Spring 2023

Stanford MEDICINE
Children's Health

Cystic Fibrosis Center **News**

23rd Annual CF Education Day

—Jacquelyn Spano, DNP, CPNP-AC/PC, CCRC

Our mission is to excel in cystic fibrosis care, to be partners with those we care for, and to be leaders in the discovery process that will produce the cure for cystic fibrosis.

March 18, 2023, marked the return of Cystic Fibrosis Education Day at the Stanford Arrillaga Alumni Center, having been on hiatus since 2019. Keynote speaker Jennifer Taylor-Cousar, MD, opened the morning, followed by a general session for all attendees before lunch. The afternoon included two breakout sessions, one focused on pediatrics and the other for adult populations. Jennifer Taylor-Cousar, MD , is a professor of adult and pediatric pulmonary medicine at National Jewish Health, where she

The Stanford CF care team

Continues on page 2

In this issue

23rd Annual CF...continued from page 1

serves as the medical director of Clinical Research Services. She oversees the care of children with pulmonary disease and adults with cystic fibrosis. Dr. Taylor-Cousar is also co-director of the Adult CF Program and director of the CF Therapeutics Development Network research that is conducted at National Jewish Health. She has been site primary investigator on more than 40 studies and global site investigator on three studies. Her investigator-initiated research focuses on the development and evaluation of novel therapies for the treatment of CF. Dr. Taylor-Cousar is the chair of the Cystic Fibrosis Foundation's Women's Health Research Working Group. She received her undergraduate degree in human biology from Stanford University in 1993. She completed her doctorate in medicine in 1998, a combined residency in Internal Medicine and Pediatrics in 2002, and a combined fellowship in Adult and Pediatric Pulmonary Medicine in 2006 at Duke University Medical Center. She obtained her master's in clinical science at the University of Colorado in 2015.

The morning session launched with Dr. Taylor-Cousar's presentation titled "Until It's Done for Everyone." After a review of the basic CF pathophysiology and historical approach to medical treatment, she emphasized the importance of cystic fibrosis transmembrane conductance regulator (CFTR) genetics and recently approved therapies. The presentation focus was to understand disparities in early diagnosis and the gaps in care and research for people with CF who identify as Black, Indigenous, and people of color. Additional highlights included "Maternal and Fetal Outcomes in the Era of Modulators" (the Mayflowers study), which is the first prospective multicenter observational study in women with CF who become pregnant. In closing, her presentation discussed the future directions in CF therapeutic developments.

The opening session followed with John Mark, MD's presentation , "Integrative Medicine in Cystic Fibrosis: Stress and Lung Health," which discussed how chronic stress and adverse childhood experiences (ACEs) may affect lung health, as well as how implementing the integrative medicine or holistic approach to care can reduce stress. There was special consideration of how the integrative medical approach to the care of a patient with cystic fibrosis may improve overall health. Dr. Mark provided case examples, interventions, and integrative medicine approaches to CF care.

Yelizaveta Sher, MD, clinical professor of Psychiatry and director of Psychiatric and Psychological Services for the Stanford Adult CF Program, presented on "Mental Health in the Era of Highly Effective Modulator Therapies." "The International Depression Epidemiological Study" (TIDES, 2014) reported an increase of anxiety and depression in cystic fibrosis patients as compared with community samples of those unaffected. She reviewed mental health in cystic fibrosis, case reports series, CFTR expression in the brain, medication interactions with modulators, and effects of highly effective modulators in mental health effects of those with cystic fibrosis.

Julie Matel, MS, RD, CDE , cystic fibrosis dietitian, spoke on a new perspective on nutrition. "Health at Every Size" is adopting an individual approach to nutrition. We are now navigating a changing nutritional landscape in nutrition in the age of highly effective modulator therapies with increasing body mass index (BMI) and weight gain. Health at Every Size (HAES®) supports people in adopting health habits for the sake of health and well-being, not weight control or weight loss. HAES encourages eating in a flexible manner that values pleasure and honors internal cues of hunger, satiety, and appetite, finding joy in movement, and becoming active and more physically vital while accepting and respecting the natural diversity of body sizes and shapes. Julie brings it all together by providing resources to implement HAES into practice.

The morning sessions included Carlos Milla, MD, and Laveena Chhatwani, MD, reviewing details of the "CF Center Report." CF Program Specific Registry details for both pediatrics and adults were reported. More information about the "CF Center Report" will appear in the next newsletter.

Education morning concluded with an update on both pediatric and adult advisory councils. Reports were presented by Brandy Zahner from the Cystic Fibrosis Foundation and Siri Vaeth from the Cystic Fibrosis Research Institute (CFRI). Highlights included exciting upcoming events for 2023.

