I remember to take a pill every day, apply a patch every week or insert a ring every 3 weeks? Is it reasonable to go to a clinic every 3 months for a Depo shot?
Side effect threshold: All patients have differing thresholds when it comes to side effects. Although severe side effects are very rare with all of the birth control methods, there is usually a short adjustment period, which could include a few predictable side effects.	Can I tolerate minor nausea, headache, or breast tenderness? Is it okay if I have some unpredictable bleeding for the first few months?
Family planning: What does the time frame look like for your contraceptive needs? Each method has a different duration of action, and this can be important for family planning purposes.	Are you planning a pregnancy in the next year, 3 years, 10 years? Are you approaching menopause?

Special considerations: Drug interactions

The most common drug interaction I am asked about involves antibiotics. There is no data to support that hormonal birth control is ineffective while on most antibiotics. There are very select antibiotics that do interact with hormonal birth control, but it is worth noting that most of these antibiotics are rarely used in treating CF. However, there has been some concern regarding drug interactions with Orkambi. Per Vertex, Orkambi may lower the efficacy of hormonal birth control. This means that women who are using any form of hormonal birth control should be using a back-up birth control method such as condoms while taking Orkambi.

Special considerations: Hormones and pulmonary exacerbations

Research recently published in The New England Journal of Medicine has suggested that there may be a relationship between hormone levels and CF exacerbations. More specifically, they found that there was a relationship between CF exacerbations and patients’ hormonal cycles.

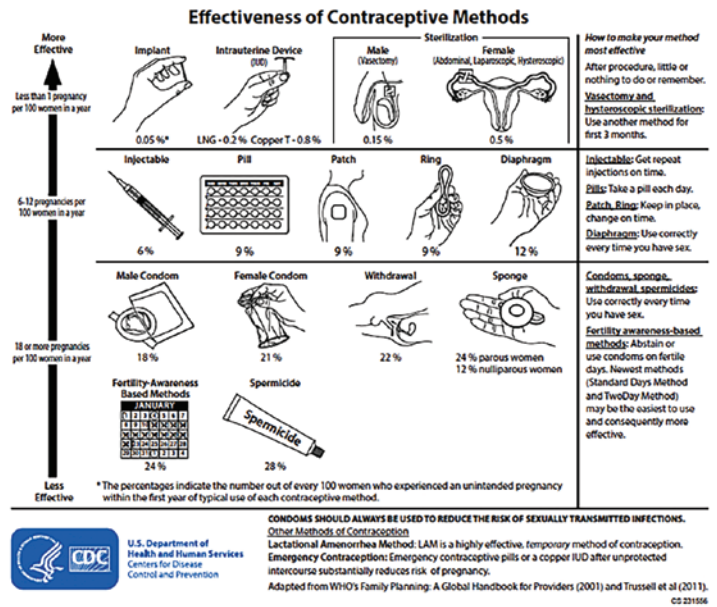
They also found that women on combined oral contraceptive pills had lower rates of exacerbation and used fewer antibiotics than women who were not on combined pills. Of note, this study only included patients who grew pseudomonas in their sputum cultures.

Summary

Contraception is a complex topic that is becoming of increased importance to CF patients. Although there is limited data regarding CF and contraception, your health care team can help in finding the safest and most effective method for you.

References:

Chotirmall, Sanjay H., Stephen G. Smith, Cedric Gunaratnam, et al. “Effect of estrogen on pseudomonas mucoidy and exacerbations in cystic fibrosis.” *The New England Journal of Medicine* 2012; 366:1978–1986.



Heart-Healthy Fats

BY MARIANNE REES SCHROEDER, RD

Milk, butter, cheese – For most adults living with cystic fibrosis, those food items are staples in an everyday high-calorie, high-protein diet. Fat found in dairy products pairs well with most meals, and is excellent at boosting calories. But don’t be fooled. Dairy is not the only option available. You’re probably well aware of avocado and trail mix, but what sets these fats apart from fats found in dairy and butter?

For starters, the fat found in dairy is primarily saturated, which means that there is a single bonded hydrogen atom attached to every carbon atom. The fatty acid is saturated with hydrogen. Think of a row of movie seats at a theater showing a new action movie that was just released this week. On opening night, every seat will be occupied – the theater is saturated with people. And, there is not a lot of room to move around because it’s crowded. The structure that those saturated carbons and

hydrogens create is stiff and straight, so saturated fats are usually solid at room temperature. Saturated fats have a similar impact on cell membranes in your body. Consuming too many saturated fats may contribute to a more rigid environment in your body.

