Fall 2023

Stanford MEDICINE
Children's Health

Cystic Fibrosis Center **News**

Adult Cystic Fibrosis Center Updates

—Paul Mohabir, MD

Dear CF Community,

We are pleased to report that our Adult Cystic Fibrosis (CF) Center continues to thrive both clinically and academically. Our partnership with California Pacific Medical Center (CPMC) in San Francisco as one of our affiliated CF centers has proven to be an asset. We are in the process of trying to expand our clinical presence by partnering with other centers. Importantly, we just received notification that the Cystic Fibrosis Foundation (CFF) has granted us a five-year accreditation, which is the maximum period that can be given. I would like to personally thank our clinical team for their vast efforts that have supported this award. The collaboration with our CF patients, their families, and the community at large has been paramount in achieving our successes.

Adult CF team

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Research

Our focus this year has been to heighten our research program. We have strategically developed an outcomes research team that is exploring innovative CF topics such as long-term outcomes, CF and pregnancy, perspectives on primary care physicians in the CF population, and the impact of the duration of antibiotic usage and the relationship to lung function over the lifetime of CF patients.

Staffing Updates

In your upcoming clinic visits you will notice a few new faces and the loss of a few members. Dr. Alicia Mirza has joined our CF program as our associate program director. Dr. Mirza is a familiar face, as she completed her pulmonary and critical care training here at Stanford, where she had a focus on CF care. Dr. Mirza returns to us with significant clinical and leadership skills, as she was the program director of the adult CF center at Kaiser Permanente Oakland. Dr. Mirza will also collaborate with Dr. Laveena Chhatwani to enhance and develop our CF quality improvement endeavors. Dr. Chhatwani continues to provide outstanding CF care in combination with her extensive knowledge in lung transplantation.

Farewell to Jennifer Cannon

Our ever-so-delightful, dedicated, and determined nurse practitioner Jennifer Cannon has relocated to Connecticut with her family. Although we have been saddened by her leaving, I am thrilled that she is considering a career in continued adult CF care at a nearby university.

Jennifer Cannon (back row, center)

Farewell to Elika Rad

One of our veterans and pioneers of APPs in our CF clinic, Elika Rad, NP, will be transitioning out of CF care into a new role, a first of its kind, where she will be training in an APP fellowship in Administration at Stanford Health Care. Elika has provided world-class CF care since 2008 and will now be able to share her expertise and her advocacy with a wider array of care providers. We are proud that our CF program has served as a platform for our team members to advance to such phenomenal heights.

Mary Helmers, Dr. Moss, Elika Rad (left to right)

Farewell from the CF Team

Elika is considered the "OG" of the Adult CF Center. Our community of patients and professionals have been so lucky to have access to Elika's brilliant mind and compassionate heart for all these years. She has been with the adult team since its inception in 2009, and her expertise in all things CF is unparalleled. Elika embodies confidence and clinical wisdom along with a magnetic personality; she is the

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total package of an extraordinary health care professional. Her leadership on the CF team has helped guide clinicians in all disciplines for many years, and she will be deeply missed. We wish her all the best in her new journey with her fellowship. We extend our wholehearted thanks to Elika for her incredible years of service. The program will not be the same without her!

Elika Rad (far right)

Adult CF Clinic: Get to Know Your Advisory Council

STANFORD ADULT **Cystic Fibrosis** Advisory Council

Did you know the Adult CF Clinic has a six-person Patient & Family Advisory Council (PFAC)? The current group began meeting last summer. Each month, we gather virtually to connect with one another and discuss the patient perspective on our clinic.

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. Right now, we've been talking about a few things: getting established as a PFAC group, supporting transitions from the pediatric clinic, and testing out advanced care planning conversations. 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 (chair) 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, 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. Kate Yablonsky 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 Adult CF Clinic are welcome to become Advisory Group members. Not only are family members welcome to join, they are encouraged.