The afternoon pediatric sessions provided more insight into pediatric-specific topics, including transition from the pediatric sector to the adult CF clinic. Holly Cooper, MD, from Endocrinology, spoke on cystic fibrosis–related diabetes, treatment, and new diabetes technology. Maggie Ridenhour, PT, DPT, had everyone sitting more upright, teaching us why breathing mechanics, posture, and exercise matter for everyone, with a special focus on CF health needs. A presentation by Deborah Menet, LCSW, offered information on partnering with your school district to support a child with cystic fibrosis health needs. She reviewed federal laws, legal rights for every child with CF, resources for a 504 Plan, and just supporting your child.

The afternoon adult session highlighted topics pertinent to the over-18 age group. Paul Mohabir, MD, presented "Cystic Fibrosis Pregnancy Outcomes" in the new millennium, followed by the patient perspective from Kate, a 34-year-old female with cystic fibrosis who is married with a 2-year-old son.

Meg Dvorak and Kate Yablonsky, both LCSWs, spoke about "Adulting with CF": the practice of behaving in a way characteristic of a responsible adult, especially the accomplishment of mundane but necessary tasks. Adults need to plan for a life ahead, including beyond high school, careers, financial planning, investments, health insurance, and families of their own, living well with CF across a life span.

Taylor Lewis, PhD, CSCS, CMT, PRT, completed the afternoon with his presentation, "Exercise in CF." He reminded us of the benefits of exercise and reviewed exercise physiology and laws of motion: how much, what type, and general program workouts that can balance the quality of life.

In reviewing all the dynamic presentations of this 23rd Annual CF Education Day, a common theme emerges: A lifetime of good health while living with cystic fibrosis is achieved by a balance of many variables—medical interventions, exercise, nutrition, sleep, and care of the mind as well as the body. Cystic fibrosis is present in all populations. Health care and research needs to be inclusive to address everyone's unique individuality across a life span.

Mark your calendar for the next live in-person CF Education Day, March 16, 2024!

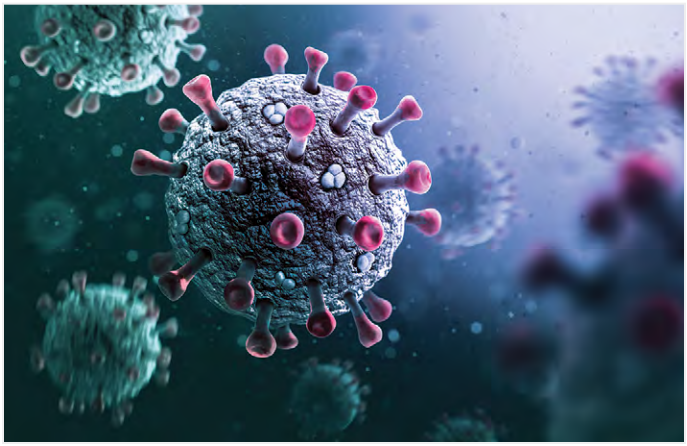
COVID-19, Flu, and RSV—What to Know About the 'Triple-demic' and Cystic Fibrosis

—By Elizabeth Burgener, MD

It has been more than three years since the start of the COVID-19 pandemic, and we have seen changes in patterns of other seasonal respiratory viruses. Notably this past fall we saw high rates of COVID-19, influenza (flu), and respiratory syncytial virus (RSV), which is quite early for seeing so much flu and RSV.

The COVID pandemic has seen multiple surges and lulls since it first appeared in early 2020. Notably there were peaks in January 2021 and in January 2022 with the appearance of the omicron variant, followed by a smaller surge in the early summer of 2022. We have since seen a relatively stable low incidence of infection, likely a result of high vaccination rates, the approval of pediatric vaccines, and later the approval of the bivalent booster. However, in the late fall of 2022 we have again seen COVID numbers rise. While the rise was noticeable, the number of cases was not nearly as high as the peaks we saw in previous surges.

Influenza season usually spans the fall to winter and peaks in December to February, which is why we typically encourage patients and their families to receive the flu vaccine in the fall. However, since 2021 we have seen lower numbers than usual, likely a result of masking and social distancing. This year, we have seen a significant rise in influenza cases and a higher-than-usual peak in November. Our patterns of influenza seasonality mirror what happens in six months prior in the Southern Hemisphere, so this was not totally unexpected.