Unsaturated fats, however, are like the showing of the original Ghostbusters film from 1984 that I attended last weekend. Every row of the theater had at least one unoccupied seat (most had many open seats). The theater was unsaturated, and there was a lot of flexibility for seating (which is truly unfortunate given that Ghostbusters is a classic). Unsaturated fats are more typically fluid or liquid at room temperature and provide more flexibility in the body. This is because unsaturated fats have a kinked structure in which some carbon atoms are not attached to a hydrogen atom but, instead, have double bonds to other



carbons, kinking the fatty acid. Popular unsaturated fats include olive oil, olives, avocado, nuts/seeds, and fatty fish like salmon or sardines.

Prioritizing unsaturated fats promotes heart health because unsaturated fats create a more fluid cell membrane, which helps reduce inflammation. Unsaturated fats may also contain the antioxidant vitamin E, which is another ally for fighting inflammation. Cystic fibrosis is an inflammatory condition, so choosing fats that support anti-inflammatory action in the body may help mitigate your body's inflammatory response.

Look up choosemyplate.gov and the American Heart Association for more information on sources of these heart-healthy fats. Remember, your doctor and dietitian may recommend you eat different amounts of fat than what is recommended on those websites, so run any potential dietary changes past them first. Check out the recipes below for a twist on some well-known heart-healthy fatty foods!

Nutrition Stripped's Olive Cashew Cheese

INGREDIENTS

1 cup raw cashews (soaked for 1 hour or more)
 ¼ cup filtered water
 ¼ cup nutritional yeast
 2 tbs. lemon juice
 2 cloves garlic

2 tbs. white wine (use wine you'd actually drink) or 1 tbs. raw apple cider vinegar
 1 tbs. Dijon mustard
 1/3 cup of your favorite mixed olives, such as Kalamata or green olives
 Sea salt and pepper, to taste

INSTRUCTIONS

1. Roughly chop and pit the olives.
2. Add all ingredients into your Vitamix or high-speed blender and blend until thick and creamy.
3. Add the noted ingredients to make each individual cashew cheese listed in the blog post.
4. It will be the consistency of thawed or stirred cream cheese and will harden further after it's been chilled.
5. Store in the refrigerator for 5 to 7 days.



Alton Brown's Sherried Sardine Toast

INGREDIENTS

2 (3.75 oz., 2-layer) tins of brisling sardines in olive oil
 2 tbs. finely chopped parsley leaves, divided
 1 tbs. sherry vinegar
 1/4 tsp. lemon zest (reserve the lemon and cut into 4 wedges)
 Freshly ground black pepper, to taste
 4 (1/2-inch thick) slices crusty bread, such as sourdough, country loaf or rye
 1 ripe Hass avocado
 Coarse sea salt, to taste

INSTRUCTIONS

1. Drain the oil from 1 tin of sardines into a small bowl and set aside.
2. Drain the oil from the other tin into another small bowl and whisk in 1 tbs. of parsley, 1 tbs. vinegar, 1/4 tsp. lemon zest, and black pepper to taste. Add all of the sardines, stir to combine and set aside for up to 1 hour.
3. After 45 minutes, put an oven rack 3-inches from the broiler and heat the oven using the highest broiler setting. Brush each slice of bread on 1 side with the reserved oil.
4. Put the bread, oil side up, onto a cooling rack set inside a half sheet pan and broil for 2 to 3 minutes, or until golden brown and crisp.
5. Halve the avocado and remove the pit. Smash the flesh in each half with a fork.
6. Spread the avocado evenly onto the toasted bread, and evenly distribute the sardines on top of the avocado. Pour any remaining dressing on top and garnish with the remaining parsley.
7. Season lightly with sea salt and serve with lemon wedges.

CF Clinical Research at Stanford

BY ZOE A. DAVIES, PNP, CCRC

Advances in pulmonary and nutritional treatments have markedly improved the life expectancy of cystic fibrosis patients from just 14 years in 1969 to approximately 40 years today. Many of these amazing advances are the result of successful clinical research efforts supported, in part, by the nonprofit affiliate of the Cystic Fibrosis Foundation (CFF), the Cystic Fibrosis Foundation Therapeutics Inc. (CFFT).

