Winter 2023

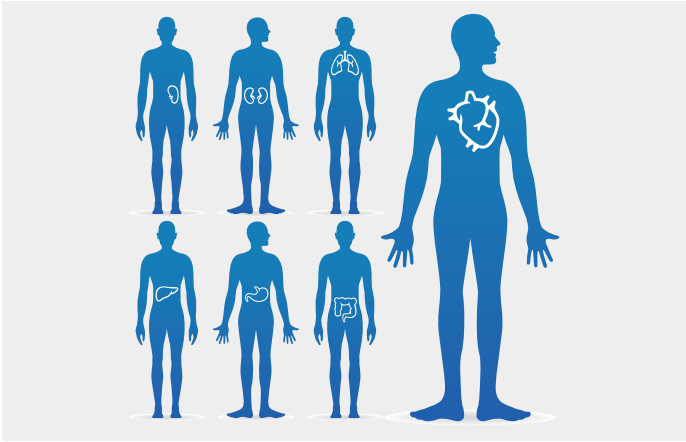
Stanford MEDICINE
Children's Health

Cystic Fibrosis Center **News**

Modulator Therapy: Beyond the Lungs

—Ryan Dougherty, MD

It almost goes without saying at this point that Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) highly effective modulators (HEMs) are a huge success story with enormous impacts on the lives of people living with cystic fibrosis. The medications considered to be highly effective are ivacaftor (Kalydeco) for people with gating mutations such as G551D and elexacaftor/tezacaftor/ivacaftor (Trikafta) for those with at least one copy of the delta F508 variant. These medications work by improving the ability of CFTR channels to conduct chloride and bicarbonate (Kalydeco), as well as by increasing the amount of working CFTR channels available at the surface of epithelial cells (Trikafta). The HEMs were approved based on their ability to improve lung function (FEV1) and reduce pulmonary exacerbations.



Probably nobody living with CF needs reminding that CF is not just a lung disease. The CFTR protein is expressed in lots of other organs and tissues. This is why CF is a multisystem disease

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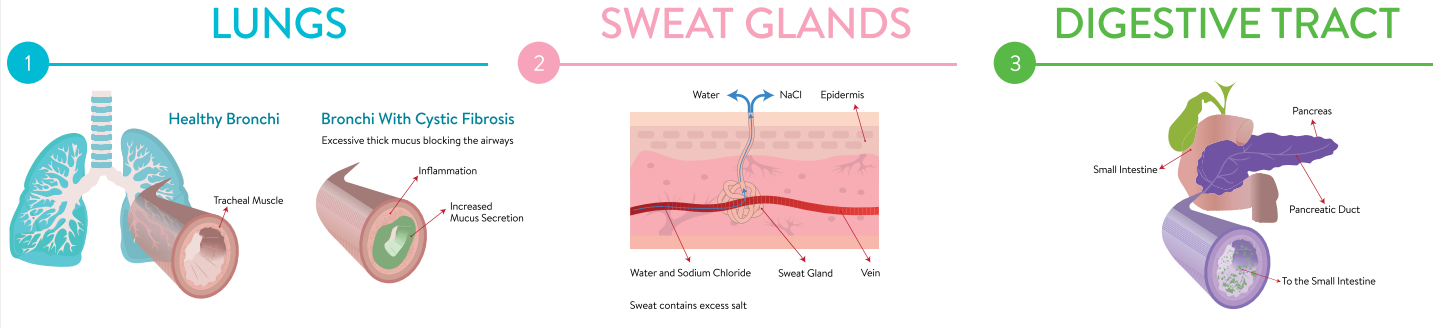

Organ systems and CF

and not just a lung problem. Do the HEMs also benefit the rest of the body? Believe it or not, much less is known right now about the effects of the HEMs outside of the lung. These are referred to as "extrapulmonary effects." However, data is mounting to help answer this question, and what we know so far is really exciting and encouraging. Let's explore this together.

Let's start, of course, with the pancreas and GI tract. Weight gain is an exciting benefit observed in many patients after starting modulator therapy. The leading thought on how this happens has to do with improved intestinal absorption of nutrients. The CFTR channel conducts bicarbonate ions, and the modulators increase bicarbonate secretion, resulting in a higher pH within the small intestine. The pancreatic digestive enzymes work better in an alkaline environment. I would also note that HEMs tend to reduce gastroesophageal reflux (GERD) symptoms. This is also probably a result of improved intestinal pH. Do HEMs increase the production of pancreatic enzymes directly? The answer depends probably on your specific mutations and how young you are when starting these. Pancreatic insufficiency usually occurs by 4 years of age. Studies show increases in fecal elastase, a marker of pancreatic function among children ages 2 to 5 taking ivacaftor. If they are started at a very early age, it is possible that HEMs can prevent or delay the onset of pancreatic insufficiency. Other studies in older people show reduction in pancreatic enzyme dosages while taking modulators.

