Spring 2024

Stanford MEDICINE Children's Health

Cystic Fibrosis Center **News**

Why Vitamins Are So Important in Your Cystic Fibrosis Care

Eric D. Zee, MD

Ever wonder why your provider annually checks and prescribes vitamins, especially vitamins A, D, E, and K? People with cystic fibrosis (CF) are at risk of problems with nutrition because of pancreatic insufficiency and the poor absorption of fats. These include the fat-soluble vitamins. These risks are even greater in those with cystic fibrosis–related liver disease. In those with vitamin deficiencies, data shows that there is an increased risk of infections, including with *Pseudomonas aeruginosa*. Pancreatic enzymes have been a big part of therapy in the digestion of fats in people with CF. These include vitamins A, D, E, and K. Thus, using supplemental vitamins is a regular part of CF care that includes products such as ADEK, AquADEKs, and DEKAs. That's why the cystic fibrosis team asks about diet and monitors vitamin levels as part of the patient's annual CF labs.

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In this issue

Why Vitamins...continued from page 1

Vitamins are involved in everyday functioning in our bodies. Vitamin A is involved in many bodily processes, including vision and bone health, and as an antioxidant protecting our cells. We normally get vitamin A from our diets, including dairy, cereals, eggs, fruits, and vegetables. Vitamin D has roles in fighting infections and regulating calcium metabolism for maintaining strong bones. We get vitamin D from our diet and through production in our skin with the help of sunlight. There are not that many foods that actually have vitamin D, but they do include fatty fish, liver, dairy, and egg yolks. Of all the vitamins, vitamin D is most at risk of being deficient.

Vitamin E is an antioxidant, helps with cognition, and also keeps our cells healthy. Vitamin E can be found in nuts, seeds, and oils. Deficiency in vitamin E can lead to anemia and neurological problems.

Vitamin K can be obtained through the diet in dark green leafy vegetables like broccoli, kale, and spinach. Interestingly, vitamin K is also produced by intestinal bacteria. It helps with cell metabolism, circulation, and blood clotting. While the CF team has specific recommendations for fat-soluble vitamins, there are no specific recommendations for water-soluble vitamins (like vitamins B and C).

As people with cystic fibrosis are becoming healthier with good nutritional habits, pancreatic enzymes, supplemental vitamins, and now highly effective modulator therapy like Trikafta, research continues on changes in dosing and how to give it. We are also learning more about how these vitamins impact our immune system and as antioxidants.

References

Senthilkumar S, Hendrix SJ, and Schindler T. Update on the management of vitamins and minerals in cystic fibrosis. Nutr Clin Pract. 2022 Oct;37(5):1074-1087. doi: 10.1002/ncp.10899.

Recipe: No-Bake Energy Balls

Great for a snack and easy to make in minutes. There are many variations on this recipe, so feel free to sub in/out ingredients to your taste.

Ingredients

- 1 cup rolled oats (or millet, buckwheat)
- ½ cup nut or seed butter (peanut, almond, tahini)
- ½ cup ground flaxseed
- ½ cup mini chocolate chips (or raisins, seeds, coconut)
- 4 tbsp honey (or maple syrup, prune puree)
- 1 tsp vanilla extract

Instructions

- Mix well and roll into 1-inch balls. Chill in refrigerator. Simple!

Nutritional info

- Total recipe: 2,204 calories; 252 g carbs, 132 g fat, 45 g protein

Pediatric CF Updates

Your Pediatric Pulmonary Fellows: Trang Dinh, MD, Jean Lee, MD, Kalen Hendra, MD, Jeff Ni, MD, and Krystal Jin, MD

Encountering a Pediatric Pulmonary Fellow: What to Expect?

- A specialist-in-training in pulmonary medicine.
- A medical provider who collaborates closely with pediatric residents, attending physicians, and other health care professionals to ensure comprehensive respiratory care for children.

Navigating Patient Care: The Fellow's Role

- Conduct comprehensive evaluations, interpret diagnostic tests such as pulmonary function assessments and chest x-rays, and perform bronchoscopies.
- Collaborate on personalized treatment plans with attending physicians.