The COVID-19 virus

RSV is a very common cause of childhood illness, and most children have had RSV by the time they are 2 years of age, providing some amount of immunity. It causes annual outbreaks in all ages but generally causes common- cold- like symptoms in adults. It can, however, cause severe disease in children younger than 2 years of age with chronic lung disease, such as CF, and can less commonly cause issues for adults with severe chronic lung disease, such as CF. RSV has seasonality, with previous seasons spanning November to April, with the peak in February. However, after the winter of 2020--2021, the RSV season has shifted. There was an uncharacteristic late- summer surge in 2021. Then this past fall, we saw an RSV appear in September and start to surge in November, with peak cases in December higher than we've seen in the past five years.

Continues on page 5

COVID-19...continued from page 4

Thus, the current "triple-demic" we saw was really the aligning of three peaks as we entered the "respiratory season." This also aligned with our communities and schools transitioning back to a state of normal living with social gatherings, large events, and less masking in general.

While COVID, flu, and RSV cases peaked in early winter, it is during that time of year that we also see other viruses such as metapneumovirus, rhinovirus, and coronavirus causing respiratory infections. We saw high numbers of patients experiencing symptoms of upper respiratory tract infections. Some patients developed lower respiratory tract infection or a CF exacerbation, which can necessitate treatment or admission to the hospital.

So for our patients with CF and their families, we recommend continuing to do the most you can to keep yourselves healthy. First and foremost, we recommend yearly flu shots and vaccination against COVID-19 for those that who are eligible. Hand hygiene helps but is not the only mitigation. Masking in (or avoiding) crowded indoor environments, staying home when experiencing new symptoms, and having home COVID antigen test kits at home for use when symptomatic or post exposure are also recommended. In the event of symptoms, do call your care team, as many patients with CF are eligible for anti-viral medications for both influenza and COVID-19 infection. Live your life, but stay safe out there!

CF Weight Management: A Focus on More Than Just the Numbers

—By Julie Matel, MS, RD, CDE

We are experiencing a changing landscape in our approach to nutrition in individuals with cystic fibrosis (CF). With intensive efforts to improve body mass index (weight compared with height) and with more widespread use of highly effective CFTR modulator therapies (such as Trikafta, Orkambi, and Kalydeco), we are seeing a major improvement in growth and weight outcomes. While this is what we were hoping for, some individuals with CF may find the added weight gain distressing or challenging, especially within a culture that prizes thinness.

Weight management, as a nutrition strategy for cystic fibrosis, has most often focused on achieving an optimal body mass index (BMI) or weight for height, which has been correlated with improved growth and lung function outcomes.

Historically, there has been a push to promote a high-calorie diet, the "legacy CF diet," focused on encouraging individuals to eat whatever they want, with the widespread use of oral nutrition supplements or tube feedings, to achieve a goal of weight gain. While this was a necessary approach that resulted in the desired weight gain, in the era of highly effective CFTR modulators, we are finding that individuals are experiencing an improved appetite. Many individuals on Trikafta, Kalydeco, or Orkambi, have been able to gain weight with much less effort, often resulting in some individuals surpassing BMI goals.

On the other hand, weight management for the general population has traditionally focused

Continues on page 6

CF Weight...continued from page 5

on watching portion sizes, achieving a lower calorie diet, and increasing exercise. While this approach might work for individuals in the short term, there is data to suggest that most folks end up regaining weight that is lost. In fact, in one meta-analysis that looked at more than 29 long-term weight-loss studies, more than half of weight that was lost by participants was regained within two years, and about 80% of weight lost was regained within five years.[1] In addition, dieting can lead to a preoccupation with food and increased psychological and emotional distress.[2]

A novel course is to take a weight-neutral approach that focuses on health at every size and encourages self-care. Examples of this explore moving the body for fun by participating in activities that one enjoys.

Individuals are encouraged to engage in intuitive eating practices, which focus on tuning in to hunger and satiety, while recognizing how foods make us feel and contribute to health. And finally, helping folks to incorporate healthy sleep habits and effectively manage stress as a whole-body approach to wellness is recommended.

As part of my clinical practice, I am looking at ways to focus on overall health and wellness while I work with clients as we embark on a new era of CF nutrition!

[1]Anderson JW, Konz EC, Frederich RC, Wood CL. Long-term weight-loss maintenance: a meta-analysis of US studies. Am J Clin Nutr. 2001;74(5):579–84.