What about diabetes? CF-related diabetes (CFRD) occurs from progressive destruction of pancreatic islet cells. The U.S. and U.K. partnered in collecting registry data from CF patients taking Kalydeco. This data showed a lower prevalence of CFRD in the Kalydeco group compared with the untreated control group. Smaller studies show improvements in glucose tolerance or reduced insulin requirement when taking Kalydeco, as well as improved insulin secretion among people with CF with mildly impaired glucose tolerance ("pre-diabetes"). It is worth mentioning that these studies are far from conclusive, and results are not seen in every person taking modulators.

Before we leave the GI tract, let's not forget about the liver. CFTR is expressed in cells called cholangiocytes lining the bile ducts. CF liver disease (ranging from mild to severe) affects 40% of people with CF. The U.S./U.K. Ivacaftor Registry also reported lower incidence of hepatobiliary complications, which include gallstones, liver disease, cirrhosis, fatty liver, and abnormal liver enzymes. We need larger studies to confirm

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this, but it is possible that HEMs may prevent or even occasionally reverse hepatobiliary disease, especially if started at a young age.

Did you know that bone cells also express CFTR? Reduced bone density leading to osteoporosis can occur in CF. CFTR is expressed in bone cells called osteoblasts. Reduced CFTR function in these cells leads to increased production of other cells called osteoclasts, which are responsible for bone absorption. In an exciting study of seven adults with CF and the G551D mutation, ivacaftor use for 1.7 years led to significant improvements in lumbar spine bone density. CFTR also affects the ways that muscles work and use oxygen. Small studies show increases in exercise capacity, walking distance, and improved physical activity.

Of course, we can't ignore the effects of CF on fertility. HEMs can improve fertility in women. For example, in one report, seven out of 12 women who previously reported infertility became pregnant an average of 3.2 months after starting ivacaftor, which is remarkable. Experts theorize that this may be due to improvement in viscoelastic properties of cervical mucus (i.e., less thick) along with alterations in hormone production. Modulators are predicted to have very little impact on male fertility, as the mechanism is congenital bilateral absence of the vas deferens (an abnormality that occurs early in fetal development).

Chronic sinusitis is very common in CF, resulting from thickened nasal/sinus secretions similar to what occurs in the respiratory tract. A few small studies of people on ivacaftor show improvement in symptoms (such as runny nose, postnasal drip, thick nasal discharge) and signs of sinusitis on CT scans.

Finally, don't forget that immune cells, like neutrophils and macrophages, also express CFTR. Ex vivo studies (taking blood cells out of the body and studying them in the lab) show some evidence of improved ability of these cells to fight infections.

It is important for me to point out that much of what I have outlined comes from studies of Kalydeco in individuals with gating mutations. Studies like PROMISE are underway examining the many extrapulmonary effects of Trikafta in eligible people. Much of what I have shared with you is preliminary, and we will learn more in the coming years. I should also remind you that it is important to continue your CF therapies unless you and your care team have agreed that it is safe to reduce or discontinue some of them. We have a lot to learn, but the future is bright indeed!

"Small studies show increases in exercise capacity, walking distance, and improved physical activity."

References

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Taylor-Cousar, J.L. (2020). CFTR modulators: Impact on fertility, pregnancy, and lactation in women with cystic fibrosis. *Journal of Clinical Medicine*, 9(9), 2706. doi:10.3390/jcm9092706.

NACFC 2023 Highlights

—Amanda Keen, MSN, RN

Another excellent North American Cystic Fibrosis Conference has wrapped for the year, and we heard some exciting updates in genetic therapies, expanding therapies for those who are not modulator eligible, simplifying the standard of care, and improving reproductive and mental health. The plenary sessions were very well attended with notable enthusiasm and engagement from the audience.

From Day 1, "Genetic Therapies for All: Harnessing Cross-Disease Knowledge for Breakthroughs in Cystic Fibrosis," Alexis Thompson, MD, a leading expert in sickle cell disease, spoke on the direction of genetic therapies in their field and shared a patient success story. Dr. McCray discussed gene addition and gene editing in animal models, as well as trials using CRISPR and various vectors for use in humans.