What is a Pediatric Pulmonary Fellow?

A Pediatric Pulmonary Fellow is:

A **specialist-in-training** to take care of children with pulmonary conditions.

A **medical doctor,** they have completed medical school and a pediatric residency.

Tips for Picky Eating

Julie Matel, RD, and Wendy Chin, RN

Picky eating is a challenge for any parent; however, it can be especially frustrating for families of kids with cystic fibrosis. Good nutrition is essential to help kids with cystic fibrosis grow optimally and is linked to improved lung function outcomes. We know that many children with CF, despite improvements in nutrition seen with modulator therapies, and those with CF who aren't eligible for modulator therapies, continue to have higher energy needs than their peers.

Because of the added pressure for kids with CF to eat, families often experience particularly stressful mealtimes. It is not uncommon for families to develop maladaptive strategies to "get their kids to eat" that are not very effective and can further contribute to stress and unpleasant meal experiences.

Here are some examples:

Child: ***Yuck, I don't like it!***
Parent: You have to take a bite.

Child: ***Whining/crying/belligerent***
Parent: I made it, and you are going to eat it.

Child: ***Spitting out food***
Parent:If you won't eat it, what else would you like?

Child: ***Leaving the table***
Parent: I'll make you something else.

Here are some words and actions parents can use that may help relieve mealtime stress and lead to better meal experiences. Remember, consistency is key. You may not be perfect all the time, but practice, patience, and time will help!

Parents' words and actions that help:

- Encourage polite table manners by saying, "If you don't want to eat it, just say, 'No, thank you.'"
- Encourage trying new foods by saying, "If you would like to try a bite, you may spit it politely into a napkin if you don't like it."
- Ignore whining/crying behavior; turn your back and engage in conversation with other family members until it stops.

- If the child leaves the table, ask them to return by saying, "You don't have to eat, but I would like for you to sit with us for 10 minutes until the meal is over."
- Offer one or two familiar foods that your child typically likes, and let them have as much of that food as they would like.
- If a child is engaging in eating or trying a new food, offer praise by saying, "I like how you came to the table for dinner when I called you" or "I like how you tried a new food tonight!"

Here are some more ideas for how to cope with picky eating and help your child try new foods:

Picky eating:
- Involve your kids with making grocery lists, picking out new foods to try at the grocery store, and helping with meal preparation; kids will usually be more invested in trying foods that they are involved in preparing.
- Offer limited choices: "Would you like broccoli or green beans with dinner tonight?"
- Enjoy eating family meals together; engage in conversation without distractions like TV and cell phones.
- Offer the same foods for the whole family; let kids see you enjoy a wide variety of healthy foods; talk about colors, shapes, and textures on the plate.

How to encourage trying new foods:
- Start with small portions of a new food, even a small taste; your child may become overwhelmed with large servings.
- Offer one new food at a time; a meal might consist of old favorites and one new food to try.
- Be a role model; try new foods yourself, describe the taste, texture, and smell to your child.
- Offer new foods many times; it may take 10–15 tries of a new food before your child accepts it—be patient!

Make food fun!
- Use a cookie cutter to cut foods into fun and interesting shapes.
- Encourage your child to invent and prepare new snacks.
- Name a food your child helps create, like Amy's Amazing Salad.

Keep in mind that for most kids, trying new foods gets easier in the school-age years. Others may have more serious food aversions and require specialized care with an occupational therapist—kids with ARFID, for example (avoidant/restrictive food intake disorder). If you have concerns about your child, ask your primary pediatrician or CF team for advice.

Resources

MyPlate.gov

Ellyn Satter's *Feeding with Love and Good Sense: 18 Months Through 6 Years* (Kelcy Press, 2014). See EllynSatterInstitute.org to review other resources.