In collaboration with industry and academic partners, the CFFT developed a robust drug development pipeline in order to meet the overall mission of improving the lives of patients with CF. However, since CF is considered a rare disease that affects less than 200,000 people nationwide, it was difficult to recruit adequate numbers of patients into clinical trials or to hire enough trained clinical research staff. Recognizing this need, the CFFT founded the CF Therapeutics Development Network (TDN) in 1998. It was initially comprised of seven clinical research centers; Stanford joined as the eighth site in 1999. From there, it rapidly expanded and now consists of a total of 77 sites. This development and expansion of the TDN has helped ensure there are a large number of dedicated, trained CF researchers broadly distributed across the United States in order to increase access for eligible CF patients. However, with the recent progress that has been made in CF and the subsequent number of upcoming clinical trials, the lack of trained research coordinators has remained a big problem. In an effort to help with this issue, the TDN recently provided increased funding to selected sites in order for them to hire and train even more research staff. Fortunately, Stanford was one of those sites, and now we have eight dedicated research staff members.

Twice a year, individuals involved in clinical research have the opportunity to get together to network, share ideas, discuss current research projects and help educate and train the “newcomers.” This occurs at the TDN Spring Meeting in April and at the annual North American CF Conference in October. This past April, the spring meeting was held in San Antonio, Texas. Due to the growing numbers of new personnel, the main focus of this particular meeting was training and education. Plenary sessions consisted of descriptions of upcoming studies, reviews of the next generation of modulator drugs and a parent/patient panel that focused on the research experience. There were multiple breakout sessions that varied in topic from “Becoming a Leader” to “Managing Multiple Projects” and “Faculty Development.” During the evening, the TDN hosted a dinner and social event at the Institute of Texan Culture, where individuals were recognized for their years of service in CF research. Jackie Zirbes, Zoe Davies and Carlos Milla all received acknowledgement for providing more than 20 years of service. Following the general session, there was a clinical research boot camp for the new research coordinators — all 150 of them! Our own Wendy Valencia and Sean Ryan were among the attendees, and Colleen Dunn was one of the instructors. Sessions included topics such as “The Difference Between Researcher and Care Provider,” “Consenting,” “Protocol Feasibility Review” and “Study Budgeting and Negotiation.” The meeting provided all of the newcomers — most of who were probably overwhelmed — with the necessary tools to effectively do their jobs.

All in all, our group found the meeting both informative and fun. We have numerous CF studies going on, and we always enjoy getting new research participants. If you are interested in finding out more about participating please call us at 650 736-0388.

Adult Cystic Fibrosis Center Update

BY RONNI WETMORE, RN, MS

REMINDER AND EXPLANATION OF PRESCRIPTION REFILL REQUESTS

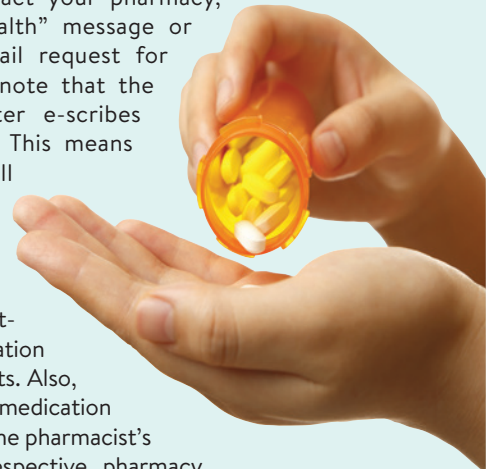
Some of you have expressed frustration with prescription refills, and this article aims to explain why there are occasional “glitches” in your routine prescription refills.

When you contact your pharmacy, send a “my health” message or leave a voicemail request for a refill, please note that the Adult CF Center e-scribes all medications. This means we do not call your pharmacy or fax refills to your pharmacy. By e-scribing refills, we can better track medication refills and requests. Also, the e-scribed medication goes directly to the pharmacist’s desk at your respective pharmacy.

