Fall 2025

Stanford MEDICINE
Children's Health

Cystic Fibrosis Center **News**

The Sleep Factor: Optimizing Sleep Is Essential to Your CF Care Plan

—Caroline Okorie, MD, MPH, FAASM

By now, many recognize that good sleep is an important contributor to overall well-being. Through the years, we've developed a better understanding of the function of sleep and its multidimensional benefits, including growth, recovery, and immune system regulation. It is during sleep that we consolidate our learning and memories and can process emotions. Poor sleep is associated with sleepiness and fatigue, decreased quality of life, poor growth, poor recovery from stress, and even decreased lung function.1 With this in mind, it becomes evident that optimizing sleep quality/quantity is essential to your overall health and CF care plan.

In today's world, there are more factors than ever that prevent people from getting a good night's sleep. Demanding schedules, stress, and technology may all play a role in compromising our rest. It may be helpful to periodically perform a "life audit" around our sleep to consider any changes we can make to improve it. Healthy sleep habits can include:

- Getting bright, natural sunlight exposure in the morning and afternoon.

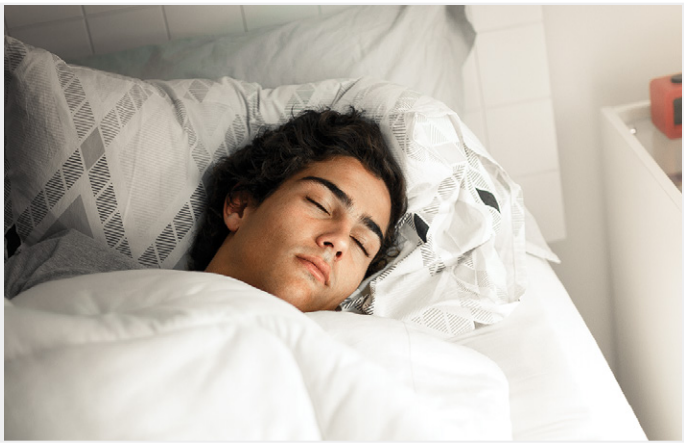
Continues on page 2...

In this issue

The Sleep Factor...continued from page 1

- Maintaining a regular sleep-wake schedule (minimizing variability on weekends/holidays).
- Sleeping in a cool (60–68 degrees F), quiet, and dark or dimly lit area.
- Reserving the bed for sleep only.
- Minimizing caffeine, avoiding at least seven hours before bedtime.
- Avoiding bright light or overly stimulating activities within 60 minutes of bedtime.
- Incorporating a relaxing wind-down routine 30–60 minutes before bedtime.

Beyond healthy sleep habits, it is important to recognize when medical evaluation and/or treatment is needed to improve our sleep.



During sleep, physiological changes in breathing can exacerbate symptoms of pulmonary disease or upper airway obstruction. The amount of air exchanged in one minute (i.e., minute ventilation) decreases, as does the lung volume in each breath. Upper airway resistance (or obstruction) increases, particularly during rapid eye movement (REM) sleep. Living with CF can add reasons for poor sleep quality with coughing, pain, frequent stooling, reflux or heartburn, abdominal discomfort, overnight feeds, medication side effects, and respiratory treatments all cited as common nighttime issues. Approximately 50% of patients with CF report disturbed sleep with increasing risk with advanced lung disease. 2 Over 80% of children with CF experience nocturnal coughing, compared with less than 5% of children without CF. Discussing nocturnal issues (including cough, pain, and reflux) with your CF team is important in working to resolve them. Even important therapies like nighttime airway clearance or overnight feeds may contribute to sleep disturbance. Discuss with your CF team to see if adjusting therapies in an attempt to minimize sleep disruption may be reasonable in the context of your medical needs. Together, you may be able to come up with a better solution!