KidsHealth.org, ARFID page

Experience of Care (XoC) Survey

Providing the best experience of care to our patients and families is important to us. We are excited to participate and ask for your support. Designed by a committee of care team members, adults with CF, and parents from across the country, the survey includes questions about infection prevention and control, the way the care team responds to your questions and concerns, care planning, and overall communication and quality of the care experience. This survey is short and easy to take, and it asks about in-person and virtual-care experiences. The feedback and comments captured in the survey will let us know what is most important to you, build trust, and improve care. Creating a better care experience is important to the whole team—patients and families, clinicians, and professional staff. Your responses to the survey will be kept anonymous and will not be linked to you or your child's name or birth date. You will be surveyed following an in-person clinic visit and/or a telehealth visit (by phone or video).

EXPERIENCE OF CARE

We have **discontinued sending SMS text messages;** however, we will **continue to collect XoC survey data by sending invitations to people with CF and families who provide their email address.** Please make sure that we have a current email address on file so that we can hear from you! If you receive a survey invitation after your next visit, we would appreciate a few minutes of your time to share your feedback. Thank you in advance for helping us to provide you and your family with the best care experience. If you have questions or concerns, please reach out to our team.

Join the Pediatric Advisory Council

We need to hear from parents and would love for you to join the council.

The CF Care Team and Parent Council Members are seeking to expand participation and are exploring creative ways to facilitate this.

We are a group of parents whose children receive care from the Stanford CF Center. We work in partnership with members of the pediatric CF Team, with the shared goal of providing the highest quality of care and service to patients and families.

To achieve this goal, the Council seeks to:

- Enhance communication between the CF Team and CF families.
- Develop resource materials to assist patients and their families.
- Provide input—from a family perspective—on issues relating to CF care.
- Assess needs of patients and families, and work in partnership with the Care Team to enhance resources/service delivery.
- Serve as a voice for families receiving CF care at Stanford Medicine Children's Health.

The CF Parent Advisory Council is overseen by the Department of Family Centered Care at Stanford Medicine Children's Health.

If you are interested in joining, please contact Kirsten McGowan at KMcGowan@stanfordchildrens.org.

Child Life Specialists at Stanford

Understanding pain

Did you know that child life specialists can help you/your child prepare for painful procedures? Child life specialists can provide developmentally appropriate education and strategies to help cope with pain through activities, play, and distraction. Here is some helpful information from Stanford Medicine Children's Health:

How is pain level communicated?

For infants, toddlers, and other nonverbal children, pain is measured based on movements, behavior, and vital signs. For example, your child may act differently from normal when in pain, crying, making faces, moving in a certain way—or the opposite: Your child might be quiet and still because they are afraid of moving or don't have enough energy to show how they feel. For school-age children, they are shown the faces scale and asked to point to the face that best describes how much pain they have. For older children, they will rate their pain on a scale of 0 to 10, where 0 means no pain, and 10 means the worst pain imaginable.

Tips for pain management

- Ask for pain relief prior to or when pain first begins—it is better to control pain earlier rather than later.
- Bring music and other things from home, such as a favorite toy or blanket, to comfort your child.
- Stroke or massage your child's face, arms, feet, or any other parts of his or her body. There are also devices such as the Buzzy™ that vibrate on the skin in order to "confuse" the pain signals.
- Rock, hold, or carry your child if possible.
- If your child is an infant, give your child something to suck on, such as a pacifier.
- Distract your child with play or games. Games such as the interactive Piñataz, by a Stanford physician and team, have proven successful in addressing needle anxiety (Medical Moment).

Buzzy™ device for pain management

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Body Composition and Exercise in Cystic Fibrosis

Taylor Lewis, PhD, ACSM-CEP, CSCS, CMT, PRT

Over the years, various health trends and advancements have emerged in managing and treating cystic fibrosis (CF) that have been aimed at improving the quality of life and life spans of people with cystic fibrosis (pwCF). CFTR modulator therapies have revolutionized CF treatment by addressing the underlying cause of the disease. Modulator therapy has shown remarkable efficacy in improving lung function and weight gain.

