

# Cystic Fibrosis Center News

## International Mentoring Training Initiative

—Mary Helmers, RN, BSN, Relief Nurse Coordinator for Special Projects

The Stanford Pediatric CF team received our training certificate from the Cystic Fibrosis Foundation (CFF) last year at NACFC, 2023 in Arizona. After completing the training, the Cystic Fibrosis team at Stanford Medicine Children’s Health, in partnership with the U.S. Cystic Fibrosis Foundation, hosted our colleagues from Peru to share our experiences in the care of people with cystic fibrosis during the week of March 3–10, 2024.

Our week was filled with collaboration, education, sharing of practices in all aspects of CF care, and excitement to embark on this partnership with the goal of improving the quality of care, clinical outcomes, and life expectancy of people living with cystic fibrosis in Peru. The Peru team also met with the directors of the adult CF Center, Dr. Mohabir, the Pediatric Endocrine department, Dr. Cooper, and the Pediatric GI department,



Peru and Stanford teams at Mary Helmer’s home

Dr. Sellers. They also met our local nonprofit CFRI President, Siri Vath-Dunn. We view the visit as the continuation of a long-term relationship between our centers, and we hope to learn as much from the Peru CF team as they do from us.

We spent a little time exploring and touring the beautiful sights surrounding us here at Stanford—

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the Stanford University campus, the bookstore, and both pediatric and adult hospitals/CF clinics. We took our Peruvian colleagues on a tour of San Francisco, followed by dinner as we continued our collaboration. Continuing to give them a taste of our culture here, we welcomed them into my home, where we prepared a homemade Italian dinner. It was a warm and memorable evening.

We will continue on our journey of collaboration and education with the goal of helping improve the quality of care for all those living with CF in Peru. The team members included are Carlos Milla, MD-CF Center director; Jackie Spano, DNP; Mary Helmers, RN, BSN; Jake Brockmeyer, pharmacist; Debbie Menet, LCSW; Julie Matel, nutritionist; Jessica King, RT; and Laura Banuelos, Admin.

## IMTI Peru Team Visit

*—Debbie Menet, LCSW, Pediatric Clinical Social Worker, CF Center, Palo Alto*

Stanford Medicine's CF Pediatric Center, through a grant from the CF Foundation, has had the honor of mentoring a CF Pediatric team from Edgardo Rebagliati Martins National Hospital in Lima, Peru. The Peru team visited our CF Center in March 2024.

The team from Peru included a GI doctor, pulmonologist, nurse, dietitian, social worker, physical therapist (who provides RT services), and representative from their local nonprofit, FIQUI. It was a pleasure to introduce the team to our CF Center's interdisciplinary team work, a standard in CF Center care, as well as share



**Peru team with Dr. Mohabir**



**Dr. Milla presenting Michael with certificate**

specific information about each discipline's work with our children with CF and families. The team also shadowed clinic, toured both pediatric and adult hospitals, met the CF team at Stanford Hospital, and attended our annual CF Education Day. Additional highlights included tours of San Francisco and the Stanford campus, and introducing them to local wines and food.

It has been a delight forming a relationship with the Peru team. We are excited to continue this relationship and continue to support people and families with cystic fibrosis around the globe.

# Welcome Our New Fellows

## Welcome to Stanford, Drs. Spoorthi Davala and Daniel Nachreiner!

### Meet Dr. Davala

I was born and raised in the South Bay Area and ventured out to Boston University for both undergrad and medical school. I was fortunate enough to come back to the West Coast for my pediatrics residency at UCSF Benioff Children's Hospital Oakland. During residency, I found myself drawn to pulmonary medicine because of the wide range of acuity and pathophysiology it encompasses. Additionally, I am passionate about caring and advocating for children with complex respiratory illnesses in both the acute and nonacute care settings.

Outside of work, I love oil painting, gardening, baking, being outdoors, hiking, and spending time with my family and friends!