Screening for and treating primary sleep disorders may also be an important part of your CF care plan. Obstructive sleep apnea (OSA) may present with symptoms of snoring, night sweats, daytime sleepiness, and insomnia. Risk of OSA is increased if there is chronic nasal congestion/sinus disease. CF lung disease can be associated with low oxygen levels (hypoxemia) or carbon dioxide retention (hypoventilation).3 An overnight oximetry study can assess oxygen levels and heart rate when sleeping. A polysomnography (sleep study) can offer more detailed data and assess for respiratory and neurological abnormalities in sleep. Treatment for sleep apnea may include treating nasal congestion with anti-allergy therapies, or surgical intervention if indicated. CPAP (continuous positive airway pressure) or bilevel (biphasic positive airway pressure) may also be used, and some machines can offer additional breathing support for those with advanced lung disease.

Insomnia is characterized by difficulty falling asleep, difficulty staying asleep, or waking up too early (and not falling back asleep) despite having the opportunity to sleep. The approach to insomnia is usually step-wise, starting first with an assessment for all possible contributing factors. Again, consider if pain, discomfort, or pulmonary symptoms are making it tough to sleep. Next,

Continues on page 3...

The Sleep Factor...continued from page 2

consider if another primary sleep disorder may be contributing to your symptoms. Insomnia associated with a restless discomfort or the urge to move arms or legs may suggest restless legs syndrome (RLS). RLS is often associated with low iron stores (indicated by serum ferritin) and can be treated with iron supplementation.

Circadian rhythm dysfunction is when the sleep/wake patterns are not in alignment with your needs. This can go a bit beyond simply being a "morning lark" versus "night owl." If the healthy sleep habits noted above don't solve the problem, more intervention may be needed. Interestingly, there is growing evidence of an association between CFTR dysfunction and circadian rhythm dysfunction, meaning that patients with CF may have poor sleep regulation related to an underlying genetic cause of CF.

Encouragingly, studies suggest that CFTR modulators may help improve sleep quality in young adults; 4 however, more research is needed.

For chronic insomnia, believe it or not, medication is not the first choice of treatment. Cognitive behavioral therapy for insomnia (CBT-I) is considered the gold standard treatment and can help you align your sleep drive with natural wakefulness patterns. Studies have shown that even digitally delivered CBT-I is more effective than medication and has continued long-term benefits in adults with insomnia.5 You may also benefit from various evidence-based mind-body interventions to improve your sleep quality.6,7 Even young children can perform and benefit from these practices: active breathing exercises, mindfulness practices, gentle movement, massage or acupressure, biofeedback, and clinical hypnosis.

It's always a good idea to discuss any and all medications and supplements you're considering with your CF team. Even some widely available, over-the-counter options can have important safety concerns, so a discussion with your team is the best way to remain safe. Of note, researchers are currently working to better understand the role that melatonin supplements may have in the care of CF, so your CF team can help you navigate and understand new medical findings.

How do you know if you should have a formal sleep evaluation? Consider one if:

- You experience daytime sleepiness, brain fog, or difficulty concentrating.
- You have difficulty falling or staying asleep.
- You have an FEV1 level below 65%.
- You wake up with morning headaches.
- You snore.
- You have chronic nasal obstruction or sinus disease.
- You experience nightly leg discomfort or restlessness.

Sleep is a critical component of your health, especially as you manage cystic fibrosis. Multiple factors can contribute to poor sleep quality, and addressing these concerns is essential for improving your overall well-being and should be incorporated into your CF care plan. If you are experiencing problems with your sleep, be sure to talk with your CF team so they can support you and help you feel your best!

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Pediatric CF Updates

Welcome New Fellows!