Left to right: Paul Mohabir, MD, Carlos Milla, MD, Elika Raad, NP, Alicia Mirza, MD, Meredith Wiltse, NP

From Day 2, "'Micro-Management': The Changing Face of Infections in CF," we learned about alternative measures for infection monitoring from Luke Hoffman, MD, PhD. If patients on HEMT aren't producing sputum, potential options are the collection of samples at home, sputum induction in clinic, breath biomarkers, and cell-free DNA to detect markers in blood. Natalie E. West, MD, MHS discussed how best to treat pulmonary exacerbations and reduce antibiotic use when possible. In a related symposium looking at the SIMPLIFY study, patients on elexacaftor/tezacaftor/ivacaftor (ETI) who stopped dornase alfa had improved mucociliary clearance, and those who stopped hypertonic saline had no worsening of their condition.

Yelizaveta Sher, MD

From Day 3, "There Is No Health Without Mental Health: Progress, Challenges, and Hope for the Future," Beth Smith, MD and Anna Georgiopoulos, MD discussed progress made on research into effects of modulators on mental health, anxiety and depression, ADHD, and substance use. Psychosocial interventions now have their own pipeline of clinical trials to prioritize and advance this research. CBT, ACT, and other evidence-based treatments are being successfully tailored to CF. Shaina Blair, MSW, LCSW talked about health and wellness of the CF care team. In separate symposia sessions, Stanford's own, Yelizaveta Sher, MD, FACLP, discussed the impact of ADHD in CF. Sarah Foushee, PharmD, BCPS, CSP discussed the use and effects of CBD and THC in CF. CBD can affect drug levels and thus can impact ETI, antivirals, immunosuppressants, and more.

NACFC plenary sessions and select recordings can be viewed via the CFF YouTube channel: **https://bit.ly/3SSpukJ**.

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If you are looking for the highlights from the overall conference, there is a great summary that can be viewed at **https://youtu.be/CGCJ-9khUi8**.

Front row, left to right: Laura Banuelos, Cathy Hernandez, Mary Helmers; back row, left to right: Lani Demchak, Tina Conti, Jessica King

Staff Favorites

A few of our Stanford staff share their highlights from the conference:

"My favorite talk took place on the last day—"Hot Topics for Nursing"—a lot of the talks were ideas on how to improve clinic workflow, patient adherence to appointments, and treatment. It would be great to have some more RN discussion groups—triaging, discussing resources, usage of EMR."—**Wendy C.**

"Nuts and Bolts for the New CF Member was the most impactful class I attended. Listening to a coordinator, social worker, dietitian, researcher, and pharmacist describe their roles in helping people with cystic fibrosis prompted a shift in my perspective, from viewing my work through a personal lens to understanding our broader, holistic impact. The best part by far was listening to the families share their real, heartfelt stories. It just made me feel so thankful to be a part of this mission and helping out these families." —**Sam K.**

"I attended a social work symposium titled 'Trauma-Informed Care for the Healthcare Team.' Presenters discussed powerful topics such as gender-based violence and medical trauma, and their disproportionate rates in the CF community. Bringing trust-based relational interventions into the clinical space is an effective way to address these disparities for our patients."—**Amanda K.**

"At NACFC, we had the opportunity to learn about the latest developments in CF treatment. Researchers presented data on cutting-edge genetic therapies being developed. Two examples of aerosolized medications being researched are mRNA replacement therapies and antisense oligonucleotides. While there will be some time before these types of medications are fully developed and approved, these approaches hold the potential to target the underlying causes of CF on an individualized basis and serve as a path forward to a cure."—**Alicia M.**

"Some of my favorite NACFC content was around the impact of hormones on overall health. There were some great talks on how estrogen affects pulmonary exacerbations, the impact of testosterone levels on sexual functioning, and how a better understanding of hormones by providers may help improve quality of life for people with CF. It has inspired me and the team to educate ourselves more on this topic!" —**Kate Y.**

"I attended a Lunch and Learn session titled 'Excellent Teams.' This talk discussed attributes of successful small research teams. It also included a panel of speakers discussing their successes and challenges in their small research teams. I gained many ideas from this discussion regarding how our research team communicates with our community of people with CF and their families and how we can improve."—**Tina C.**

Screening for Cystic Fibrosis Related Diabetes (CFRD): Continuous Glucose Monitoring as a Potential Tool

—Julie Matel, MS, RD, CDE

Many of you may be due for your annual labs and are dreading the oral glucose tolerance test (OGTT). After all, this test has many drawbacks. The Glucola® that you or your child is required to drink tastes horrible, the study is a two-hour time commitment, and it requires you to be fasting for at least eight hours. Not to mention the blood draw itself, which requires multiple pokes and is uncomfortable, to say the least.

