CF Research: A Family’s Perspective

—Tina Conti, RRT-NPS, C-NPT

As a research coordinator, I delight in getting to know my patients and their families. The Wilson family is one that I’ve gotten to know quite well over the last year. Kareese (10) and Henry (8), siblings who both have cystic fibrosis (CF), live in Redding, California, with their mom, Jessi, dad, James, and little sister, Bernice (Bunny), and have been patients at Stanford’s CF Center since they were infants. Kareese and Henry have been involved in a research study with me for the past year. Both have celebrated birthdays, started a new school year, and been involved in extracurricular activities, and they remain committed to the study. Kareese had participated in a study when she was much younger, so when asked about her feelings about starting another research study, she admitted, “I was a little nervous about the blood draws, but this was my second study, and I have some good memories of the first one.” Henry added that he “was excited to do a research study.” Kareese and Henry have needed to have their blood drawn hundreds of times in their lives, but Kareese’s veins are small

Continues on page 2...
and hard to find, often leading to multiple pokes for one lab draw. Understandably, Kareese has had a great deal of anxiety surrounding the blood draws. Throughout the study, she has struggled with each blood draw but always persisted. I continue to ask her if she still wants to proceed in the study, and she never hesitates to reply yes. Not only has Kareese grown in height and weight since starting the study, but she now gets her blood drawn with much less worry and fear. I am so proud of how much she has overcome.

The Wilsons fly down from Redding for every visit, often staying overnight in a hotel. School and work sometimes get missed, but Jessi and James stated, “The medication has been life-changing for our family. With each study, we have seen weight gain, increased lung function, less hospitalizations, and quicker return to baseline after an illness. This makes our everyday CF care feel more manageable, and as a result, our family has been able to travel more and the kids have been able to participate in more school activities/sports.” Kareese “likes staying in the hotels, getting extra tablet time, and earning money.” She “also likes helping science improve CF care for other kids.” Henry, on the other hand, enjoys “getting a day off of school, earning money to save and spend, and doing the blood draws.” Both kids love earning money for their research visits, and I think it gives them a sense of independence. Kareese plans to save her money for a trip to Greece!

Participating in CF research can seem daunting and time-consuming, but each study aims to increase quality of life, to learn from people with CF (pwCF), and to move closer on the path to a cure. Here are the messages that the Wilson family want to share with other pwCF or families considering research participation:

James and Jessi (mom and dad): “The beginning is always the most time-consuming, with long medical days and missed school and work. However, the increased health and considerable CF symptom reduction makes it worth it each time. We live four hours away, so we try to treat each visit as a mini-vacation. The kids love staying in the hotels, and we try to pick a museum to visit or a different activity to look forward to for each visit. The biggest benefit, though, is access to a new medication sooner. After each study, we have been able to stay on the new medication until it is approved by the FDA, and then our insurance takes over. Being on newer and better medication years sooner is the number one reason we do drug studies.”

Kareese

Continues on page 3...
Henry: “I would tell other kids to do a study because it helps your body and helps doctors know what kinds of medicine you need.”

Kareese: “I would tell other kids to try it because they might feel better on the new medicine.”

If you are interested in participating in research or just want more information, please let us know by scanning the QR code below.

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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.

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Continues on page 4...
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/parent emails, since they are not secure. Please note that any email sent to the team will be responded to by 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 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 are to carry your child’s CF PASSPORT in your wallet.

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.

**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
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). 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.

If you are interested in joining, please contact Kirsten McGowan at KMcGowan@stanfordchildrens.org.
Recipe: Summer Rolls
—Kayo Nakano, Clinical Research Assistant

Ingredients
• 1 package spring roll rice paper
• 1 package rice noodles
• Pork belly (Note: Can substitute with any protein. Pork belly is the more traditional cut, but you can use pork shoulder for a leaner version. Simply boil it on its own, or with smashed ginger and sliced shallots for a bit more fragrance, then slice thin.)
• Large shrimp that have been peeled and deveined (Note: Boil them until they just turn color (opaque). You can also purchase cooked shrimp to save even more time. Slice the shrimp in half down the spine so that they lie flat and thin for easy rolling.)
• 1 cup lettuce, torn
• 1 cup cucumber, thinly sliced
• 1 cup cilantro, chopped
• 1 cup mint, chopped
For additional vegetables, you can add: jicama, bell pepper, carrot, celery (julienne all veggies).

Instructions
Step 1: Wet the rice paper. Dip a rice paper wrapper in warm or room-temperature water until all surfaces are wet. Quickly remove the wrapper from the water and place it on a clean, flat surface or large plate. After a few seconds, the rice paper will become pliable and clear.
Step 2: Add noodles, vegetables, and cilantro, mint, and any of your favorite Vietnamese herbs toward the bottom middle of the rice paper.
Step 3: Add protein: add the pork belly and shrimp. Shrimp is placed toward the top of the rice paper so that it can be seen through the rice paper when rolled. This is for presentation purposes only and optional.
Step 4: Fold in both sides, making sure the ends are straight.
Step 5: Roll the spring roll: starting from the bottom, roll the wrapper up tightly. Continue rolling until the spring roll is sealed.