### Meet Dr. Nachreiner

I was born in the East Bay (John Muir Hospital!) and moved up to Oregon when I was 10 years old. I went to Boston College for undergrad and UMass for medical school. I am very excited to be back on the West Coast. My passion for pulmonology started when I was doing research at Boston Children's Hospital and making a de-escalation pathway off of continuous albuterol for patients presenting with asthma exacerbations. My favorite part of pulmonology is that it provides continuity of care, complex physiology, and a mix of procedures and clinical care. In my free time, I enjoy running, playing soccer, and watching sports.



## Pediatric CF Center Updates

### Helpful Tips and Reminders

- Did you know that you can get assistance with your PG&E bill? The Medical Baseline Program is an assistance program for residential customers who depend on power for certain medical needs. PG&E forms for medical equipment/devices (nebulizer/compressor, oxygen, CPAP/BIPAP) can be found on the PG&E website (<https://www.pge.com>) under *Save Energy & Money: Help Paying My Bill: Medical Baseline Program*.
- To expedite your clinic visit, please remember to bring your **CF Binder** with you to clinic and the most recent **CF Action Plan**.
- Your prescription request can take up to 72

hours to be processed. Please keep in mind that even after we send the script to the pharmacy, it can still take another 48–72 hours for the pharmacy to process. It is important for you to stay on top of your refills and request them **at least one week before you are due to run out**.

### Helpful hints for requesting refills:

- Call your pharmacy first to find out if you have refills available.
- If you have a refill, great! Then they will process. Keep in mind that your pharmacy will return your prescription back to the shelf if it is not picked up after a few days.
- Your pharmacy should call us if you have no refills.

*Continues on page 4...*

*Pediatric CF...continued from page 3*

### **MyChart (Secure Electronic Correspondence)**

MyChart is a secure way to communicate with your provider and CF care team. The CF care team cannot respond to patient or parent emails, since it is not secure. Please note that any email sent to the team will be responded to with a phone call. **Your CF care team can only communicate with you via MyChart or by phone.** If you/your child has a clinical need/question, please call the CF RN line at (650) 736-1359.

If you have not signed up already, **PLEASE** sign up for **MyChart at your next clinic visit.**

### **Annual Testing**

Our goal is to get all annual testing done on or around your child's birthday. You will receive a phone call prior to the clinic visit to remind you that annual tests are needed.

Included in the annuals are:

- Lab work (for some patients, this includes the glucose tolerance test, which starts at age 6).
- Chest x-ray (this is a walk-in test at 730 Welch Road, no appointment needed).
- Audiogram (not for all patients; some medications can affect hearing over time).
- Liver ultrasound (not for all patients, starting at age 6).
- Comprehensive pulmonary function testing (starting at age 8).
- Bone density scan (DEXA), starting at age 12.

### **For scheduling, contact:**

730 Welch Outpatient Lab/X-ray: (650) 725-9302

Short Stay Unit Scheduling: (650) 497-8953

Audiogram scheduling: (650) 498-4327

Radiology (any imaging like chest x-ray, liver ultrasound, DEXA scan—at Sunnyvale only): (650) 497-8376

Pulmonary Function Lab: (650) 497-8655

If you have any issues coordinating these tests with your appointment, please call the **CF Clinic Office Assistant at (650) 498-2655** or the **CF RN Line at (650) 736-1359.**

### **Infection Control**

Patients should wear surgical masks (yellow, blue, or white) to and from all clinics/hospital. The masks should fit around the nose and mouth.

Make sure you bring your **CF PASSPORT** with you! Use the **PASSPORT** around the hospital wherever you have an appointment, test, or procedure.

**Remember:** Parents/Patients to carry your child's **CF PASSPORT** in your wallet.

#### **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

### **CF Passport**

**If for some reason you do not have one or tossed it, please ask for one when you come to your next clinic appointment.** We now have them in English and Spanish.

# We need your help!

The Pediatric CF Center continues to take part in the CFF (Cystic Fibrosis Foundation) quality improvement initiative XoC (Experience of Care survey).