Navigating the Future: Advanced Care Planning in Cystic Fibrosis

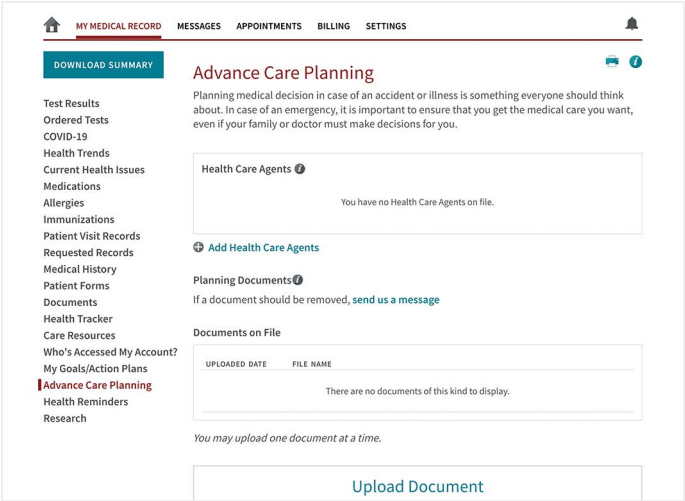
—Alicia Mirza, MD

As people with cystic fibrosis (CF) journey through life, the importance of advanced care planning becomes increasingly evident. Advanced care planning involves making informed decisions about medical treatments, interventions, and end-of-life care preferences. It empowers individuals with CF to maintain control over their health care choices and ensure that their wishes are respected, even in the face of uncertainties that the condition may bring. While the CF Foundation highlights the importance of advanced care planning for those with advanced lung disease, it also recommends early advanced care planning for all adults with CF.[1] At the Stanford University Adult Cystic Fibrosis Center, we are working to improve our process for having these important conversations.

With advancements in medical science and therapies, the prognosis for individuals with CF has improved significantly over the years. As a result, many individuals are living longer. Even with this progress, some people are still dealing with significant health challenges and unpredictability in disease progression. It is important to have good provider-patient communication about a person's health and possibilities for the future. Advanced care planning involves open and honest conversations between patients, their families, and their medical teams. These discussions should address a range of topics, including goals of care, preferences for medical interventions, and decisions regarding end-of-life care. It is essential to have these conversations early, well before they become urgent matters.

Elements of Advanced Care Planning

1. **Setting goals and preferences.** Advanced care planning starts by considering personal values, lifestyle preferences, and treatment goals. People should think about what quality of life means to them. Stanford Medicine has collaborated with national experts to create a guide for these conversations.[2] Some examples include talking about what someone's most important goals are if their health worsens. What hopes and worries do they have for the future? If their health worsens, what are they willing to go through for the possibility of gaining more time? This might include discussions about the use of mechanical ventilation, transplant considerations, and other treatments that may arise in the future. How much do their loved ones know about their wishes?
2. **Choosing a surrogate decision maker.** Designating a surrogate decision maker or durable power of attorney for health care decisions is important for everyone. This surrogate decision maker will advocate for the patient's wishes if they are unable to



Advanced planning tab in Myhealth

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communicate or make decisions themselves. It's important to choose someone who understands the patient's values and is willing to respect and uphold their preferences.

3. **Documentation.** Putting one's advanced care planning preferences in writing is vital. Our CF team will document advanced care planning conversations in the Stanford medical record. Providing copies of these documents to both the medical team and the surrogate decision maker ensures that everyone is on the same page.
4. **Regular review and update.** Advanced care planning is not a one-time event. As circumstances change, so might a patient's preferences. It is important to review and update the advanced care plan periodically, especially after major life events or changes in health status.

Advanced care planning is an integral aspect of CF care that empowers patients to take control of their health care decisions. Engaging in advanced care planning conversations can be emotionally challenging, but they are an essential part of CF care. Our CF team, including care providers, nurses, and social workers, is here to support patients and their families through these discussions. Our goal is to facilitate conversations by providing information about prognosis and treatment options. We want people to feel empowered to ask questions and express their concerns openly. By discussing their preferences, individuals with CF can ensure that their voices are heard.

Through these conversations, people can find peace of mind in knowing that their wishes will be honored and respected, contributing to a greater quality of life and improved overall well-being.

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CF Family Advisory Council Back to School and Sports

—Kirsten McGowan

Fall is here, and that means school (and possibly sports) are back in session! The parents of the Family Advisory Council (FAC) put together some tips and ideas for making life easier when things get busy.

If you have input or an idea for the CF Family Advisory Council (FAC), please email Kirsten McGowan at kmcgowan@stanfordchildrens.org.