References

[2]Health at Every Size: The Surprising Truth about Your Weight, by Linda Bacon, PhD

Intuitive Eating: A Revolutionary Program That Works, by Evelyn Tribole, MS, RD, and Elyse Resch, MS, RD, FADA, CEDRD

Anti-Diet: Reclaim Your Time, Money, Well-Being, and Happiness Through Intuitive Eating, by Christy Harrison, MPH, RD

Mindful Eating, by Jan Chozen Bays

Sweet Potato and Black Bean Chili

Ingredients

1 T plus **2 tsp** extra-virgin olive oil

1 medium-large sweet potato, peeled and diced

1 large onion, diced

4 cloves of garlic, minced

2 T chili powder

4 tsp ground cumin

½ tsp ground chipotle chile

¼ tsp salt

2½ c water

2 15-ounce cans black beans, rinsed

1 14-ounce can diced tomatoes

4 tsp lime juice

½ c chopped fresh cilantro

Sweet potato and black bean chili

Directions

Step 1

Heat oil in a Dutch oven over medium-high heat. Add sweet potato and onion and cook, stirring often, until the onion is beginning to soften, about 4 minutes. Add garlic, chili powder, cumin, chipotle, and salt; cook, stirring constantly, for 30 seconds. Add water and bring to a simmer. Cover, reduce heat to maintain a gentle simmer, and cook until the sweet potato is tender, 10 to 12 minutes.

Step 2

Add beans, tomatoes, and lime juice; increase heat to high and return to a simmer, stirring often. Reduce heat and simmer until slightly reduced, about 5 minutes. Remove from heat and stir in cilantro.

Tips to Help Build Sustainable Fitness Goals

—By Taylor Lewis, PhD, CSCS, CMT, PRT

There are many ways to improve health, which is why creating your health and wellness goals can be so overwhelming at times. We all know that exercising/physical activity is a great tool to improve your mental and physical well-being; however, finding what approach works best for you and creating a plan to follow are often barriers that we all come up against. We want to help reduce those challenges and have created three tips that will help you to build a blueprint so that you can reach your health and wellness goals.

Tip 1: Create a Realistic Goal

One of the biggest mistakes we make in the beginning is that we often create unrealistic goals. For example, generally, losing or gaining 15 pounds in one month isn't realistic or healthy, but it can be realistic to lose or gain 15 pounds in three to six months.

Health goals are a journey, not a sprint. Remind yourself, "Faster is not necessarily better." You need to enjoy the process, not hate it. You don't want to beat yourself up because of setting expectations that are too high or that do not fit your lifestyle.

Tip 2: Write It Down

After you figure out a realistic, attainable goal, write it down. Be as precise as possible. Where will you accomplish this goal (e.g., gym, living room), what equipment might be needed, and can you measure it (e.g., if you want to increase your steps to 5,000 a day for three days a week, do you have the tools to do so?)? If you can't measure it, you will not be able to measure your progress accurately.

Tip 3: Set Your Environment

Last but not least, does your goal fit into your current environment? You need to look at your lifestyle (e.g., your work and/or family needs, environment, etc.). Make sure that you can achieve your goal within your current environment. If not, what are some ways you can change your environment to ensure that your goal is successful? Do you need to create a space in your house to work out in or carve out time each day for physical activity? If you cannot change your environment, you may need to adjust your goal to fit your current lifestyle needs.

It is natural to create lofty goals, as we often put high expectations on ourselves and want to see results quickly. It is in our DNA to want to see results fast. The biggest barrier we are all up against is actually just showing up and staying consistent. The hardest part about of the workout is just showing up. So, a great first goal might be to show up and stay consistent. Furthermore, remind yourself that there will be harder days, "failure days," and also great days, and everything in between. Try to limit black-or-white thinking styles such as thinking about only what you did today, but rather think about what you do over the entire week. Take one day at a time, and remind yourself that, little by little, you will get closer to your goal. Smaller steps to progress are much more effective in the longer run than short-term, quick-fix health programs.

You want to create a lifestyle that improves your mental and physical well-being in the long-run.

Pediatric CF Center Update

—Mary Helmers, RN, BSN

Social Media Updates

Website:
http://med.stanford.edu/cfcenter.html

Like us on Facebook:
Cystic Fibrosis Center at Stanford

Twitter account:
Stanford CF Center—@cf_stanford

Helpful Tips!

Did you know that you can get assistance with your PG&E bill? PG&E forms for medical equipment/devices can be found on the PG&E website under "Medical Baseline Allowance Application for Medical Baseline Enrollment and Recertification," and **you can now apply online.**

Or you can print the form, fill it out including all your medical devices (e.g., nebulizer/compressor, if you use oxygen, CPAP, or BIPAP), and bring the form with you to your next CF clinic visit; your provider will sign it and you'll mail it to PG&E.

Helpful Reminders!

To help expedite your clinic visit, please remember to bring your **CF Binder** with you to clinic, along with the most recent CF action plan.

MyChart (secure electronic correspondence)
If you have not signed up already, **PLEASE** sign up for **MyChart at your next clinic visit.**

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 it is not a secure site. 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.