Once the RN (Ronni or Julian) has received your request for a refill, we review your medication list and complete the prescription on the medication page of your chart. We review the medication requested, labs (if required), dosing requirements and number of refills allowed, and we confirm the pharmacy where we should send the refill. Once we have completed our part, we forward the prescription to the NP who is covering medication refills on that particular day. The NP then reviews the refill request and officially signs it via the e-scribe procedure, and it is sent to your pharmacy.

Please wait until the end of the business day (5:00 PM) before going to your pharmacy to pick up the medication. There are many refill requests that are sent to this office on a daily basis, and our NPs set aside time at the end of the day to review and sign off on all requests received over the course of the day, as they are serving patients and working in the clinic during the day. It is also a good idea to phone your pharmacy to confirm your prescription is ready for pick up before you head to the pharmacy. Also, regarding nebulizer cups and supplies, be advised we always order 3 refills for supplies, so you can also contact your pharmacy to request refills for nebulizer supplies just as you do for your medications.

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Cystic Fibrosis Parent Advisory Council: Meet the new mentor!

BY KIRSTEN MCGOWEN

The CF Parent Advisory Council seeks to address the needs of all families seen at the Pediatric CF Clinic at Lucile Packard Children's Hospital Stanford. We would like to introduce Kirsten McGowen, our new parent mentor, who is currently seeing families with children up to 3 years old in the clinic but hopes to expand to seeing older children as well.

Kirsten has a 6-year-old son with CF who is seen by the CF team at Packard Children's. As a parent mentor, Kirsten will be part of the care team in the clinic. Parent mentors are not medical providers, so they cannot answer any medical questions, but they can help support families in a number of ways. We are effective managers of our own children's health care and are trained to provide support, modeling, suggestions and validation to parents who are building their own partnerships with the CF team. Some things mentors can talk about during a visit:

- Coping with the initial diagnosis
- Understanding what it's like to live with CF (managing care at home)
 - Coordinating care, breathing treatments, meals, etc.
- Navigating clinic appointments (and how to get the most out of them)
 - Obtaining and managing information during a visit
 - Getting questions answered by the team
- Supporting families on their CF journey

If you have input for the CF Parent Advisory Council, please email Amy Baugh, co-lead parent, at abaugh@stanfordchildrens.org.

New Pediatric Staff Members



Eric Hamberger, MD: Eric's interest in pulmonary medicine stems from his passion for biophysics and respiratory physiology. Through his residency training at North-Shore LIJ in New York, he refined that passion in the pediatric population, for whom pulmonary diseases remain the most common reason for hospitalization. For him, pulmonary medicine and cystic fibrosis embody a broader theme in pediatrics: disease entities of systemic significance that combine basic science with multiple physiologic processes. Though he has spent most of his life on the East Coast, he is more than excited to venture west to start his pulmonary fellowship at Stanford and join its community of caring, compassionate life-long learners.



Candace Middleton, RCP, CPFT: Candace is a Memphis, Tennessee, native. Her interest in medicine started at a young age as the primary care taker for her father, who suffered from blindness, heart disease and chronic respiratory distress. At 18 years old, she worked as a respiratory technician at Regional Medical Center in Memphis while she attended the University of Memphis to earn her bachelor's degree in biology. To overcome obstacles blocking her educational goals, Candace joined the United States Navy. As a hospital corpsman, she put her years of respiratory experience to use on humanitarian missions all over the world. She was able to complete a civilian community college's respiratory degree to become a board-certified respiratory therapist in 2006. She has traveled all over the world providing respiratory care to people in need through her role in the military and as a health care traveler. As of May 2016, Candace has decided to settle her husband Bobby and their 1-year-old son Carter in the Bay Area and make the Stanford family her home. Being new to the pediatric cystic fibrosis clinic, she welcomes all teaching opportunities.

New Adult Staff Members



Marianne Rees Schroeder, RD: Marianne graduated from Bastyr University in Nutrition and Culinary Arts and completed her dietetic internship with California State University, Sacramento. During her free time, she enjoys cooking, hiking and interior design.

In Memoriam



Nanci Yuan, MD, clinical associate professor of pediatric pulmonary medicine at the Stanford University School of Medicine, died on July 1 of colon cancer in Santa Clara, California. She was 47.