Back to School

- Starting a new school year is fun and exciting—working with your child's teachers/staff keeps open communication about your child's needs.
- Meet with school staff so that everyone is up to date and on the same page with enzymes, accommodations, and extra steps for your child.

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CF Family...continued from page 5

- Update IEPs, 504s, and health plans! Make sure that new medications, changes in your child's care plan, or other accommodations are added.
- **Pro Tip!** Consider asking your child's teacher if you can speak with or write a short letter/email to the parents of the other children in your child's class about the basics of CF so the entire class can be supportive. We read a book entitled Who I Am! A Children's Guide to Cystic Fibrosis to my son's first-grade class, and the kids all loved it and were able to connect with everyone having different needs.

Sweat it Out

- The weather can stay hot through the fall in the Bay Area, and people with CF lose more salt when they sweat—
- Pack your child with lots of water and salty snacks (pretzels, chips, salted nuts) for school and activities.

- Gatorade and electrolyte drinks are helpful to replace salt during hot weather.
- **Pro Tip!** Add ¼ tsp salt to 12 oz of Gatorade/sports drink for even more salt support.
- Medications like enzymes are temperature sensitive (they don't work as well if they get too hot), so don't keep them in risky areas such as pockets or cars or leave them in direct sunlight.

Busy Busy Busy

- With school back in session, it's normal for schedules to fill up again with homework, after-school activities, sports, etc., and parents can feel overwhelmed with juggling it all.
- Routine is important and can make life easier once school starts. Agree on a bedtime and wake-up time, and have your child help set alarms to keep everyone on track. Have your child pack their bags and snacks the night before so that the morning rush isn't as hectic. Encourage older children to make a daily schedule so they can anticipate when to do treatments, hang out with friends, play sports, do homework, etc.
- **Pro Tip!** Don't be afraid to ask for help! When life gets busy, it's important to get help when needed. Ask a friend/grandparent/sibling to babysit or take someone to soccer practice. Set up a carpool with another family to share drop-off/pickup duties.

Here Come The Germs!

- Cold and flu season comes around this time every year, so encourage good handwashing.
- Stay home and rest when sick.
- **Get your flu shot! Pro Tip!** If you can, have an older sibling/friend get their flu shot at the same time to set a good example and make vaccines less scary for little ones.

Pediatric CF Center Updates

—Mary Helmers, RN, BSN

Helpful Tips and Reminders

- Ask us about medical assistance programs for your bills.
- Bring your CF Binder and Passport to your appointments.

CYSTIC FIBROSIS PASSPORT

- **Please escort me to a private room**
- **Please follow contact/droplet precautions (see CF Isolation Policy)**
- **Gown, mask, gloves for all health care providers**
- **Clean all surfaces after patient contact**
- **Please remember to use good hand washing/gel/foam cleanser before and after patient contact**

- Sign up for MyChart.
- Request refills at least one week in advance.
  - Call your pharmacy first to find out if you have refills.
  - If you have no refills, request in MyChart.
- Annual visits scheduled around your child's birthday will include: lab work, chest x-ray (CXR), bone density scan (12-plus years old), pulmonary function tests (7-plus years old), audiogram (6-plus years old), liver screening, and sputum cultures.
- Patients should wear the surgical masks to and from all clinics/hospital. They should fit around the nose and mouth.

XOC (Excellence of Care) Surveys

The Cystic Fibrosis Foundation (CFF) will be sending quarterly surveys to all our patients and families after a clinic visit. Surveys (in English and Spanish) are currently being sent via text or email.

Providing the best experience of care to our patients and families is important to us and the CFF. The CFF convened a multidisciplinary committee to create the survey and include perspectives of people with CF, parents of children with CF, representatives from the CFF, physicians, nurses, and other care team disciplines, including social work, respiratory therapy, and nutrition.

The goal of this survey is to hear directly from patients and families about their care experience. This survey is short, easy to take, and 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 birthdate.

XOC surveys will be sent to every patient/family one to two days after your visit via text or email. Make sure that we have a current email address or mobile phone number on file so we can hear from you!

> "There's never been a better time to share your thoughts and feedback!"