Nutritional support and physical activity remain a cornerstone in CF management. High-calorie, high-protein diets are often recommended to meet the increased energy needs of pwCF. Caloric increases are essential in CF; however, it is also vital to be mindful of the types of foods that pwCF are consuming. According to the National Institutes of Health, 1 in 6 children and adolescents (2 to 19 years of age) are overweight (16.1%), and almost 1 in 5 are obese (19.3%). In addition, 40.9% of adults with CF are considered overweight or obese (NIDDK, 2022). The Physical Activity Alliance (2022) reported that 21% of youth and children completed 60 minutes of physical activity a day, and 42% of youth demonstrated adequate cardiorespiratory fitness.

With life expectancy increasing in pwCF, the importance of using tools to maintain quality body composition and physical activity levels is key to maximizing life expectancy and quality of life.

So, what is body composition? Body composition refers to the proportion of fat, muscle, bone, organs, and other tissues within the body. It is an essential aspect of overall health and development, influencing factors like metabolism and risk of chronic diseases later in life. In the clinical setting, the body mass index (BMI) is commonly used as a screening tool to place individuals in different weight categories, such as underweight, normal weight, overweight, and obesity. BMI measures body composition by dividing a person's weight in kilograms by the square of their height in meters. It is important to note that BMI is not the best screening tool to measure nutritional status and overall health, as it does not directly measure body fat or account for muscle mass and bone density.

Conversely, fat-free mass, consisting of bone, muscle, organs, and extracellular fluid, would better represent body composition. Furthermore, evidence suggests that the whole-body fat-free

> "...whole-body fat-free mass index (FFMI) is more strongly associated with percent predicted forced expiratory volume (ppFEV1) than BMI in pwCF."

mass index (FFMI) is more strongly associated with percent predicted forced expiratory volume (ppFEV1) than BMI in pwCF (Mason & Rogol, 2022). Improving body composition by building muscle mass and improving bone mineral density through strength training and physical activity are low-hanging fruit that can improve the quality of life in pwCF.

Improving the quality of life and human performance starts with increasing the time spent being active. Evidence supports the idea that decreased muscular strength and cardiorespiratory fitness are common in pwCF (Kinaupenne et al., 2022). Muscular strength and cardiorespiratory fitness are important markers for physical and mental health in youth and adults. Increased muscular strength is associated with a decreased length of stay in the hospital and a higher survival rate in chronic illness (Casey et al., 2022). In addition, greater aerobic fitness strongly correlates to lung function and reduced mortality in pwCF.

Body composition and physical activity level are important markers for understanding and tracking the overall health and longevity of pwCF. Cardiorespiratory and strength training are essential tools to increase bone mineral density, muscular strength, and aerobic capacity. All of these factors contribute to improvements in fat-free mass and lung function. The overarching goal to improve body composition and physical health starts with understanding our body composition. In addition, understanding where a person's activity level is compared with the current recommendations is a quality starting point. The human body is built to move, yet we are moving less and consuming more calorie-dense foods than ever before. Maintaining quality body composition and staying physically active, especially outside in the sunlight, are cornerstones in pursuing longevity in health and human performance.

References

Casey, P., Alasmar, M., McLaughlin, J., Ang, Y., McPhee, J., Heire, P., and Sultan, J. (2022). The current use of ultrasound to measure skeletal muscle and its ability to predict clinical outcomes: A systematic review. Journal of Cachexia, Sarcopenia and Muscle, 13(5), 2298–2309. https://doi.org/10.1002/jcsm.13041

Kinaupenne, M., De Craemer, M., Schaballie, H., Vandekerckhove, K., Van Biervliet, S., and Demeyer, H. (2022). Physical activity and its correlates in people with cystic fibrosis: A systematic review. European Respiratory Review, 31(165), 220010. https://doi.org/10.1183/16000617.0010-2022

Mason, K.A., and Rogol, A.D. (2022). Trends in growth and maturation in children with cystic fibrosis throughout nine decades. Frontiers in Endocrinology, 13, 935354. https://doi.org/10.3389/fendo.2022.935354

National Institutes of Health: National Institute of Diabetes and Digestive and Kidney Disease. (2021). Overweight and Obesity Statistics. Retrieved from https://www.niddk.nih.gov/health-information/health-statistics/overweight-obesity

Physical Activity Alliance. The 2022 United States Report Card on Physical Activity for Children and Youth. (2022). Retrieved from https://paamovewithus.org/wp-content/uploads/2022/10/2022-US-Report-Card-on-Physical-Activity-for-Children-and-Youth.pdf

Child Life Specialists at Stanford…continued from page 7

Additional resources to help

Call Child Life Services at (650) 497-8336.