Dipping sauce ingredients
• ¼ cup peanut butter (or sunflower seed butter, hoisin sauce, etc.)
• 3 tablespoons lime juice
• 1 tablespoon soy sauce
• 1 tablespoon brown sugar
• 2 cloves garlic, finely minced
• 3–4 tablespoons hot water

Instructions
Combine all ingredients except hot water and mix until smooth. Add hot water 1 tablespoon at a time and stir until desired consistency is reached. Makes 3 tablespoons if eaten right away or 4 if refrigerated.

Nutrition (per roll)
Calories, 177; fat, 8 g; carbohydrate, 13 g; protein, 3.5 g
Great Strides

Thanks to all who attended the Great Strides walks in Walnut Creek and San Francisco! We enjoyed getting to talk with families, friends, and people with CF at the events and look forward to more walks across the country to support the Cystic Fibrosis Foundation. As they say at the CFF, let’s “continue to make Great Strides in our efforts to find a cure for CF!”

References
ImaginACTION program

- What is ImaginACTION? ImaginACTION is a skill that uses our natural ability to focus and be absorbed in experiences to help feel better in some way. ImaginACTION is part imagination, because it is something you do in your brain. But it's also part action, because it literally changes your experience in your body. Another name for it is self-hypnosis.

- What can ImaginACTION help with? You can choose from 10 different learning categories, such as “I want to be able to sleep,” “I want to better manage my chronic pain,” and “I want to be more in control of my feelings.”

- There is also a category called “I want to feel calm during procedures and pokes,” with a game-plan PDF. The game plan is a fun resource to utilize to help create coping plans for procedures in the clinics, especially for the sputum culture tests (see pages 9–10).

- Link here: imaginaction.stanford.edu

Game Plan resource document
GAME PLAN
BECAUSE YOU ARE THE BOSS OF YOUR BRAIN AND BODY!

Everything your medical team does is to HELP you be or get healthy!
How will this procedure help you be healthier?

IF there can be a choice (sometimes there isn’t), where on your body do you want to do the procedure?

Who do you want to be there?

What position? Lap? Next to someone? Laying down? Sitting up?

Where do you want your parent/caregiver to be?

What do you want them to do?

Who do you want to talk, if anyone? Who would you like to be quiet?

People who talk:

People who stay quiet:

Do you want to watch the procedure or focus on something else?

The procedure

More fun something else

Do you want to be told what is going on before and /or during the procedure?

Yes, before

Yes, during

No...I’d rather just pay attention to something else

If you do want to be told when the needle goes in, what words do you want used to let you know?

1-2-3 count

"Here it comes..."

Something else?
Which skills do you want to use today?
Choose and circle as many or as few as you like!

BLOCK THE SIGNAL:
Would you like either or both of these?
☐ Numbing medicine  ☐ Vibration

DISTRACT YOURSELF:
What would you like to focus on?
☐ Video: which one? __________________________
☐ Distraction card __________________________
☐ Something else? __________________________

USE YOUR IMAGINATION:
Where would you like to go in your imagination today?
_____________________________________________________________________
_____________________________________________________________________

BREATHE FROM YOUR BELLY:
As you take those good, deep breaths, do you want...
☐ Someone to breathe with you? Who? __________
☐ Bubbles  ☐ A pinwheel  ☐ Nothing. I’ll do it myself!

REMEMBER YOU ARE AWESOME!
What is a great memory you could think about today?
_____________________________________________________________________
_____________________________________________________________________

If possible, before it’s time for the procedure, would you like someone (a nurse or child life specialist) to help you understand what will happen during the procedure?  ☐ Yes  ☐ No, I’m okay

😊 And remember to remind everyone that it helps you if the adults KEEP CALM...😊

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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 Clarametyx Study

Who can participate?
We are looking for people 18 years of age and older with cystic fibrosis and chronic pseudomonas infection.

What is involved?
A onetime IV infusion of the study drug, along with your regular 28-day course of inhaled antibiotic therapy for the treatment of your pseudomonas infection.

How long is the study?
The study is a little over a month long, with seven in-person visits.

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

Interested in other research opportunities?
Check out the Clinical Trial Finder (via the link “Find a Clinical Trial”) on CFF.org

Philanthropy Corner with Lucile Packard Foundation for Children’s Health

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.

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

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!
Events

The 24th Annual CF Education Day occurred March 9 with a great turnout! We had speakers from within Stanford’s own CF Center, as well as organizations such as the CF Foundation.

- **Evolution of CF Care, with Albert Faro, MD**
  - Dr. Faro took us through a history of CF and how far the care model has come. With 132 pediatric, 119 adult, and 35 affiliate programs, we are providing patients with interdisciplinary team care across the country. The patient registry is a novel system for tracking of clinical markers to ensure high-quality care and promote evidence-based research. A special focus of the CF Foundation’s research directions is mental health, with an emphasis on anxiety and depression. As was discussed widely at NACFC this last year, anxiety and depression occur two to three times more in people with CF. Other exciting future directions include the advancement of health equity and leveraging of technology.