There has never been a better time to share your thoughts and feedback! We want to hear from YOU! 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.**

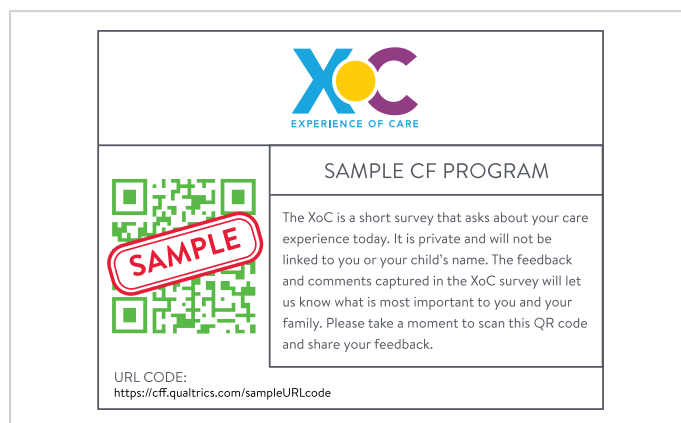
Designed by a committee of care team members, adults with CF, and parents from across the country, the survey includes questions about infection prevention and control, the way the care team responds to your questions and concerns, care planning, and overall communication and quality of the care experience. This survey is short and easy to take, and 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.** You will be surveyed following an in-person clinic visit and/or a telehealth visit (by phone or video). **We have discontinued sending SMS text messages and emails;** however, we will continue to collect



XoC survey data by having you click on a QR code (see example below). The QR code (in English and Spanish) will be handed out at CF clinic, and we ask that you take the survey right after the clinic visit. We value 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 any of your CF team members or Wendy Chin, RN, program coordinator.



XoC flyer sample

# Monica's Muesli

Monica Elazar, Regulatory Affairs

Adapted from <https://www.food.com/recipe/bircher-muesli-65238>

## Ingredients

- 1 1/3 cups milk (you can use low-fat or soy if preferred)
- 2 tablespoons sugar
- 2 tablespoons honey
- 1/2 teaspoon vanilla extract
- 3 cups rolled oats
- 3/4 cup fresh orange juice
- 1/2 cup plain yogurt
- 1/4 cup sultanas
- 1/2 cup light cream (for whipping)
- 2 tablespoons slivered almonds
- 1 or 2 Granny Smith apples, peeled and grated (optional)
- Ground nutmeg or cinnamon (optional)
- 1 to 2 cups mixed fresh fruit, peeled and diced (such as raspberries, strawberries, melon, apple, banana, grapes, kiwi fruit, pineapple, mango)

## Directions

1. Heat the milk and dissolve the sugar and honey in the hot milk. Add the vanilla. Pour the hot mix over the oats. Add orange juice, yogurt, and sultanas.
2. Mix well, cover, and refrigerate or leave in a cool place overnight, or this can be eaten warm rather than cold.



3. When ready to eat, whip the cream and fold it through the muesli with the slivered almonds (and grated apple if desired).
4. If the consistency is firmer than you prefer, add more milk or cream to taste.
5. Drizzle with cream.
6. Sprinkle with cinnamon or nutmeg, and serve with fresh fruit.
7. Instructions

## Nutritional Information

Amount per serving: calories, 488; carbohydrates, 76g; protein, 14g; fat, 15g.

# Events

**Summer Scamper 2024** was a success! Our Pulmonary/CF Center team, Lungevity, was there to run the 5K and also run an activity booth at the Family Festival. We had pinwheel kits for kids to assemble and learn one of the foundations for pulmonary function tests, blowing on command.

The event overall raised over \$655,000! Please consider participating with us next year—more details to come!