The Pain Management Service can provide many different kinds of treatments for pain. Talk to your doctor about whether your child needs to be seen by the Pain Management Service.

The Family Resource Center located on the ground floor of the Main building has many helpful resources on pain, including books, relaxation tapes, music, and movies that you can check out. Call (650) 721-0874.

References

Stanford Medicine Children's Health (2024, March 6). Understanding pain. Retrieved from https://www.stanfordchildrens.org/en/services/pain-management/understanding-pain.

Medical Moment: Dealing with needle-related anxiety during trips to the doctor (8 March, 2024). Retrieved from https://www.wndu.com/2024/03/08/medical-moment-dealing-with-needle-related-anxiety-during-trips-doctor/

Adult CF Updates

Adult CF Clinic: Get to Know Your Advisory Council

Did you know the Adult CF Clinic has a seven-person Patient and Family Advisory Council (PFAC)? Each month, we gather virtually to connect with one another, discuss the patient perspective on our clinic, and offer guidance and feedback to our care team.

Advisory goals

The PFAC is a two-way experience. Each year, we set goals about what we want to learn and how we want to support the CF clinic—and our community of patients and families. This year, we are working on creating welcome bags for new patients and inpatients, exploring the best way for people with CF to be prepared for emergencies/disasters, and recruiting BIPOC and people not on modulators to our group. We've also been able to invite staff from the clinic to join us and talk about what they're working on behind the scenes.

Who's on the PFAC?

Siblings Anna and Kate came to the Stanford CF clinic after "graduating" from the pediatric clinic at Lucile Packard Children's Hospital Stanford in the late 2000s. Anna loves to sing (not during PFAC, we promise), and Kate has given birth to two tiny CF carriers. They are joined by Shawn, who was diagnosed with CF at age 50, and Angela (chair), who was diagnosed at age 28. Shawn is a superb track and field coach, and Angela is a chef and cartoonist. Finally, we've got Jacob—a dog whisperer—and Will, our requisite Bay Area engineer. Jacob is passionate about video games, and Will recently organized a CF fundraiser/treasure hunt. Rebekah, our CF mom on the council, just joined us this year. Kate Yablonsky, one of the CF social workers, is our staff adviser.

Drop in—or join us

We want to grow, so if you're interested in sitting in on a meeting or joining the PFAC, contact Kate Yablonsky at kyablonsky@stanfordhealthcare.org or (650) 444-6512 to learn more! Any patients or family members from the CF Adult Clinic are welcome to become Advisory Group members. Not only are family members welcome to join, they are encouraged.

Upcoming Events

Save the date for Summer Scamper!

Summer Scamper is a great fundraising event for our patients, like Doris.

Doris and family

Doris was a 2015 Summer Scamper Patient Hero representing the Pulmonology/Cystic Fibrosis Center. She is photographed with her family and doctor, Carol Conrad, MD.

Doris' lifelong battle with cystic fibrosis, which has included needing oxygen 24/7, hasn't kept her from becoming a legend in her elementary school in Menlo Park. She is known as "The Lipstick Girl," as she never leaves the house without a layer of her favorite gloss.

Doris will never forget June 3, 2014, the day she received the call from pulmonologist Carlos Milla, MD: A set of donor lungs became available, only two weeks before her ninth birthday. "I was praying to get a lung transplant before my birthday. When I got the call, I was crying and scared and happy all together," she says. After her double lung transplant, Doris was able to take deep breaths for the first time in her life.

Doris and Dr. Conrad

Max was diagnosed with lymphoma and treated at Lucile Packard Children's Hospital Stanford. He and his family were among the top five fundraisers for the 2023 Scamper event.