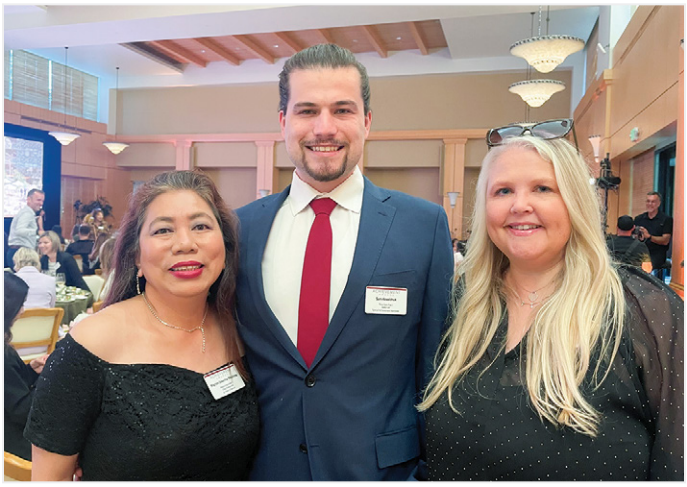
Hi everyone, I'm Amrita Sunkad, I am from a small coastal town in South India, I finished my medical education back home. The advancement in evidence-based medicine brought me to the East Coast of the United States for my residency. I grew interested in pulmonology for the wide pathology, ranging from foreign body and asthma to respiratory care in patients with chronic disease. The most fascinating aspect of pulmonology is how the remarkable development of the lungs throughout the first 10 years of life affects respiratory health. In my free time, I enjoy painting, hiking, and spending time with my family and friends.

Hi everyone, I'm Kate Mackin! I was a pediatrics resident at Stanford after completing medical school at the University of Southern California, and I am so excited to be staying for pulmonology fellowship. I was born and raised in Cleveland, Ohio, and am a big Cleveland sports fan. In my free time I love yoga, working out, baking, and hiking. I can't wait to work with you all over the next three years!

Congratulations to Migon Severina Madayag and Samuil Kovalchuck, RT, the winners of the Gold Rose Award, Grace "Employee of the Year" Award, and Excellence in Leadership Award

The Gold Rose Award, which recognizes employees who exemplify PCARES values and are extraordinary in their work with colleagues and our patients and families, was presented to 12 exceptional individuals. These real influencers have consistently gone above and beyond in their roles, embodying the spirit of teamwork and compassionate care:

- Respect for others
- Innovation
- Teamwork and collaboration
- Willingness to teach, mentor, educate
- Resource management
- Successful leadership



Madayag, Samuil Kovalchuck, RT, and Amy Allen MSN, RN, CPN

Adult CF Updates

Cannabis and Drug Interactions in Cystic Fibrosis

—Emily Chu, PharmD, and Denise Kwong, PharmD, BCPS

Cannabis use—whether for medical or recreational use—can carry the potential for drug–drug interactions. Cannabis-based products mainly contain cannabidiol (CBD) and delta-9-tetrahydrocannabinol (THC). These cannabinoids can affect how your liver processes different medications. For example, CBD can slow the liver's ability to process and eliminate CFTR modulators. When a CFTR modulator such as Trikafta or Alyftrek stays in your body longer, it can increase the chances of experiencing side effects or toxicity. On the other hand, CFTR modulators may slow the liver's ability to process and eliminate THC, which can enhance psychoactive side effects from THC.

Another important consideration is that the effect of cannabis can vary based on the route of consumption. When inhaled, THC and CBD rapidly enter the bloodstream through the lungs. This route also has the added danger of increasing inflammation and oxidative damage to the lungs. When cannabinoids are orally consumed, a portion of them gets processed and eliminated by the liver first, so that less is available to circulate throughout the body. When applied topically, there is minimal absorption; the cannabinoids act

locally and mostly stay in the epidermal layers of the skin. This difference in how your body processes cannabis can lead to unpredictable concentrations of THC and CBD and therefore varied interactions with other medications.

It is important to let your health care providers know if you are using cannabis and before you start any new medications, vitamins, or herbal supplements. Do not change your medications without talking to your doctor first. Additionally, it is important to have your pharmacist check for potential drug interactions to minimize risk of adverse effects to help you make an informed decision.

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Continues on page 6...

Adult CF...continued from page 5

Safe Medication Storage

—Emily Chu, PharmD, and Denise Kwong, PharmD, BCPS

General tips

- For most medications, store them in a cool, dry area.
- Do NOT store medications in areas with high humidity or heat, as it can damage the medications and they will no longer be effective. For example, storing medications in the bathroom cabinet is not recommended, as there can be high humidity in the bathroom.
- Room temperature is 68–77 degrees Fahrenheit. Refrigerator temperature is 36–46 F.
- When traveling with medications that require refrigeration, consider a compact medication cooler for the flight and calling ahead to make sure you will have access to a refrigerator in the accommodations where you will be staying.
- Before extended travel, make sure to communicate with the pharmacy in advance so they can initiate insurance overrides if necessary or start to fill medications slightly earlier (three weeks) to stockpile supply beforehand.