Pediatric Clinic Staff Updates

Farewell to Mary Helmers

—Carlos Milla, MD

The Stanford CF Center coordinator, Mary Helmers, RN, announced her plans for retirement and will be stepping down from her position in November of this year. It will be bittersweet to see Mary step down. She has been at the core of our programs for over 30 years, and there is much that the Stanford CF Center and the Northern California CF community owe to Mary's tireless dedication to our patients and families. She started her career at Stanford in 1985 and has had a truly exceptional career in pulmonary medicine and cystic fibrosis. Her time as nurse coordinator in the Cystic Fibrosis Center at Stanford began in 1992, and since then she has meaningfully touched the lives of countless patients and families. Mary is a highly decorated member of the CF community, being recognized for her contributions with the CFRI Professional Excellence Award in 2004, the Lucile Packard Children's Hospital Stanford Grace Award in 2014, and the CFRI Champion of the Year Award in 2020. She has enriched the career development of many medical professionals, not only in her day-to-day mentoring but also in the many conferences and presentations in which she participated. She has inspired and mentored fellows, junior faculty members, and students and guided them successfully on their course through the field of CF.

Though Mary will be sorely missed by her co-workers and patients, she will continue to contribute her CF expertise through participation in the CF Foundation's International Mentor Training Initiative. In this program she will help medical practitioners in low- and middle-income countries develop the skills to improve the care of CF patients.

Jackie Spano, Colleen Dunn, Zoe Davies, Mary Helmers, Elika Rad (left to right)

Pediatric CF Team

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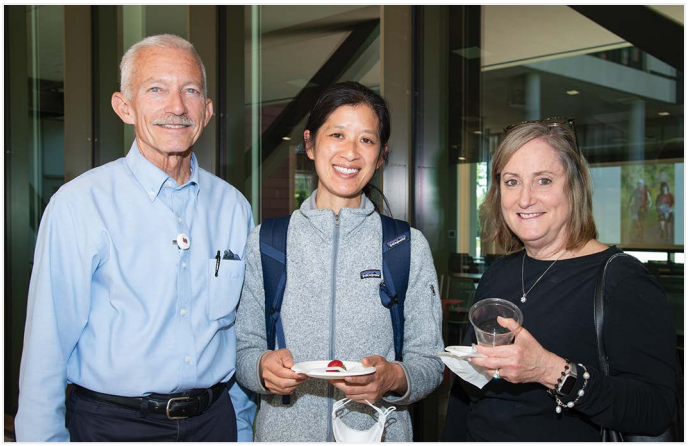
Mary Helmers, Dr. Cornfield

Mary Helmers, Dr. Moss, Elika Rad (left to right)



Dr. Mark, Dr. Lee, Mary Helmers (left to right)

Jake Brockmeyer, Liz Beken, Mary Helmers, Cathy Hernandez (left to right)

Farewell to Dr. Elizabeth Burgener

—Paul Bollyky, MD

I am so excited about Dr. Burgener's new lab and new clinical role as an assistant professor at Children's Hospital Los Angeles (CHLA). From the moment she started with us here at Stanford for her training, it was clear that she had the talent and commitment needed to make an impact as an independent investigator in CF research.

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Lani Demchak, Monica Elazar, Tina Conti, Dr. Burgener, Jackie Spano (left to right)

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In the interim, she made outstanding contributions both to our science and to the care of individuals with CF. All of us in the Bollyky Lab will miss her friendship, her keen insights, her enthusiasm, and how she made every team she was a part of better. The good news is that she isn't going far, and we will continue to collaborate far into the future.

Farewell to Jessica King

—Mary Helmers, RN

Jessica has been with the CF Center since 2020 as a registered respiratory therapist. She served as a committee member of the CF Family Advisory Council, in which she helped promote partnerships between patients, families, and health care providers to navigate patient care. Prior to CF, she was part of the Stanford family working in the Division of Pediatric Gastroenterology, Hepatology and Nutrition.

In 2023, Jessica received the CF Foundation's Kristen McFall Memorial Respiratory Therapist Award. What an amazing honor! She has built great relationships with patients and within the CF community.

Jessica King, Murielle Hanania, Laura Banuelos, Julie Matel (left to right)

Jessica relocated to the Sacramento area with her family. It is her hope to continue to contribute to the CF community. We wish her all the best on her next adventure!