**SAVE THE DATE** for our next CF Education Day: Jan. 25, 2025, at the Arrillaga Alumni Center.



Back: Laura, Samuel; front: Lani, Wendy, Kayo, Amanda



Laura, Lani, Dr. Justin Baker, Kayo

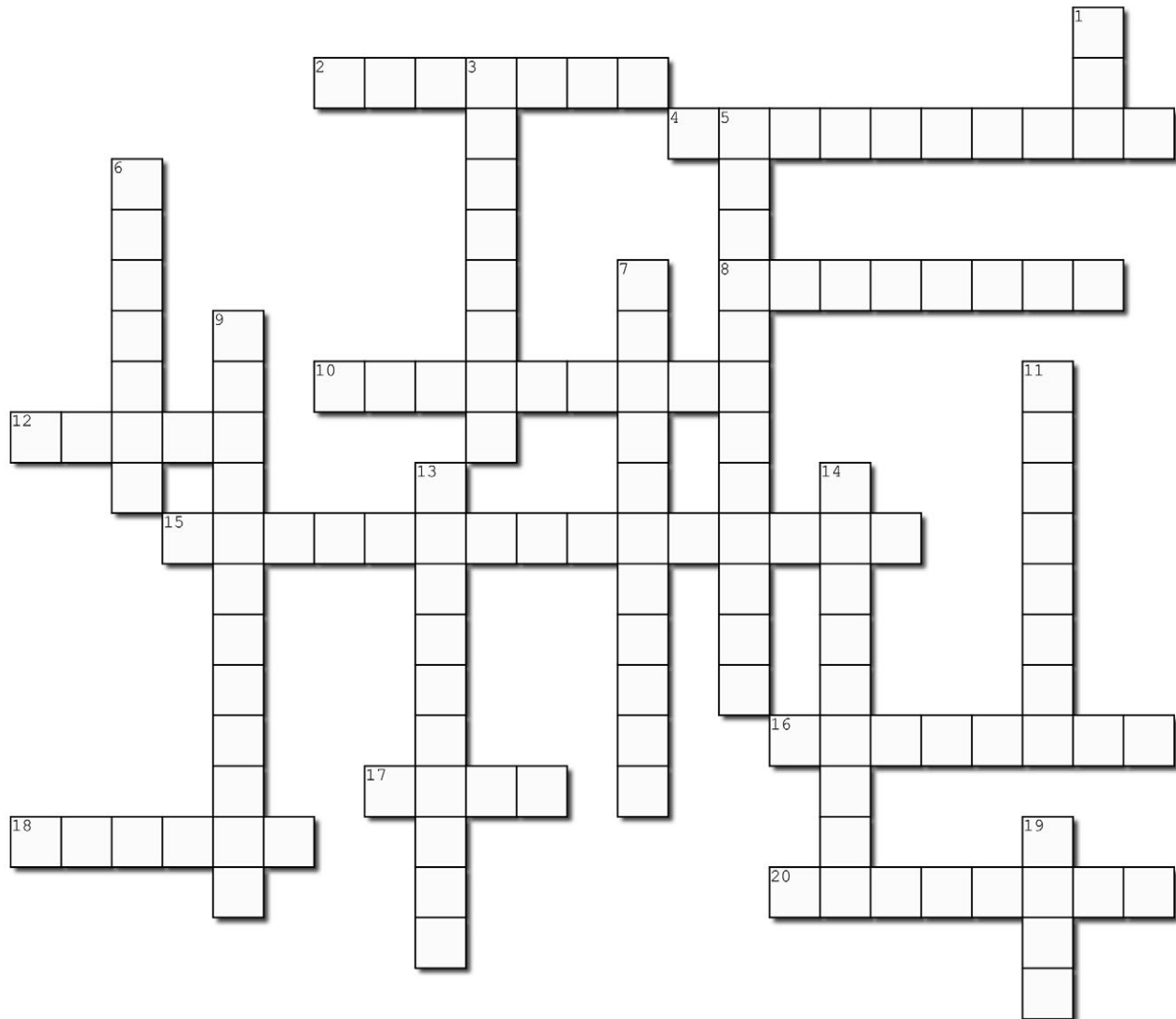


Wendy, Laura, Amanda, Kayo



Pinwheel assembly activity at our table

# CF 101 Crossword



Created using the Crossword Maker on TheTeachersCorner.net

## Across

2. Someone with one copy of the CFTR variant
4. Chest physical therapy using cupped hands
8. Anion channel non-functional in CF
10. Modulator medications that help with protein folding (Ex: lumacaftor)
12. Bodily fluid that can be tested to measure salt concentration
15. Procedure where donor organs replace the original organs
16. Organ that secretes digestive enzymes and insulin
17. Abbreviation for lung volume exhaled in 1 second
18. Bodily fluid that can be taken from the lungs and tested for infection
20. 3 drug combination modulator medication

## Down

1. Age at which Trikafta is approved to start
3. Database on the health status of patients with CF
5. A worsening of respiratory symptoms
6. Most common gene variant in CF
7. Modulator medications that help open the gate at the cell surface (Ex: ivacaftor)
9. 2 different copies of the gene variant
11. Specific alleles or variants an individual has in a gene
13. A test of lung volume and flow
14. Class of drugs that corrects and potentiates CFTR
19. Gene that creates the protein resulting in CF

See solutions on page 12.