- Pill boxes or other medication organizers can be a useful way to remember to take your medication.
- Certain medications commonly used for cystic fibrosis patients have special storage requirements. If you are unsure, check with your health care providers, such as your doctor or pharmacist.

Name	Storage
Kalydeco (ivacaftor)	Store at room temperature.
Orkambi (lumacaftor/ivacaftor)	
Symdeko (tezacaftor/ivacaftor)	
Trikafta (elexacaftor/tezacaftor/ivacaftor)	
Alyftrek (vanzacaftor/tezacaftor/deutivacaftor)	
Creon or Zenpep (pancrelipase)	Most formulations need to be stored in their original container at room temperature.
Insulin	Unopened and unused insulin can be kept in the fridge until the manufacturer's expiration date. Once opened, the insulin can be kept at room temperature until the beyond use date (BUD). This BUD can vary based on the insulin type and brand. Check with your doctor or pharmacist.

Continues on page 7...

Adult CF...continued from page 6

Name	Storage
Inhaled (Tobramycin)	(Tobi) Powder: Store in original package at room temperature and protect from moisture. Solution: Store in refrigerator (36–46 F). If kept at room temperature, it will be good for up to 28 days. Protect from light.
Pulmozyme (dornase alfa)	Store in refrigerator (36–46 F) in protective foil packaging to shield from light and heat. Once an ampule is opened, the entire contents must be used or discarded.
Albuterol	HFA inhaler: Store at room temperature. Nebulization solution: Store at 36–77 F. If removed from the foil packaging, use within one week or according to manufacturer's recommendation.

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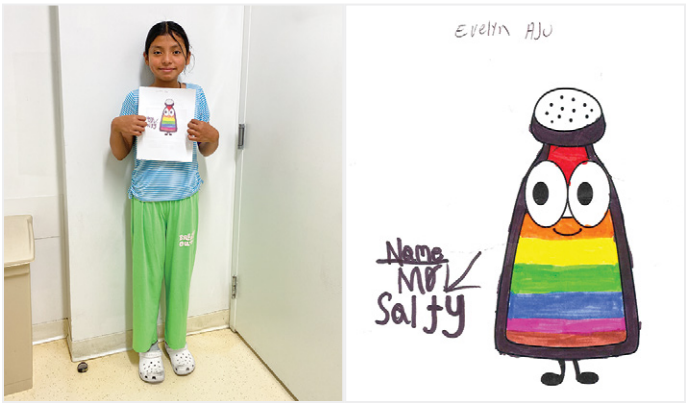
Patient Family Advisory Council (PFAC)

Winner of the Salt Shaker Mascot Contest

Meet our newly named mascot: Salty! Shout out to Evelyn Aju-Hernandez, who submitted the winning name.

Our salt shaker is a seasoned professional who's always handy in a pinch, loves rock music (favorites include Electrolyte Orchestra and Saline Dion), is totally into crystals, and is passionate about protecting the ocean. A big thank you to everyone who sent in creative ideas—we had so much fun seeing your submissions!