Welcoming New Staff

A warm welcome to Wendy Chin, RN, who will be joining us as the CF nurse coordinator. Wendy was born and raised in San Francisco and has 13 years of nursing experience, most recently in the Pulmonary Department at UCSF. She is most passionate about patient advocacy and increasing health equity for everyone.

In her spare time, she likes to do jigsaw puzzles with her husband and their two daughters, ages 5 and 9. Wendy has recently started a new hobby of amigurumi, which is the Japanese art of crocheting small stuffed animals. She is excited to form strong relationships with the CF families at Stanford and looks forward to meeting everyone!

Wendy Chin, RN

Fetal Delivery of Trikafta via Maternal In Utero Administration: A New Era for Early Cystic Fibrosis Treatments

—Jake Brockmeyer, PharmD, BCPS, BCPPS

Introduction

Cystic fibrosis (CF) is a challenging genetic disease that mainly affects the lungs, pancreas, liver, and digestive system. For parents expecting a child with CF, the journey can be filled with anxiety and uncertainty, especially if previous children have already faced complications related to the disease. However, there is a glimmer of hope on the horizon: a groundbreaking approach exploring fetal delivery of Trikafta, the three-drug combination cystic fibrosis transmembrane conductance regulator (CFTR) modulator medication—elexacaftor/tezacaftor/ivacaftor—via maternal in utero administration. This emerging treatment strategy offers the potential to improve fetal outcomes in pregnancies affected by CF, paving the way to a brighter future for affected families.

Understanding CF and Its Impact on Newborns

CF occurs when a child inherits two mutated copies of the CF gene, one from each parent. The gene encodes the CFTR protein responsible for maintaining the balance of salt and water in and out of the body's cells. In individuals with CF, the mutated gene produces a malfunctioning form of this protein, leading to the production of thick, sticky mucus that can affect and damage the lungs, pancreas, liver, and intestines. One of the significant challenges seen in newborns with CF is the development of meconium ileus, a bowel blockage caused by an abnormally sticky substance present in a baby's intestines before birth. Meconium ileus can occur during fetal development and continue to cause digestive complications throughout life. Children born with

CF and meconium ileus often require intensive medical management during infancy, such as intestinal surgery, to resolve the obstruction, which can lead to extended hospitalizations and multiple procedures in the early stages of life.

The Potential of Trikafta in Fetal Treatment and Current Evidence

Trikafta is a revolutionary three-drug combination, first approved in 2019, that targets specific gene mutations underlying CF. While the medication is currently only approved for patients with CF who are 2 years of age or older, recent reports have shown that Trikafta administration during pregnancy might have unexpected benefits for the fetus. The concept of delivering Trikafta to the fetus via maternal in utero administration has sparked excitement within the medical community. Early reports suggest that this approach might reduce signs of CF at birth in affected babies, potentially

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sparing them from prolonged hospitalizations, severe complications, and surgeries.

To date, several case reports have documented the use of Trikafta in pregnancies where the mother either has a CF diagnosis herself or carries the CF gene. In one notable case carried out here at Stanford, a healthy mother without CF (but carrying the CF gene), expecting her third child with CF, trialed Trikafta during her pregnancy with guidance and support from her CF and obstetric care teams. The drug was administered twice daily as labeled for a patient with CF, starting from when she was 26 weeks pregnant, and the results were nothing short of remarkable. Ultrasound scans revealed that the bowel blockage observed earlier in the fetal development had stabilized. As the pregnancy progressed, the fetal MRI showed no signs of a blockage. When the baby girl was born, she did not require surgery for bowel complications, unlike her two brothers before her, who had the same genetic condition and were affected by many of the resulting complications seen in newborns. This case offers hope and opens the door to a new era in CF treatment during pregnancy.

Challenges and Multidisciplinary Approaches

The use of Trikafta in pregnancy requires careful consideration and collaboration between various medical experts, including obstetricians, neonatologists, and CF specialists. The safety and efficacy of this approach must be thoroughly evaluated, and potential maternal and fetal risks must be balanced against potential benefits. Ethical considerations are also vital, and informed consent is essential when exploring any novel treatments for a fetus. Close monitoring of the mother's health is necessary to ensure that the drug does not cause harm, and long-term follow-up is crucial to assess the impact of Trikafta on the child's development.