Yuan, who was known for her devoted work with children who have severe forms of inherited muscle dysfunction and sleep disorders, built the Pediatric Sleep Center at Lucile Packard Children's Hospital Stanford into a nationally recognized program that now delivers diagnostic and therapeutic care to almost 2,000 children annually. She helped write the standards for caring for children with severe congenital muscle disease and introduced a home ventilator program that allowed young patients with chronic respiratory failure to receive life-sustaining breathing support at home rather than in the hospital, letting them spend more time with their families.

"Nanci was completely comfortable advocating for her patients, and she did so with great courage and integrity," said David Cornfield, MD, chief of the Division of Pulmonary Medicine and a longtime colleague of Yuan's. "She provided incredible service to patients and their families," said Richard Moss, MD, professor emeritus of pediatrics, who hired Yuan to help build the division in 2003. "Nanci was fantastic about going from A to Z, everything from the initial evaluation to finding the best treatment for a patient."

Dr. Yuan made a huge impact in the lives of her patients and will be sorely missed.

Pediatric CF Center Update BY MARY HELMERS, RN



MY CHART (Secure Electronic Correspondence):

If you have not signed up already, please sign up for My Chart at your next clinic visit. My Chart is a secure way to

communicate with your provider and CF care team. Please note that the CF care team cannot respond to patient/parent emails, since My Chart is not a secure site, but any emails sent to the team will be answered with a phone call. We do not always check emails on a daily basis. If you or your child has an urgent clinical need or question, please call the CF RN line at (650) 736-1359. It takes only a minute to sign up. If you need help, one of the front desk staff will be happy to assist you with the process.

CF PASSPORT: Parents and patients: Remember to carry your child's CF Passport in your wallet. If for some reason you missed placed or tossed out your CF Passport, please ask for one when you come to your next clinic appointment. We now offer them in English and Spanish.



HELPFUL REMINDERS: To help expedite your clinic visit, please remember to bring your CF binder with you to the clinic as well as your most recent CF action plan.

PRESCRIPTIONS: Just a reminder that it can take up to 72 hours to process your prescription request. Although we strive to turn them around sooner, this has always been our policy. Please keep in mind that even after we send the prescription to the pharmacy, it can still take another 48 to 72 hours for the pharmacy to fill the prescription (this is especially true for mail order pharmacies). It is important for you to stay on top of your refills and send your refill requests at least 1 week before you are due to run out.

HELPFUL HINTS FOR REQUESTING REFILLS:

- Call your pharmacy first to find out if you have refills left.
- If you have a refill left, great! They will process it.
- Your pharmacy should call us if you have no refills left.

Remember: We cannot guarantee your request will be filled the same day or within 24 hours.

ANNUALS: Our goal is to get all annual testing done on or around your child's birthday. Included in the annual tests are lab work (for patients of all ages), the 2-hour oral glucose tolerance test (OGTT; for patients age 6 and older, and for pancreatic insufficient patients), a chest X-ray, a bone-density scan (for patients age 12 and older), a full pulmonary function test (starting at age 7), and a baseline audiogram (starting at age 6). Please let us know if you have not had any of these tests done with your annual exam

WEAR YOUR MASK: We have turquoise-colored masks that we ask all CF patients to wear. They are handed out at the front desk. These masks have smaller filters that provide more protection when walking near the construction areas outside. We would like all patients to wear them when going to and from all clinics and the hospital and when you walk outside the medical center. The mask should fit firmly around the nose and mouth. If you have not received a mask, ask the front desk staff or a member of the CF team.

LASTLY: With all the exciting research being done in CF, new drug advances for CF patients are genotype specific. We need to have copies of genotype/sweat chloride test results for all our CF Center patients. If you have a copy of the original result, please bring it with you to your next clinic appointment. If your child had these tests done at an outside lab or another CF Center, please contact them and ask them to fax a copy of the results to (650) 497-8791, ATTN: Mary Helmers, RN, Pediatric CF Coordinator. We need these test results for all our patients. Our plan is to have patients re-genotyped if there is no documentation on file. Thank you for your help with this task.