Evelyn Aju-Hernandez with her winning design

Current and Upcoming Research

Active Studies

Name	Brief description	Criteria	Contact(s)
BEACON A Phase 1/2 Single Dose Escalation Study Evaluating the Safety and Tolerability of VX-522	Phase 1/2 clinical trial of inhaled mRNA gene therapy in people with CFTR genotype not responsive to modulator therapy. Currently, recruiting for multiple ascending dose (MAD) cohort	• 18-65 years old • CFTR variant non-responsive to modulators	Lani
BEGIN-OB-19 A Prospective Study in Infants and Young Children (BEGIN)	Prospective longitudinal study to observe the effects of either ivacaftor (Kalydeco) or elexacaftor/tezacaftor/ivacaftor (Trikafta) on growth	• <6 years old • Eligible for modulators • Not currently on either med	Tina
BMX-04-002 A Phase 2b study to evaluate Bacteriophage with PSA	Double-blind, placebo-controlled, multicenter study will evaluate the efficacy, safety and tolerability of twice daily inhaled bacteriophages (BX004)	• 18+ years old • CF and P. *aeruginosa*	Tina
CMTX-P1-CT002 A Phase 1b/2a Study to Evaluate the Safety of CMTX-101	Phase 1b/2a clinical trial to determine the safety and tolerability of IV administered CMTX-101 along with standard of care treatment	• 18+ years old • CF and P. *aeruginosa*$^{+}$	Lani
NBSA Newborn Screening Accuracy Project	Study collecting blood samples from patients with rare CF mutations to ensure newborn screening tests are accurate in all ages	• Diagnosed with rare CFTR variant	Tina
PROMISE Study to evaluate the effects of ETI	Post approval, real-world, observational study to understand the effects of elexacaftor/tezacaftor/ivacaftor (ETI) in clinical use	• >6 years old • >=1 copy of F508del	Jackie
REACH-OB-23 A REsearch Study to Advance the CF THerapeutics Pipeline for People without Modulators	Prospective, longitudinal, observational research study to obtain research quality (i.e., monitored research) CF outcome data.	• 12+ years old • CFTR variant non-responsive to modulators	Lani
ReCode2 A Phase 1/2 Multiple Dose Escalation Study Evaluating the Safety and Tolerability of RCT2100	Phase 1/2 clinical trial of inhaled mRNA gene therapy in people with CFTR genotype not responsive to modulator therapy	• 18-65 years old • CFTR variant non-responsive to modulators	Lani

Continues on page 9...

Current and upcoming...continued from page 8

Active Studies

Name	Brief description	Criteria	Contact(s)
RESPIR-102 A Phase 1b/2a Study of Aerosolized RSP-1502	Phase 1b/2a clinical trial to evaluate the safety, tolerability, and efficacy of tobramycin plus CaEDTA in ascending doses administered via nebulizer	• 12+ years old • CF and P. *aeruginosa*$^{+}$	Lani
Ridgeline A Phase 3 evaluating the Safety and evaluation VNZ/TEZ/D-IVA	A Phase 3, Open-label Study Evaluating the Long term Safety and Efficacy of Vanzacaftor/Tezacaftor/Deutivacaftor Triple Combination Therapy in Cystic Fibrosis Subjects 2-11 Years of Age	• 2-11 years old • Diagnosed with CF	Tina
Timberline A Phase 3 evaluating the Safety and evaluation VNZ/TEZ/D-IVA	A Phase 3, Open-label Study Evaluating the Long term Safety and Efficacy of Vanzacaftor/Tezacaftor/Deutivacaftor Triple Combination Therapy in Cystic Fibrosis Subjects 2-5 Years of Age	• 2-5 years old • Diagnosed with CF	Tina

Philanthropy Corner with Lucile Packard Foundation for Children's Health

Stanford MEDICINE Children's Health

Lucile Packard Foundation

Are you passionate about making a difference in the lives of CF patients and their families? Reach out to us today to learn more about how you can get involved. Whether you're interested in contributing personally or creating connections with others aligned with our mission, your support is instrumental in advancing CF research and care.

Consider joining us on this journey toward a brighter, healthier future for every child affected by cystic fibrosis. Together, we can make a tangible impact and ensure better outcomes for generations to come!

Contact:
Dominique Ta at Dominique.Ta@LPFCH.org or (650) 461-9943. Learn more at www.lpfch.org

Healthy Potato Soup

From The Mediterranean Dish.