# Adult CF Updates

## Farewell to Meg Dvorak

The Stanford Cystic Fibrosis Center would like to take the opportunity to thank Meg Dvorak, LCSW, for her more than 14 years of service to the CF community. As many of you may already know, Meg will be transitioning to a new position at Stanford on Aug. 26, 2024. In a fitting next step for her illustrious career, she will be joining the psychiatry department and providing individual therapy to posttransplant patients.

During Meg's time as the social worker for the adult CF team, she has witnessed the transformation of cystic fibrosis treatment, as well as what is possible for people with CF in their lives. She has been a pioneer of Cognitive Behavioral Therapy for Cystic Fibrosis (CF-CBT), acting as one of the first interventionists in the pilot study that has now transformed the way mental health care is being delivered in CF centers. She has mentored countless CF social workers as they developed new and innovative ways to support the CF patient population. For years, she has led NACFC's Psychosocial Collaborative, growing it from a small, preconference workshop to a highly sought-after, standing-room-only session that people travel early to attend. She has

facilitated support groups for people with CF through CFRI for over a decade and was honored as CFRI's CF Professional of the Year in 2016.

In the midst of all this incredible community work, Meg never failed to center the needs of the individual in front of her, in the clinic or the hospital room, advocating tirelessly so that our patients can have the best possible quality of life.

The Stanford Adult CF Center will not be the same without Meg. She will be missed, but the legacy she leaves behind will endure, improving the lives of people with CF for generations to come.

**Thank you, Meg!**

**With love,  
Your CF Family**



**Dr. Sher, Meg, Elika**



**Left to right: Meg, Gauri, Kristal, Kate**



**Adult CF Team with Dr. Al Faro on Ed Day**

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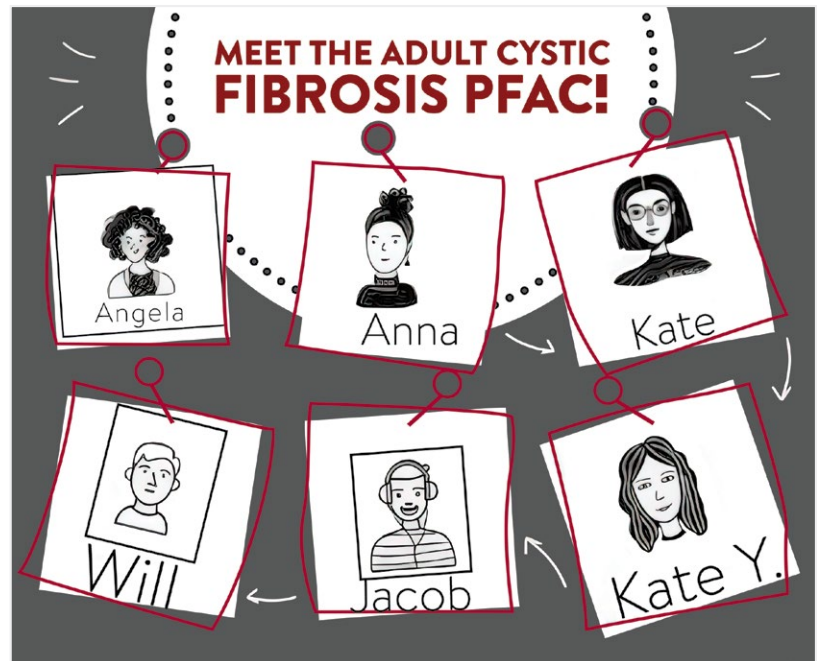
*Adult CF...continued from page 9*

### Meet the PFAC

Did you know the Adult CF Clinic has a 7-person Patient & 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.

Siblings **Anna** and **Kate** came to the Stanford CF clinic after “graduating” from the pediatric clinic at Lucile Packard 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 & 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 advisor.