For more information, visit www.summerscamper.org

Family and friends of Patient Hero, Max, seen at Scamper

Summer Scamper

Sunday, June 23, 2024, 7:30 a.m.–noon
Stanford University,
294 Galvez Street, Stanford, CA

Current and Upcoming Research

Active Studies			
Name	**Brief description**	**Criteria**	**Contact(s)**
Beacon A Phase 1 Single Dose Escalation Study Evaluating the Safety and Tolerability of VX-522 (Vertex 522-001)	Phase 1 clinical trial of inhaled mRNA gene therapy in people with CFTR genotype not responsive to modulator therapy. Will be recruiting for multiple ascending dose (MAD) cohort- TBD	• 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 administration of either ivacaftor or elexacaftor/tezacaftor/ivacaftor (elex/tez/iva) on growth.	• <6 years old • CFTR variant eligible for HEMT • Not currently on ivacaftor or ETI	Amanda
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+	Amanda
NBSA Collection of Gene Mutation for Laboratory Quality Assurance: Newborn Screening Accuracy Project	Study collecting blood samples from patients with rare CF mutations to ensure that newborn screening tests are accurate in all ages	• Diagnosed with rare CFTR variant	Tina
NICE-CF A Multi-Center Study of Non-Invasive Colorectal Cancer Evaluation in Cystic Fibrosis	Colorectal cancer screening study comparing stool-based testing to colonoscopy	• 18+ years old • CF patients eligible for colonoscopy	Elvi
RESPIR-102 A Phase 1b Study of Aersolized RSP-1502	Phase 1b clinical trial to evaluate the safety, tolerability, and efficacy of tobramycin plus CaEDTA for chronic Pseudomonas aeruginosa lung infection administered via nebulizer	• 18+ years old • CF and P. aeruginosa on inhaled tobramycin	Amanda
SILP Multisite Qualification Studies Using the Slow Inhalation, Large Particle (SILP) Mucociliary Clearance Measurement Method	Observational study of the ability of study sites to follow experimental procedures and collect research quality data using a new standard operating procedure for the performance of mucociliary clearance scans	• 18-60 years old • 1 healthy control and 2 patients with CF • Non-smoking	Tina
WEARABLE RESPIRATORY Innovative Respiratory Condition Monitoring	This study is to better understand the best way to monitor the health of people with respiratory conditions	• 12+ years old • CF with history of more than one pulmonary exacerbation in the preceding year	Lani

Research Spotlight
The CF Research Team needs your help testing new therapies for people with CF. Please consider participating in a clinical trial for CF research.

Join our Wearable Device Research Study

Who can participate?
We are looking for people 12 years of age and older with cystic fibrosis.

What is involved?
Wear a health tag to monitor your respiratory status, checking your respiratory rate, pulse, sleep, activity, steps.

How long is the study?
The study lasts about six months and corresponds with your regular clinic visits

Interested?
Contact the research team cfresearch@lists.stanford.edu or scan the QR code below:

Interested in other research opportunities?
Check out the Clinical Trial Finder on CFF.org.

Philanthropy Corner with Lucile Packard Foundation for Children's Health

Stanford MEDICINE Children's Health | Lucile Packard Foundation

Empowering CF Patients and Families
At the Lucile Packard Foundation for Children's Health, we're on a mission to transform the lives of children and families through funding compassionate care and advancing groundbreaking research. As the sole fundraising entity of Lucile Packard Children's Hospital Stanford and the Stanford School of Medicine's pediatric and maternal health programs, we collaborate with individuals, corporations, and foundations to raise crucial funds enabling innovative research and the discovery of new cures and treatments.

Impact of Philanthropy for CF
Support from our community is the driving force behind our efforts, and philanthropic contributions to the Center for Cystic Fibrosis at Stanford play a pivotal role in accelerating progress toward life-changing breakthroughs and improving care for children today. Through direct support for the Center for CF, donors can fuel research endeavors aimed at discovering new breakthroughs and innovative therapies. Together, we strive to pioneer treatments that enhance the quality of life for CF patients and ultimately lead us closer to a cure.