Prep time: **15 min.** | Cook time: **35 min.**
Total time: **50 min.** | Servings: **6**

Ingredients

- 2 tablespoons extra-virgin olive oil
- 1 medium yellow onion, chopped
- 1 carrot, peeled and chopped
- 2 celery sticks, peeled and chopped
- 2 large garlic cloves, minced
- 1½ pounds yellow gold potatoes, peeled and cut into ½-inch cubes
- Kosher salt
- Black pepper
- 1 teaspoon ground cumin
- ½ teaspoon paprika
- ¼ teaspoon turmeric
- 4 cups vegetable broth
- 1 cup milk or unsweetened, unflavored plant-based milk
- ½ cup chopped fresh parsley
- 1 to 2 green onions, trimmed and chopped (both white and green parts)

Instructions

1. **Heat oil and sauté vegetables:** In a large cooking pot set over medium-high heat, add extra-virgin olive oil. Add the onions, carrots, celery, garlic, and potatoes. Season with kosher salt, black pepper, cumin, paprika, and turmeric. Cook the vegetables, tossing occasionally, for about 5 to 7 minutes until softened a bit.
2. **Add the broth and simmer:** Add the vegetable broth and bring to a boil for about 5 minutes, then lower the heat and cover the pot partially. Allow the soup to simmer for about 20 to 30 minutes or until the potatoes are cooked through and very tender.
3. **Add the milk and adjust seasoning:** Remove the pot from the heat and stir in the milk. Taste and adjust for seasoning.
4. **Use an immersion blender:** Using an immersion blender, carefully blend the soup until smooth. Alternatively, you can transfer the soup one-third at a time to a countertop blender until all the soup is smooth.
5. **Serve:** Transfer to serving bowls and garnish with a drizzle of olive oil, parsley, and chopped onions.

Notes

- To make this soup vegan, substitute milk with your favorite unsweetened, unflavored plant-based milk.
- This soup will keep in the fridge for up to 4 days. To store, allow the soup to cool, then transfer to a glass container with a tight lid. Refrigerate.
- If you prefer your soup with a little texture, don't puree it at all or only puree part of it.

Nutrition

Calories: **178.4 kcal** | Carbohydrates: **27.5 g** | Protein: **4.3 g** | Fat: **6.3 g** | Saturated Fat: **1.5 g** | Polyunsaturated Fat: **0.6 g** | Monounsaturated Fat: **3.8 g** | Cholesterol: **4.9 mg** | Sodium: **661.8 mg** | Potassium: **650.3 mg** | Fiber: **3.5 g** | Sugar: **5.6 g** | Vitamin A: **2634.2 IU** | Vitamin C: **31.7 mg** | Calcium: **85.6 mg** | Iron: **1.6 mg**

Cystic Fibrosis Center at Stanford

Pediatric providers at Lucile Packard Children's Hospital Stanford

Pediatric Center director: Carlos Milla, MD
Providers: Sumit Bhargava, MD; MyMy Buu, MD; David Cornfield, MD; Lori Lee, MD; Michael Tracy, MD; Jacquelyn Spano, DNP, RN, CPNP; Cissy Si, MD
Clinic scheduling: (650) 498-2655
Clinic and prescription refill fax: (650) 497-8791
Laura Banuelos Office Assistant/ Patient Services Coordinator: (650) 498-2655
Nurse Coordinator—Wendy Chin, RN: (650) 736-1359
CF Clinic Nurse—Liz Beken, RN: (650) 736-1359
Respiratory Therapist—Samuil Kovalchuk, RT: (650) 724-0206
Nutritionist, dietitian—Julie Matel, MS, RD, CDE: (650) 736-2128
Social Worker—Lizzy Nofziger, MSW: (650) 796-5304
Newborn Screening Coordinator—Jacquelyn Spano, DNP, RN, CPNP: (650) 721-1132
Clinical Pharmacist—Jake Brockmeyer, PharmD, BCPS: (650) 505-9419
Clinical Psychologist—Diana Naranjo, PhD

For urgent issues:

Monday – Friday, 8 a.m. – 4 p.m.:
Call the CF nurse at (650) 736-1359
After hours and weekends: Call the main hospital and ask for the on-call pulmonology doctor (650) 497-8000

Pediatric providers at Emeryville

Karen Hardy, MD; Eric Zee, MD; Manisha Newaskar, MD; Rachna Wadia, MD
CF Clinic scheduling: (650) 724-8414
Clinic and prescription refill fax: (510) 457-4236
Nurse coordinator—Neetu Perumpel, MSN, RN: (650) 724-8414
Respiratory Therapist—Lorraine MacPhee, RT: (510) 587-9631
Carol Journey, RT: (925) 239-2907
Nutritionist, Dietitian—Mikaela Burns, CRD, MPH: (510) 806-3659
Social Worker—Teresa Priestley, MSW: (925) 357-0733