Moving Forward Together

The early success of fetal delivery of Trikafta via maternal in utero administration is cause for further, rigorous exploration. The possibility of intervening before birth to improve fetal outcomes offers new hope for families facing CF complications during pregnancy. However, while the initial results are promising, large-scale studies and long-term follow-up data are necessary to establish evidence-based guidance and fully understand the potential implications of this approach.

As the medical community continues to explore this novel treatment strategy, we must remember that each case is unique, and decisions regarding treatment should be made in close collaboration with medical professionals. Nevertheless, the advancements made in the field of cystic fibrosis treatment during pregnancy are an inspiring testament to the power of scientific research and the potential to transform lives.

While the road ahead may still be paved with challenges, the progress made in delivering Trikafta to the fetus in utero offers hope and optimism for the future. With continued research, collaboration, and dedication, we move closer to a world where all children, regardless of their genetic makeup, can look forward to a healthier and brighter tomorrow. As medical professionals and families alike, let us embark on this journey together, united in our commitment to ensuring a better life for all affected individuals and moving toward our ultimate goal to make CF stand for cure found.

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Egg Muffins Recipe

A make-ahead breakfast that is perfect for on-the-go kids and adults. Customize to your liking. Adapted from Life Made Simple. See original recipe at https://lifemadesimplebakes.com/egg-muffins/.

Ingredients

- ½ lb bulk pork sausage
- 12 eggs
- ½ chopped onion
- ½ c chopped green bell pepper or to taste
- ½ tsp salt
- ¼ tsp ground black pepper
- ¼ tsp garlic powder
- ½ c cheddar cheese, shredded

Instructions

1. Preheat the oven to 350°F. Use cooking spray to lightly grease 12 muffin cups. (You can also use 12 silicone muffin liners.)
2. Heat a skillet to medium-high heat. Cook the sausage until brown and crumbly. Drain.
3. Thoroughly beat the eggs in a large bowl. Add in the onions, peppers, salt, pepper, garlic powder, and cheese. Stir.
4. Pour the mixture into the greased muffin cups or silicone liners until each is about one-third full.
5. Bake for 22–24 minutes or until a toothpick inserted into the center comes out clean.

Makes 12 muffins.

Nutritional Information (per Muffin)

Calories: 143 kcal | Carbohydrate: 1 g | Protein: 10 g | Fat: 11 g | Saturated fat: 4 g | Cholesterol: 182 mg | Sodium: 309 mg | Potassium: 130 mg | Fiber: 1 g | Sugar: 1 g | Vitamin A: 322 IU | Vitamin C: 5 mg | Calcium: 61 mg | Iron: 1 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; Lori Lee, 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
Office Assistant/Patient Services Coordinator:
Laura Banuelos ..... (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, CPNP-AC/PC, CCRC..... (650) 721-1132
Clinical Pharmacist:
Jake Brockmeyer, PharmD, BCPS ..... (650) 505-9419
Clinical Psychologist: Diana Naranjo, PhD

For urgent issues:

Monday to Friday, 8 a.m. to 4 p.m.
Call the CF Clinic Nurse ..... (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 Stanford Medicine Children's Health Specialty Services – Emeryville

Providers: Karen Hardy, MD; Eric Zee, MD; Manisha Newaskar, MD; Rachna Wadia, MD
CF Clinic Scheduling ..... (844) 724-4140
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
Nutritionist, Dietitian: Mikaela Burns, CRD, MPH ..... (510) 806-3659
Social Worker: Teresa Priestley, MSW ..... (925) 357-0733

For urgent issues:

Monday to Friday, 8 a.m. to 4 p.m.
Call the CF Clinic Nurse ..... (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 Health Care

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, RN ..... (650) 498-6840
Respiratory Therapy: Erica Collins, RCP IV; Jenny Kwok, RCP IV; Jennifer Mori, RCP; Gauri Pendharkar, RCP (CF RT Coordinator) ..... (650) 736-8892
Registered Dietitian:
Marion Seabaugh, MPH, RD, CNSC, CCTD ..... (650) 529-5952
Social Work: Meg Dvorak, LCSW ..... (650) 518-9976
Social Work: Kate Yablonsky, MSW ..... (650) 444- 6512

Routine issues/concerns during business hours (Monday–Friday, 8:00 a.m.–4:30 p.m.)