It takes only a minute to sign up—one of the front desk staff will be happy to assist you with the sign-up.

Prescriptions
Just a reminder that your prescription request can take up to 72 hours to be processed. This has always been our policy; however, we strive to turn them around sooner. Please keep in mind that even after we send the scrip to the pharmacy, it can still take another 48–72 hours for the pharmacy to process (especially mail order pharmacies). 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.
- If you have a refill, great! Then they will process it.
- Your pharmacy should call us if you have no refills.

Remember
We cannot guarantee that your request will be filled the same day or within 24 hours.

Annuals
Remember, our goal is to get all annual testing done on or around your child's birthday. At your clinic visit three months prior to when your annuals are due, the CF RN will review with you what is due. Please feel free to ask us, too.

Included in the annuals are your lab work, CXR, bone density scan (12 years of age and older), full PFTs (starting at age 7), baseline audiogram (starting at age 6), liver screening, and sputum

Continues on page 9

Pediatric CF...continued from page 4

cultures. Please let us know if you have not had any of these tests done with your annuals.

Infection Control

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

Surgical masks

COVID-19 Updates

We hope all our patients and families are doing well. We understand that the past three years have been a challenge for everyone, and we want our families to know that we are here to answer all your concerns and any questions you may have. Feel free to call the CF RN phone line at (650) 736-1359 if you have any questions or concerns or if you feel you need some additional support.

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, 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.

CF PASSPORT

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**

XOC (Excellence of Care) Surveys

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

Purpose of the survey: To hear directly from our patients and families about their care experience, the Cystic Fibrosis Foundation convened a multidisciplinary steering committee to create the new survey and include perspectives of people with CF, parents of children with CF, representatives from the CF Foundation, physicians, nurses, and other care team disciplines, including social work, respiratory therapy, and nutrition. The XOC survey focuses on shared decision-making, relationship with the care team, infection control, and overall quality of care. It also includes special questions to capture the experience of telehealth visits.

We appreciate your taking the time to fill out the surveys so that we can best serve your needs. The CF team wants to provide all of our patients and families with the best care, so we value your constructive feedback.

Meet Our New Team Members!

We are delighted to welcome **Nicholas Avdimiretz, MD**, to the Division of Pediatric Pulmonary, Asthma & Sleep Medicine at Stanford Medicine as a clinical associate professor. Dr. Avdimiretz comes to us from the Stollery Children's Hospital, Division of Pediatric Respiratory Medicine, in Edmonton, Alberta, Canada, as a clinical assistant professor and medical lead of the Pediatric Lung Transplant Program there. Dr. Avdimiretz brings expertise in the areas of lung transplantation and advanced lung diseases, cystic fibrosis, and aerodigestive. Please join us in giving a warm welcome to Nick and his wife, Taylor, to the Division and Stanford community at large.

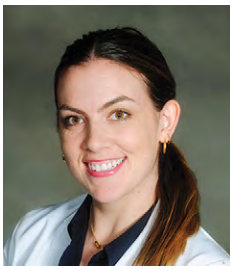
Jake Brockmeyer, PharmD, BCPS, BCPPS, is a double board-certified pediatric clinical pharmacist who completed both a general PGY-1 and a pediatrics-specific PGY-2 residency at Lucile Packard Children's Hospital Stanford. He earned his Doctorate of Pharmacy from Regis University School of Pharmacy in Denver, Colorado. He is experienced in a wide range of medically complex disease states. His professional interests include cystic fibrosis, infectious disease, pharmacokinetics, therapeutic drug monitoring, and precision medicine.

Tina Conti received her BS degree in Respiratory Care from the University of Toledo. Straight out of school, she had the opportunity to work with pediatric CF patients in acute and critical care. She enjoyed this experience but wanted to travel. After a few travel assignments around the United States at other children's hospitals, Tina landed at Lucile Packard Children's Hospital Stanford. During her 13 years at Packard Children's, she worked a few years in the PICU but spent most of her time in the back of an ambulance transporting sick patients into the hospital as a part of the Critical Care Transport Team. After years of working in critical care, Tina was looking for a change and is excited to be working with CF patients again as a research coordinator.

Lani Demchak joined the Pediatric Pulmonary Division in the role of Clinical Research Coordinator II. Lani is responsible for clinical trial operations with Dr. Milla and Dr. Bergener and supports the cystic fibrosis research team. She holds a bachelor's degree in health science from San Francisco State University and a master's degree in business administration from Notre Dame De Namur University. Her professional experience includes working in fellowship and clinical research coordination at Stanford University. Lani brings experience interacting with study patients and sites, sponsoring study teams, and managing key aspects of clinical trials to ensure study success. She and her husband are blessed with twin boys and their Great Pyrenees dog, Charly Brown. Lani enjoys wine tasting, discovering new cuisines, and taking Peloton rides in her spare time.