For urgent issues:

Monday – Friday, 8 a.m. – 4 p.m.
Call the CF nurse at (650) 724-8414
After hours and weekends: Call the main hospital and ask for the on-call pulmonary doctor (844) 724-4140

Adult providers at Stanford

Adult Center director: Paul Mohabir, MD
Associate Center director: Alicia Mirza, MD
Pulmonologists (MDs): Laveena Chhatwani, MD; Alicia Mirza, MD; Paul Mohabir, MD
Director of Psychiatric and Psychological Services: Liza Sher, MD
Infectious Disease Consultant: Joanna Nelson, MD
Advanced Practice Providers: Meredith Wiltse, NP
Clinical Pharmacist: Denise Kwong, PharmD
Adult Clinic Scheduler/Patient Care Coordinator: Patricia Morales (650) 723-0798
Adult CF Center Fax: (650) 723-3106
Nurse Coordinators: Theresa Kinney, RN and Kristel Fallon, BSN, RN (650) 498-6840
Respiratory Therapy: Jenny Kwok, RCP IV; Jennifer Mori, RRT (650) 736-8892
Registered Dietitian: Emily Yelenich, MS, RD (650) 529-5952
Social Worker: Debbie Menet, LCSW (650) 518-9976
Kate Yablonsky, LCSW (650) 444-6512

Routine Issues/Concerns during Business hours

- **CF Nurse Coordinator Line:** (650) 498-6840
- **Voicemail will be answered within 24-48 business hours, or sooner based on clinical priority.**
- **Alternatively, you can utilize MyHealth messaging for NON-URGENT NEEDS ONLY. MyHealth messages are NOT checked after hours or on the weekends.**

Urgent Issues/Concerns DURING Business Hours

Chest Clinic Call Center: (650) 725-7061

- **A message will be generated and sent to the CF Team ASAP**

Urgent Issues/concerns AFTER Business Hours:

- **Chest Clinic Call Center:** (650) 725-7061
- **A message will be generated and sent to the covering CF provider ASAP.**
- **MyHealth messages are NOT checked after hours, weekends, or holidays.**

Adult providers at CPMC

Adult center director: Ryan Dougherty, MD
Associate center director: Vinayak Jha, MD
Providers: Christopher Brown, MD; Carolyn C. Hruschka, ANP-BC
Adult clinic scheduling: (415) 923-3421
Adult CF Center fax: (415) 243-8666
Nurse Coordinator—Carolyn C. Hruschka, ANP-BC: (415) 923-3421
Respiratory Therapy—Bryan Ellis, RCP; Arthur Pundt, RC: (415) 600-3424
Registered Dietitian—Elena Zidaru, RD: (415) 237-3671
Social Worker—Scott Plymale, LSW, PhD: (415) 237-1252
Mental Health Coordinator—Amy Greenberg, LSW: (415) 923-3854

For urgent issues:

Monday – Friday, 9 a.m. – 5 p.m.
Call nurse coordinator (415) 923-3421
Evenings/weekends: Call and ask for the on-call pulmonary provider (415) 923-3421

Research

Tina Conti, BSRC, RRT-NPS, CCRC: (650) 498-8701
Lani Demchak, MBA: (650) 725-1087
Monica Elazar, DDS: (650) 723-5193
Cathy Hernandez: (650) 724-3474
Jacquelyn Spano, DNP, CPNP-AC/PC, CCRC: (650) 721-1132

CF Center at Stanford
770 Welch Rd Ste 350
Palo Alto, CA 94304

save the date

Join us for our annual Cystic Fibrosis Education Day!

Date: **Saturday, February 7, 2026**

Location: **Stanford University Arrillaga Center or join virtually**

We hope you'll be part of this special event! Stay tuned for more details and registration information coming soon.

Your feedback matters! Please take a moment to complete our short survey using the QR code provided.

Newsletter Contact Information
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