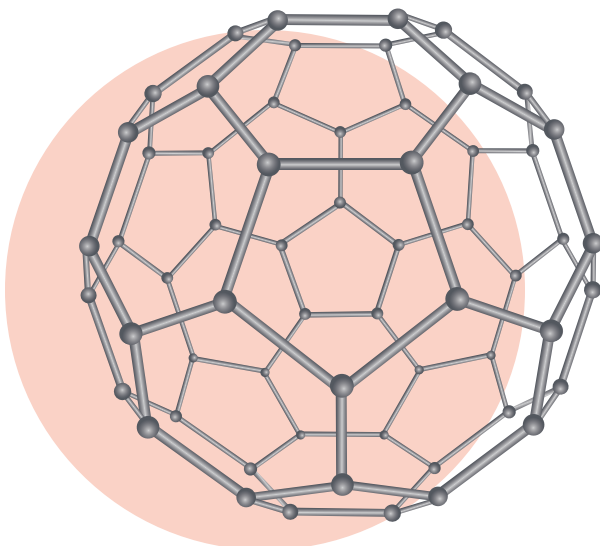
The PFAC

### 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.

### 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](mailto: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.

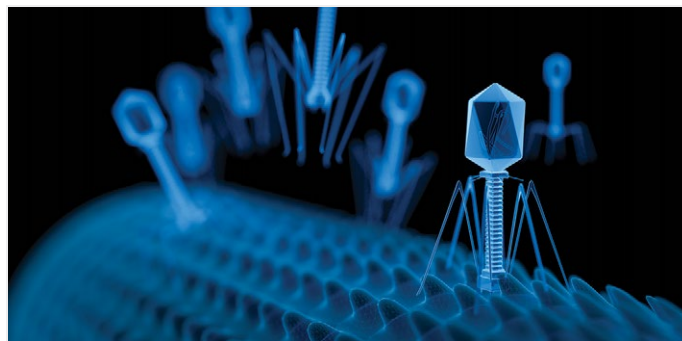


# The Future of Chronic Infections

Amanda Keen, MSN, RN

With the availability of highly effective modulator therapy (HEMT), many patients are seeing improvement in their pulmonary function along with fewer instances of exacerbations requiring hospitalization (Armbruster et al., 2024). In a recent publication in the *American Journal of the Medical Sciences*, a retrospective chart review of patients pre- and post-HEMT initiation showed that HEMT helped decrease colonization of *Pseudomonas aeruginosa* from 62% to 31.6% (Szabo et al., 2024). While this small sample-size study showed a significant effect, up to 80% of older adult patients across the U.S. have chronic infections, leaving a large number still requiring antibiotic treatment (CFF, 2024). Another recent review points out the challenge to researching this topic: Due to the decrease in sputum production, it is difficult to confirm if infections are truly eradicated (Armbruster et al., 2024). In Armbruster and colleagues' analysis, they found that not only does *Pseudomonas* persist in the majority of HEMT users, but also new strains arise (2024).

This year, the Cystic Fibrosis Foundation announced a \$5 million grant to study treatments for chronic infections and combat antibiotic resistance (Cystic Fibrosis Foundation, 2024). Clarametyx, a pharmaceutical company with a new potential treatment for *Pseudomonas aeruginosa* (Pa), is the recipient of this generous investment. The idea behind Clarametyx's therapy, CMTX-101, is to break down the biofilms created by chronic bacterial infections, which then allows antibiotics, as well as the patient's own immune system, to work directly on clearing the bacteria. Stanford is one site participating in this exciting research.



Stanford has led the way on research looking at chronic bacterial infections and the role of bacteriophages. In a paper published by Burgener, Bollyky, and Milla, bacteriophages that create biofilms were found to negatively impact health, specifically through the process of increasing antibiotic-resistant bacteria (Digitale, 2019). Dr. Burgener described the biofilms as “protecting *Pseudomonas*” from the antibiotics, thereby exposing them to a much lower dose and allowing for the drug-resistant bacteria to thrive in the lung tissue. To quote Dr. Burgener, “It’s shocking how much effect the phages have on the host immune system” (Digitale, 2019).