Jennifer Kwok joined the CF team at Stanford Health Care in 2022. She received her bachelor of science degree in 1996 and her respiratory therapy degree in 1999. She

has been working in the field of respiratory therapy for 23 years with extensive experience in ICU settings, ventilator management, bronchoscopy assistance, pulmonary function testing, and RT student preceptorships. In her spare time, Jennifer loves spending time with her family, traveling, biking, reading, and watching K-dramas. With her many years working with cystic fibrosis patients on the inpatient side, she looks forward to working with the CF team and the CF community.



Alicia Mirza, MD, is excited to be returning to Stanford as the Adult CF assistant program director. She is originally from rural Michigan and did residency in Internal Medicine and Pediatrics at UCLA. Her training concluded with Pulmonary and Critical Care fellowship at Stanford. Dr. Mirza is passionate about improving the health care experience for families and making sure her patients understand the reasoning behind their treatment plan. She is particularly interested in improving the transition process from pediatric to adult medicine. Outside of work, she enjoys hiking with her two adopted Formosan mountain dogs, listening to sci-fi and fantasy audiobooks, and going on small adventures with her husband and son.

Kayo Nakano is a clinical trial research assistant. Prior to moving to California, she was a research assistant at MD Anderson Cancer Center in Houston, Texas. In her free time, she enjoys volunteering and helping the elderly use Mac computers, shopping, gardening, etc. Her hobbies include cooking and collecting stamps and coins from around the world. She's enjoying her new field of research and working with a supportive and knowledgeable team on cystic fibrosis. She looks forward to contributing to finding a cure for this disease.

Gauri Pendharkar, BS, RCP, CPFT, has been a respiratory therapist at Stanford for the past 26 years. After working with CF patients in the inpatient setting, she transitioned to the CF outpatient clinics in 2015. She enjoys working with patients she has known all these years, as well as meeting newly transitioned ones to the center. She is married with two children. Her hobbies are cooking, gardening, and embroidery.

Marion Seabaugh, MPH, RD, CNSC, CCTD, was born and raised in upstate New York and moved out to California about six years ago. She received a Bachelor of Science in Nutrition from Cornell University and completed her registered dietitian training at the University of North Carolina in Chapel Hill. Prior to working with the Adult Cystic Fibrosis team at Stanford Health Care, she worked with the lung and heart-lung transplant program. She believes it has been fascinating to see the progress being made in the treatment of CF over the past three years and how this is impacting the nutritional needs and overall health of patients. In her free time, she loves being outdoors—surfing, camping, gardening, hiking—and trying out new recipes.

Colleen and Zoe Farewell

In 2022 we bid farewell to two dear members of the cystic fibrosis research team, Colleen Dunn, RRT, RPFT, CCRC, and Zoe Davies, RN, MS, PNP, CCRC. Colleen was the research administrator for the CF research program and worked at Stanford for the past 37 years. We want to thank Colleen for her dedication to the CF community, patients, and families.

Zoe Davies was a nurse practitioner and clinical research coordinator at the CF research center and had been with Stanford for 30 years. She has been a wonderful advocate for our CF patients and families. Colleen and Zoe were awarded the Unsung Hero award from the Therapeutic Development Network in 2022.

Pediatric Family Advisory Council Update

—Kirsten McGowen

The Basics

We are a group of parents whose children are seen at the CF Center at Stanford Medicine Children's Hospital. We work in partnership with members of the CF Care Team to improve care for patients and families. The CF Family Advisory Council is overseen by the Department of Family Centered Care.

Some of the things we do

- Assess needs of patients and families, and work with the Care Team to make improvements.
- Enhance communication between the CF Care Team and CF families.
- Develop resource materials to assist patients and their families.
- Provide input from a family perspective on issues relating to CF care.
- Serve as a voice for families receiving CF care at Lucile Packard Children's Hospital Stanford.