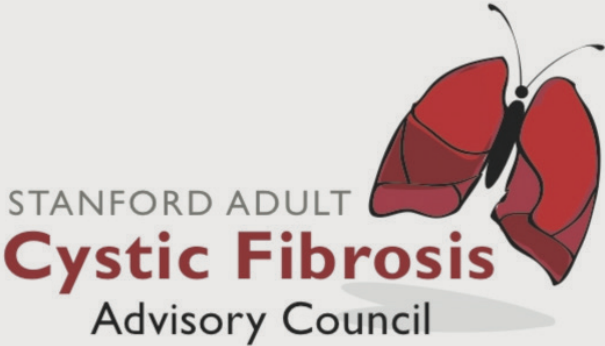
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Please allow 72 hours to have prescriptions refilled. If your medication requires a prior authorization, then you must allow a minimum of 72 hours. Many insurance companies are now requiring prior authorizations on medications that previously did not require authorizations. This is consuming more time than in the past, so please be sure to allow extra time for your refill. We work very hard to keep up to date on your prescriptions and supplies in a timely manner. Please let us know a week in advance when your prescription needs renewal, as this will keep you – and us – on a timely schedule for your continued therapies.

Both Julian and Ronni meet with our nurse practitioners daily to consult regarding your phone messages and calls. We also have a weekly meeting with our entire team to discuss our practice, our clinics and our protocols. We work together to bring you the best and most comprehensive CF care and maintain our high standards of care. Please do not hesitate to contact us with your concerns or suggestions as we all work together in this effort.

Our entire team looks forward to working together with you in 2016 and making this our best year yet.

CF Center at Stanford
770 Welch Road, Suite 350
Palo Alto, CA 94304



STANFORD ADULT
Cystic Fibrosis
Advisory Council

BY DEVIN WAKEFIELD

CF ENCOUNTERS PROJECT:
What is it? Who is it for?
Why you should care!

The CF Encounters Project aims to bridge the gap between patients' and health care professionals' expectations and sensitivities. Most patients have had one or more "moments" where they really wished the doctor, phlebotomist, nurse, technician, etc., had phrased something differently or approached something in a different way (even though we are well aware they did not have malicious intent). This project chronicles those moments in an educational format so that health care professionals can learn the diverse needs of their patient population in a CF context. This will help to build trust and respect on both sides, and we hope it will improve the quality of the patient experience.

If you have such a "moment" and would like to help with this project, please let us know!

You can contact us at stanfordcfac@gmail.com

CYSTIC FIBROSIS CENTER AT STANFORD

Pediatric Providers at Lucile Packard Children's Hospital Stanford: 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; 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
Liz Beken, CF Clinic Nurse.....	(650) 736-1359
Candace Middleton, Respiratory Therapist.....	(650) 724-0206
Julie Matel, Nutritionist, Dietitian	(650) 736-2128
Sruthi Veeravalli, Social Work.....	(650) 736-1905
Jacquelyn Zirbes, Newborn Screening Coordinator.....	(650) 721-1132

URGENT ISSUES:

Monday-Friday, 8:00 a.m. to 4:00 p.m., contact the nurse coordinator at (650) 736-1359. All other times, for children's needs, call (650) 497-8000 (Lucile Packard Children's Hospital main number)

ADULT PROVIDERS AT STANFORD:

Adult Center Director: Paul Mohabir, MD; Laveena Chhatwani, MD; Gundeep Dhillon, MD; David Weill, MD; Jennifer Cannon, NP; Kelly Johnson, NP; Elika Rad, NP; Laura Starr, NP; Meredith Wiltse, NP

Adult Clinic Scheduling.....	(650) 736-5400
Adult CF Center Fax.....	(650) 723-3106
Nurse Coordinators	(650) 498-6840
Patient Last Name A-K: Julian Liang, RN, BS	
Patient Last Name L-Z: Ronni Wetmore, RN, MS	
Respiratory Therapy.....	(650) 736-8892
Carol Power, RCP; Gauri Pendharkar, RCP	
Registered Dietitian	(650) 529-5952
Michelle Stroebe, MS, RD; Maryanne Schroeder, RD	
Natalie Chan, RD (back-up)	
Social Work	(650) 518-9976
Meg Dvorak, LCSW	

URGENT ISSUES:

Monday-Friday, 8:00 a.m. to 5:00 p.m., call the nurse coordinator.
Monday-Sunday, 5:00 p.m. to 7:00 a.m., call (650) 723-4000 and ask for the pulmonary fellow on-call
Saturday-Sunday 7:00 a.m. to 5:00 p.m., call (650) 723-4000 and ask for the adult CF ghost pager

RESEARCH:

Colleen Dunn, Zoe Davies, Sean Ryan, Wendy Valencia: (650) 736-0388

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