Luckily, there are more studies at Stanford and other research sites both stateside and abroad that are looking at different ways to break down biofilms. Some treatment modalities include combination nebulized therapies that target both biofilms and bacteria, the use of helpful bacteriophages to break down biofilms, and using viruses that target specific bacteria. A multipronged approach seems to be the key to eradicating these chronic infections, and we look forward to seeing what solutions arise from this research.

## References

- Armbruster CR, Hilliam YK, Zemke AC, Atteih S, Marshall CW, Moore J, Koirala J, Krainz L, Gaston JR, Lee SE, Cooper VS, Bomberger JM (2024). Persistence and evolution of *Pseudomonas aeruginosa* following initiation of highly effective modulator therapy in cystic fibrosis. *mBio*15:e00519-24. <https://doi.org/10.1128/mbio.00519-24>.
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- Cystic Fibrosis Foundation (2024, January 5). CF Foundation invests up to \$5M in Clarametyx Biosciences to develop a new anti-bacterial therapy. Retrieved from <https://www.cff.org/news/2024-01/foundation-invests-5m-clarametyx-anti-bacterial-therapy>.
- Digitale, E. (2019, April 17). Some viruses help protect harmful bacteria in CF patients. Retrieved from <https://med.stanford.edu/news/all-news/2019/04/some-viruses-help-protect-harmful-bacteria-in-cf-patients.html>.
- Szabo, M. M., Foushee, S. E., McPheeters, C. M., O'Hagan, A. R., Ramirez, A. M., & O'Reilly, E. A. (2024). Impact of elexacaftor/tezacaftor/ivacaftor on respiratory colonization in an adult cystic fibrosis clinic. *American Journal of the Medical Sciences*. DOI: <https://doi.org/10.1016/j.amjms.2024.02.001>.

# Current and Upcoming Research

Active Studies			
Name	Brief description	Criteria	Contact(s)
<b>BEACON</b> A Phase 1 Single Dose Escalation Study Evaluating the Safety and Tolerability of VX-522	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	<ul style="list-style-type: none"> <li>• 18-65 years old</li> <li>• CFTR variant non-responsive to modulators</li> </ul>	Lani
<b>BEGIN-OB-19</b> A Prospective Study in Infants and Young Children (BEGIN)	Prospective longitudinal study to observe the effects of administration of either ivacaftor (Kalydeco) or elexacaftor/tezacaftor/ivacaftor (Trikafta) on growth	<ul style="list-style-type: none"> <li>• &lt;6 years old</li> <li>• Eligible for modulators</li> <li>• Not currently on either med</li> </ul>	Amanda
<b>CMTX-P1-CT002</b> 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	<ul style="list-style-type: none"> <li>• 18+ years old</li> <li>• CF and <i>P. aeruginosa</i><sup>+</sup></li> </ul>	Amanda
<b>NBSA</b> Newborn Screening Accuracy Project	Study collecting blood samples from patients with rare CF mutations to ensure newborn screening tests are accurate in all ages	<ul style="list-style-type: none"> <li>• Diagnosed with rare CFTR variant</li> </ul>	Tina
<b>PROMISE</b> Study to evaluate the effects of ETI	Postapproval, real-world, observational study to understand the effects of elexacaftor/tezacaftor/ivacaftor (ETI) in clinical use	<ul style="list-style-type: none"> <li>• &gt;6 years old</li> <li>• &gt;=1 copy of F508del</li> </ul>	Jackie
<b>RESPIR-102</b> A Phase 1b Study of Aerosolized RSP-1502	Phase 1b clinical trial to evaluate the safety, tolerability, and efficacy of tobramycin plus CaEDTA in ascending doses administered via nebulizer	<ul style="list-style-type: none"> <li>• 18+ years old</li> <li>• CF and <i>P. aeruginosa</i><sup>+</sup></li> </ul>	Amanda
<b>SILP</b> Slow Inhalation, Large Particle (SILP) Mucociliary Clearance Measurement Method	Observational study using a new standard operating procedure for the performance of mucociliary clearance scans	<ul style="list-style-type: none"> <li>• 18-60 years old</li> <li>• 2 patients with CF</li> <li>• Non-smoking</li> </ul>	Tina

## Crossword solutions

Across  
2. Carrier 4. Percussion 8. Chloride 10. Corrector 12. Sweat  
15. Transplantation 16. Pancreas 17. FEV1 18. Sputum 20. Trikafta

Down  
1. Two 3. Registry 5. Exacerbation 6. F508del 7. Potentiator  
9. Heterozygous 11. Genotype 13. Spirometry 14. Modulator  
19. CFTR

# 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 Respiration study

### Who can participate?

Adults 18 years of age and older with chronic Pseudomonas infection.