What we need

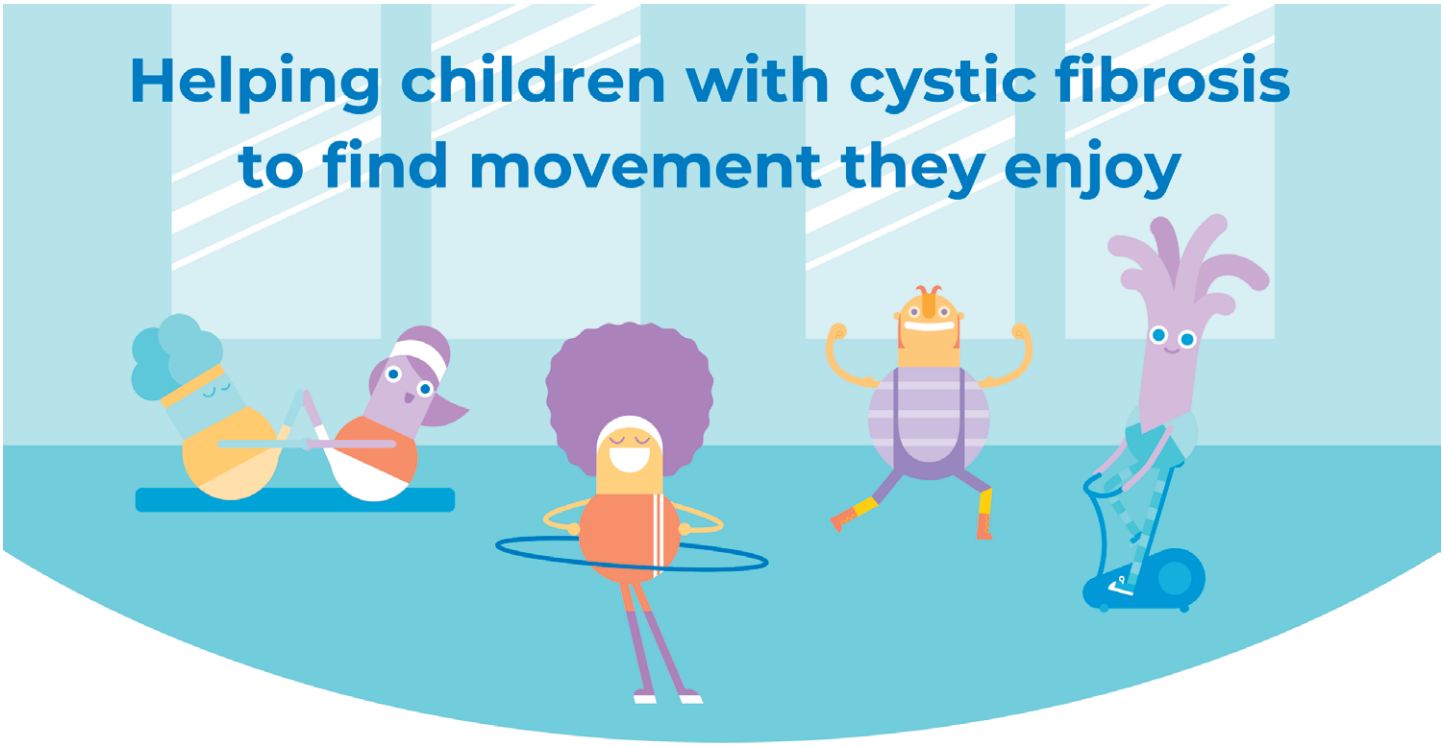
More parents! We are looking to add to our numbers for 2023 and beyond. We meet once a month for one hour via Zoom. With more members, we will be able to provide a wider range of feedback on issues related to CF care (clinic visits, annuals, going to school, transition—just to name a few).

If you are interested, please email Kirsten McGowan (CF FAC Lead Parent) at KMcGowan@stanfordchildrens.org.

Past/ongoing projects

- Ways to support non-English-speaking CF families (translation of educational materials, needs in clinic, etc.).
- Using MyChart for messaging, prescriptions, test results, and more!
- Coordinating with Emeryville location to better partner and support our East Bay CF families.
- Tips for families starting school (or summer camps, sports, etc.).
- Checklists and hacks for tracking CF meds.
- Helping the CF team with educational materials (what information do families need or want?).
- Meeting with the CF Adult Care Team to improve the transition process.
- Representing CF families at larger hospital meetings along with parents of other service lines (diabetes, NICU, heart center, cancer/hematology, IBD, etc.).

Helping children with cystic fibrosis to find movement they enjoy



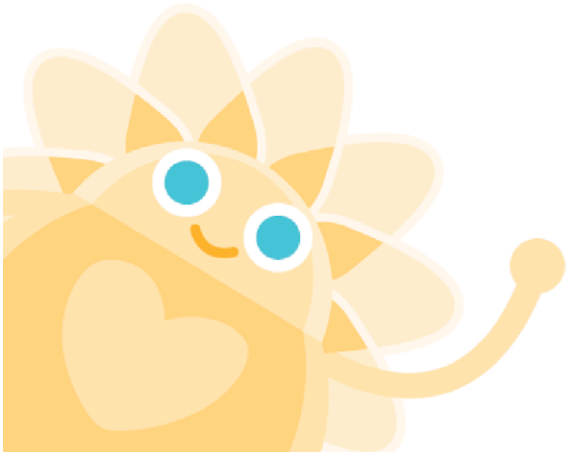
We believe that healthy habits are best planted young

Physical activity is really important to help manage life with cystic fibrosis - physically, mentally and emotionally.