- **Cystic Fibrosis Research Institute (CFRI) updates with Siri Vaeth**
  - Counseling, support groups, podcast, newsletter, retreats, and advocacy.

- **CF Foundation updates with Brandy Zahner**
  - Save the date for upcoming Northern California Great Strides events: Santa Rosa, Sept. 29, 2024; and Santa Cruz, Sept. 15, 2024.
  - CF Peer Connect, Compass, CFF Cares, conferences both virtual and in person, Community Voice.

- **Family Advisory Council updates with Arek Puzia, Adult CF Patient Family Advisory Council updates with Kate Y, and a fantastic slide deck from Angela Nida.**

- **Adult and Pediatric center breakout sessions.**
  - Our pediatric team discussed exercise, modulators, liver complications, self-care.
  - Our adult team discussed infectious diseases, cannabis, gene therapy, airway clearance.

- **For a recap of the presentations from this year and previous years’ Ed Days, visit our website at** [https://med.stanford.edu/cfcenter/CFEducationDay.html](https://med.stanford.edu/cfcenter/CFEducationDay.html)
Adult CF Updates

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.

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 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.
# Current and Upcoming Research

## Active Studies

<table>
<thead>
<tr>
<th>Name</th>
<th>Brief description</th>
<th>Criteria</th>
<th>Contact(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beacon</td>
<td>A Phase 1 Single Dose Escalation Study Evaluating the Safety and Tolerability of VX-522</td>
<td>• 18-65 years old&lt;br&gt;• CFTR variant non-responsive to modulators</td>
<td>Lani</td>
</tr>
<tr>
<td>BEGIN-OB-19</td>
<td>A Prospective Study in Infants and Young Children (BEGIN)</td>
<td>• &lt;6 years old&lt;br&gt;• CFTR variant eligible for HEMT&lt;br&gt;• Not currently on either med</td>
<td>Amanda</td>
</tr>
<tr>
<td>CMTX-P1-CT002</td>
<td>A Phase 1b/2a Study to Evaluate the Safety of CMTX-101</td>
<td>• 18+ years old&lt;br&gt;• CF and P. aeruginosa*</td>
<td>Amanda</td>
</tr>
<tr>
<td>NBSA</td>
<td>Newborn Screening Accuracy Project</td>
<td>• Diagnosed with rare CFTR variant</td>
<td>Tina</td>
</tr>
<tr>
<td>RESPIR-102</td>
<td>A Phase 1b Study of Aerosolized RSP-1502</td>
<td>• 18+ years old&lt;br&gt;• CF and P. aeruginosa*</td>
<td>Amanda</td>
</tr>
<tr>
<td>SILP</td>
<td>Multisite Qualification Studies Using the Slow Inhalation, Large Particle (SILP) Mucociliary Clearance Measurement Method</td>
<td>• 18-60 years old&lt;br&gt;• 1 healthy control and 2 patients with CF&lt;br&gt;• Non-smoking</td>
<td>Tina</td>
</tr>
<tr>
<td>YETI STUDY</td>
<td>Success with Therapies Research Consortium Protocol yETI (your ETI) STUDY</td>
<td>• 7+ years old with CF&lt;br&gt;• Prescribed Trikafta &gt;18 months&lt;br&gt;• Has access to a smart phone&lt;br&gt;• Must complete surveys/daily diaries</td>
<td>Jackie</td>
</tr>
</tbody>
</table>
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 Avdirmiretz, MD

Chest Clinic Call Center: ...........................................(415) 923-3421
Routine Issues/Concerns during Business hours
(Monday – Friday, 8 a.m. – 4:30 p.m.):
• Alternatively, you can utilize MyHealth messaging for NON-URGENT NEEDS ONLY. MyHealth messages are NOT checked after hours or on the weekends.

Pediatric providers at Emeryville

Karen Hardy, MD; Eric Zee, MD; Manisha Newaskar, MD;
Rachna Wadia, MD

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 and ask for the
on-call pulmonology doctor...........................................(650) 497-8000

Pediatric 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: Megan 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, RD: .................................................(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

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

Ineligible for CFTR modulators? A new study, Understanding the Lived Experiences of People with Cystic Fibrosis (CF) Ineligible for CF Transmembrane Conductance Regulator (CFTR) Modulators, is looking for participants ages 18 years and older with cystic fibrosis who are ineligible for CFTR modulators because of their genotype. Study participants will be asked to complete a 30-minute online survey and a one-hour virtual interview. The survey and interview are available in English and Spanish. Eligible participants who complete an interview will be compensated $200 for their study-related time. If you are interested in this study, please follow this link to answer a few questions and find out if you are eligible to participate: https://survey.euro.confirmit.com/wix/3/p880554361633.aspx

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