### What is involved?

Twice daily nebulized treatment for 14 days.

### How long is the study?

About one month.

### Interested?

Contact the research team at [cfresearch@lists.stanford.edu](mailto:cfresearch@lists.stanford.edu) or scan the QR code below:



### Interested in other research opportunities?

Check out the Clinical Trial Finder on [CFF.org](https://www.cff.org)

## Philanthropy Corner with Lucile Packard Foundation for Children's Health



Children's Health



We are thrilled to share the success of this year's Summer Scamper! This year, nearly 3,000 Scamper-ers walked, ran, rolled, donated, sponsored, and volunteered to support our patients and their families. Since 2011, our community has raised over \$6 million for children's health, and this year we surpassed our goal by raising an impressive \$650,000 to benefit patients and programs

### Contact:

Dominique Ta at [Dominique.Ta@LPFCH.org](mailto:Dominique.Ta@LPFCH.org) or (650) 461-9943. Learn more at [www.lpfch.org](https://www.lpfch.org)

across Lucile Packard Children's Hospital Stanford. The community's involvement and generous support ensures that we can continue providing essential care, advancing research, and creating transformative programs that directly impact the lives of children and families facing health challenges.

We were especially glad to see the Cystic Fibrosis team out there, spreading the word and connecting with the community. Their presence and dedication play a vital role in raising awareness and support for the Center's mission.

We extend our heartfelt thanks to everyone who participated in and supported Summer Scamper. Your dedication and commitment bring care, comfort, and hope to children and families in our community and beyond.

# CFF Resources

The Cystic Fibrosis Foundation is the world's leader in the search for a cure for CF and supports a broad range of research initiatives to tackle the disease from all angles. The CF Foundation also has a variety of programs designed to support our CF community. To learn more, visit [cff.org/support](http://cff.org/support).

## COMPASS

Call COMPASS for help with financial, insurance, legal, and other issues. Contact a dedicated CF Foundation Compass case manager:

- Call us at 844-COMPASS (1-844-266-7466)
- Email [Compass@cff.org](mailto:Compass@cff.org)
- Visit [cff.org/compass](http://cff.org/compass)

Monday–Thursday 9 AM to 7 PM ET  
and Friday 9 AM to 5 PM ET

## Get Involved with Our Local Chapter

Participate in local events, get connected with the Northern California CF community, & more! Visit [cff.org/northern-california](http://cff.org/northern-california) or email [northern-california@cff.org](mailto:northern-california@cff.org).

## Top Ten Reasons People Called COMPASS

- Insurance options
- Cost of treatments
- Drug, network, and device coverage
- Living expenses
- Transportation to/from care
- Paying utilities
- Scholarships
- Housing/lodging (inc. natural disasters)
- Home repair costs (inc. natural disasters)
- Accessing/affording food

Learn more  
by scanning  
the QR code



# 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.

If you are interested in joining, please contact **Kirsten McGowan** at [KMcGowan@stanfordchildrens.org](mailto:KMcGowan@stanfordchildrens.org).



# 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; 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 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—:**..... (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:**..... (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 – 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;

Gauri Pendharkar, RCP, CPFT (CF RT Coordinator)

..... (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) 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 ..... (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

## Other Research Opportunities

**The STOP 360 trial is looking for folks ages 6 and older with *Pseudomonas aeruginosa* infection.**

With only three visits and multiple sites across California, this is a great study in which to participate. For more information, visit [STOP 360 trial](#) or search for STOP 360 at [cff.org/Trials/finder](http://cff.org/Trials/finder).

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

**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 [cathyh1@stanford.edu](mailto:cathyh1@stanford.edu).

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