We help children with CF and their families to find movement that they enjoy so they are more likely to stick at it as they grow into a teen and a healthy adult.

We have on-demand and live sessions including:

- Mini sessions for CF clinic appointments
- Stretches to help with your lung function tests
- Airway clearance support + Vest sessions
- Calming practices
- Play-based exercise
- Breathing exercises
- Education
- A mix of cardio, strength and flexibility classes



A collaboration between Johns Hopkins CF Center, Beam and CF Yogi

Sign up for free at beamfeelgood.com/cf-youth

beam
movement to feel good

CFYOGI
yoga for cystic fibrosis

Cystic Fibrosis Center at Stanford

Pediatric providers at Lucile Packard Children's Hospital Stanford

Pediatric Center Director: Carlos Milla, MD
Providers: Nick Avdimiretz, MD; Sumit Bhargava, MD; MyMy Buu, MD; Elizabeth Burgener, MD; Carol Conrad, MD; David Cornfield, MD; Michael Tracy, MD; Jacquelyn Spano, DNP, RN, CPNP; Cissy Si, 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: Mary Helmers (650) 736-1359
CF Clinic Nurse: Liz Beken (650) 736-1359
Respiratory Therapist: Jessica King (650) 724-0206
Nutritionist, Dietitian: Julie Matel (650) 736-2128
Social Worker: Debbie Menet (650) 796-5304
Newborn Screening Coordinator:
Jacquelyn Spano (650) 721-1132
PharmD: Jake Brockmeyer (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, RN, MSN (650) 724-8414
Respiratory Therapist: Lorraine MacPhee (510) 587-9631
Nutritionist, Dietitian: Mikaela Burns, CRD, MPH (510) 806-3659
Social Worker: Teresa Priestley (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: Elika Rad, NP; 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: Gauri Pendharkar, RCP (CF RT Coordinator); Erica Collins, RCP IV; Jenny Kwok, RCP IV (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, 8 a.m. to 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, 8 a.m. to 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 Sutter Health 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, BS, MBA (650) 725-1087
Jacquelyn Spano, DNP, CPNP-AC/PC, CCR (650) 721-1132

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

Current Research Studies

MCC: Mucociliary Clearance Study: Study evaluating the use of adrenergic and cholinergic agents to increase mucociliary clearance.

Collection of Gene Mutation for Laboratory Quality Assurance: Newborn Screening Accuracy Project: Study collecting blood samples from patients of any age with rare CF mutations to ensure that newborn screening tests are accurate.

Peripheral Biochemical Monitoring Study: Study to evaluate if certain molecules that are secreted in sweat and saliva can be used to diagnose and monitor health conditions.

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.

Utility of Lung Clearance Index: LCI study to be done in a clinical setting for pediatric patients.

A prospective study to evaluate biological and clinical effects of significantly correct CFTR function (the PROMISE Study).

Innovative strategies for the study of disorders of the respiratory tract.

Vertex 445-112: A Phase 3 Open-Label Study Evaluating the Long-Term Safety and Efficacy of Elexacaftor/Tezacaftor/Ivacaftor Triple Combination Therapy in Cystic Fibrosis Subjects 2 Years and Older.

Vertex 21-121-105: A Phase 3 Study Evaluating the Pharmacokinetics, Safety, and Tolerability of VX-121/Tezacaftor/Deutivacaftor Triple Combination Therapy in Cystic Fibrosis Subjects 1 Through 11 Years of Age.

Upcoming

Vertex-522: A Phase 1 Single Dose Escalation Study Evaluating the Safety and Tolerability of VX-522 in Subjects 18 Years of Age and Older with Cystic Fibrosis and a CFTR Genotype Not Responsive to CFTR Modulator Therapy.

Observational study of adults with cystic fibrosis for colorectal cancer screening (NICE-CF): Study will compare stool-based testing to colonoscopy for colorectal cancer screening in people with CF. The study includes the collection of stool samples at home and a clinical screening colonoscopy.

Newsletter Contact Information

Editors: Lani Demchak, Mary Helmers

Visit our website at http://cfcenter.stanford.edu for more information about our center and cystic fibrosis.

To subscribe to this newsletter, please contact Cathy Hernandez at (650) 724-3474 or cathyh1@stanford.edu.

Follow us on Facebook: Cystic Fibrosis Center at Stanford.