How You Can Help
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!

Lucile Packard Foundation Staff

Contact:
Dominique Ta
Dominique.Ta@LPFCH.org
(650) 461-9943

Learn more at www.lpfch.org

Cystic Fibrosis Center at Stanford Contact Sheet

Pediatric providers at Lucile Packard Children's Hospital Stanford

Pediatric Center director: Carlos Milla, MD
Providers: Sumit Bhargava, MD; MyMy Buu, MD; Carol Conrad, MD; David Cornfield, MD; Michael Tracy, MD; Jacquelyn Spano, DNP, RN, CPNP, Cissy Si, MD, Nick Avdimiretz, MD
Clinic scheduling: .... (650) 724-4788
Clinic and prescription refill fax: .... (650) 497-8791
Laura Banuelos, Office Assistant/ Patient Service 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—Debbie Menet, LCSW: .... (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 number and ask for the on-call pulmonary doctor .... (650) 497-8000

Pediatric providers at Emeryville

Karen Hardy, MD; Eric Zee, MD; Manisha Newaskar, MD; Rachna Wadia, MD
CF Clinic scheduling: 1 (844) 724-4140
Clinic and prescription refill fax: .... (510) 457-4236
Nurse coordinator—Neetu Perumpe, MSN, RN: (650) 724-8414
Respiratory Therapist—Lorraine MacPheem, RT: (510) 587-9631
Nutritionist, Dietitian— Mikaela Burns, CRD, MPH: .... (510) 806-3659
Social Worker—Teresa Priestly, 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 number 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, Gauri Pendharkar, RCP, CPFT (CF RT Coordinator); .... (650) 736-8892
Registered Dietitian: Emily Yelenich, MS, RD .. (650) 529-5952
Social Worker: Meg Dvorak, LCSW .... (650) 518-9976
Kate Yablonsky, LCSW: ....(650) 444- 6512

Routine Issues/Concerns during Business hours (Monday – Friday, 8 a.m. – 4:30 p.m.)

- **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 (Monday – Friday, 8 a.m. – 5 p.m.)

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, RCP: .... (415) 600-3424
Registered Dietitian—Elena Zidaru, RD: .... (415) 923-3997
Social Worker—Amy Greenberg, LSW: .... (650) 518-9976
Mental Health Coordinator— Amy Greenberg, LSW: .... (415) 923-3854

For urgent issues:

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

Research

Tina Conti, BSRC, RRT-NPS:.......... (650) 498-8701
Lani Demchak, MBA:.......... (650) 725-1087
Monica Elazar, DDS: .... (650) 723-5193
Cathy Hernandez, AD: .... (650) 724-3474
Amanda Keen, MSN, RN:.......... (650) 723-4670
Jacquelyn Spano, DNP, CPNP-AC/PC, CCR:... (650) 721-1132

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

Other Research Opportunities

Getting a colonoscopy this year?
Enroll in NICE-CF and get compensated! If interested, please reach out to cfresearch@lists.stanford.edu

GEMS-CF: Mental Health Screening Tool Study
A research study is seeking participation from individuals with cystic fibrosis, 18 years and older, who would like to provide input on mental health concerns that may impact daily functioning. The first part will be a one-hour interview via videoconferencing. Participants who complete the interview will receive $50 for their time and effort. Responses will be used to help generate a new, brief general mental health screening tool that is CF specific (GEMS-CF). After the tool is developed, we would like to recontact you to complete the GEMS-CF screening tool along with other questionnaires. Participants who complete these questionnaires will receive an additional payment of $50 for their time. For more information, visit https://l8r.it/TnNt.

Know of currently enrolling studies? Send the information to us, and we will include it in our next newsletter!

Newsletter Contact Information
Editors: Lani Demchak, MBA and Amanda Keen, MSN, RN
Visit our website at http://cfcenter.stanford.edu for more information about our center and cystic fibrosis.
To subscribe to this newsletter, please contact Cathy Hernandez at (650) 724-3474 or cathyh1@stanford.edu
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