- CF Nurse Coordinator Line ..... (650) 498-6840
- Voicemails 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, 8:00 a.m.–5:00 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
Provider: 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 Work: Amy Greenberg, LSW..... (650) 518-9976
Mental Health Coordinator:
Amy Greenberg, LSW ..... (415) 923-3854

For urgent issues:

Monday to Friday, 9 a.m. – 5 p.m.
Call the 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 ..... (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, CCRC .... (650) 721-1132

Current 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)	mRNA gene therapy in 18+ yo with CFTR genotype not responsive to modulator therapy	Inclusion/Exclusion: Two (2) patients, 18–65 yo with CF and CFTR variant nonresponsive to modulators, BMI <30	Lani
CF Registry Cystic Fibrosis Clinical Database and Specimen Banking	Collect clinical information and store patients' specimens in a central bank for analysis of effectiveness of treatment and characteristics that may influence outcomes	Inclusion/Exclusion: All CF patients	Cathy
Innovative Strategies for the Study of Disorders of the Respiratory Tract	Perform diagnostic procedures on patients who have cystic fibrosis, ciliary dyskinesia, idiopathic bronchiectasis, congenital heart disease, or undiagnosed respiratory symptoms, and healthy controls	Inclusion/Exclusion: <18 yo pediatric patients, adult healthy controls	Jackie
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	Inclusion/Exclusion: Diagnosed with CF	Tina
PCD Foundation (PCDF) Registry	A longitudinal study of patients with primary ciliary dyskinesia to improve outcomes and establish a database	Inclusion/Exclusion: <90 yo with PCD	Cathy Jackie
Pf Bacteriophage and Clinical Outcomes in Cystic Fibrosis	Monitoring of patients with cystic fibrosis, chronic pseudomonas, and presence of Pf bacteriophage with banking of sputum samples at clinical encounters	Inclusion/Exclusion: >12 yo with CF with hx of Pa, >18 yo healthy controls, nonsmoking	Jackie
Pulmonary Function in People with Viral Infections	Evaluate if people with acute respiratory viral illness have detectable abnormalities in their pulmonary function	Inclusion/Exclusion: 3–75 yo with acute respiratory illness, not oxygen dependent, healthy controls, nonsmoker # to enroll: no cap on enrollees; 40 healthy controls	Jackie
RARE Rare CFTR Mutation Cell Collection	Collect intestinal epithelial cells (by rectal biopsy) from CF patients with rare CFTR mutations, to develop a cell culture bank that can be used to evaluate response to experimental therapeutics	Inclusion/Exclusion: >12 yo with CF and rare CFTR variant, no hx of organ transplant # to enroll: 250	Lani

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

Upcoming Studies

BEGIN-OB-19: *A Prospective Study to Evaluate Biological and Clinical Effects of Significantly Corrected CFTR Function in Infants and Young Children (BEGIN).*

NICE-CF: *Observational study of adults with cystic fibrosis for colorectal cancer screening. Study will compare stool-based testing to colonoscopy for colorectal cancer screening in people with CF ages 18+.*

Longitudinal Characterization of Respiratory Tract Exacerbations and Treatment Responses in Primary Ciliary Dyskinesia: *To provide critical data needed to inform the design of future interventional trials of respiratory exacerbation prevention and treatment in children and adults with primary ciliary dyskinesia (PCD).*

RESPIR-102: *A Double-Blind, Active-Controlled, Multiple-Ascending Dose, Phase 1b Study of Aerosolized RSP-1502 Delivered VIA the PARI LC Plus Nebulizer in Subjects with Cystic Fibrosis and Chronic Pseudomonas aeruginosa Lung Infection.*

SILP: Slow Inhalation, Large Particle (SILP) Mucociliary Clearance Measurement Method performed in 1 healthy control and 2 patients with cystic fibrosis.

Vertex 121-106: A Phase 3, Open-label Study Evaluating the Long term Safety and Efficacy of Vanzacaftor/Tezacaftor/Deutivacaftor Triple Combination Therapy in Cystic Fibrosis Subjects 1 Year of Age and Older.

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 cathyh1@stanford.edu. Follow us on Facebook: Cystic Fibrosis Center at Stanford.