Because of the drawbacks related to the OGTT, researchers have been trying to determine a better way to gain the very important information that the OGTT provides. Mainly, "Am I or is my child at risk for developing CFRD?" This is important information because we know that individuals with CF who go on to develop diabetes are at increased risk for a more rapid decline in nutrition parameters and in lung function, and have an increased mortality risk. On the flip side, individuals in whom diabetes is caught in the early stages have been shown to have improved outcomes, including improved nutrition status, lung function, and mortality.

At this point, you may be wondering what other CFRD screening options are out there. One important modality being considered is continuous glucose monitoring (CGM). CGM is done with a small device, about the size of a quarter, that has a tiny wire on the underside, which is quickly inserted just below the skin. It is typically placed on the upper arm; however, it can be worn in other places on the body as well if preferred. The device tests interstitial fluid (fluid between the

cells) for glucose every few minutes and sends wireless information to a smartphone. Interstitial fluid closely correlates to blood glucose and can be interpreted to determine overall fluctuations in blood sugar over a prolonged time. Some of the benefits of using CGM are that it is easy to place and relatively painless, even for young children. The CGM device is usually worn for seven to 14 days, with information that can be downloaded remotely to the diabetes team; or, alternatively, the CGM device can be removed at home and sent in by mail for interpretation. Another benefit of using CGM is that glucose information gathered is in response to real-life living situations (including typical diet and exercise patterns).

You may be wondering why we aren't currently using CGM instead of OGTT for CFRD screening. While research into this question is ongoing, it has been difficult to determine standards for glucose cutoff values, distinguishing between individuals with impaired glucose tolerance versus CFRD and seeing how those

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values correlate with clinical outcomes such as lung function or nutritional status.

Until this question is answered, at Stanford Medicine Children's Health we have been using CGM for individuals who have shown abnormal glucose values with the OGTT. This hopefully reduces some of the burden of having to perform more frequent OGTT studies, while allowing us and our diabetes partners to determine the best clinical approach for closely monitoring or treating individuals with impaired glucose tolerance and CFRD. While the OGTT remains the gold standard for diabetes screening, the CGM provides an important monitoring tool for individuals with, or at risk of developing, CFRD.

References

Chan, C.L. (2021). Continuous glucose monitoring in cystic fibrosis—Benefits, limitations, and opportunities. *Journal of Cystic Fibrosis*, 20(5), 725–26. doi:10.1016/j.jcf.2021.07.016.

Kumar, S., Pallin, M., Soldatos, G., and Teede, H. (2022). Comparison of continuous glucose monitoring to reference standard oral glucose tolerance test for the detection of dysglycemia in cystic fibrosis: A systematic review. *Journal of Clinical & Translational Endocrinology*, 30, 100305. doi:10.1016/j.jcte.2022.100305

Kumar, S., Soldatos, G., Ranasinha, S., Teede, H., and Pallin, M. (2023). Continuous glucose monitoring versus self-monitoring of blood glucose in the management of cystic fibrosis related diabetes: A systematic review and meta-analysis. *Journal of Cystic Fibrosis*, 22(1), 39–49. doi:10.1016/j.jcf.2022.07.013.

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Weiss, L., et al. (2023). Screening strategies for glucose tolerance abnormalities and diabetes in people with cystic fibrosis. *Diabetes & Metabolism*, 49(3), 101444. doi:10.1016/j.diabet.2023.101444.

XoC 2023 National Report

—Amanda Keen, MSN, RN

Your voices were heard!

From October 2021 to 2023, the Experience of Care (XoC) survey collected important data from you. Here is what we learned:

- 205 programs invited people with CF and families to complete surveys. Seventy-six percent of invited pediatric programs participated, and 79% of adult programs.
- We can improve ease of communication and scheduling visits. While 67%–88% of respondents are always able to get a response from their care team without difficulty, closer to 60%–75% are always able to schedule a visit.
- We can improve efficiencies during clinic visits. Only 21% to 38% of respondents felt the amount of time spent waiting between care team members at clinic visits was "very short."
- People with CF and their families are not always comfortable speaking up about care decisions or about well-being.
- We are doing an even better job of wearing PPE in clinic.

You can view the report in the Resource Library on My.CFF.org. Any questions? Contact XoC@cff.org

What's Next? We Still Need Your Input!

—Mary Helmers, RN, BSN

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 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**; 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 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.

Upcoming Events

Save the Date!

- Spring walks
  - **Sacramento Great Strides**: April 13, 2024, at the CHP Academy, West Sacramento
  - **Walnut Creek Great Strides**: April 14, 2024, at Heather Farm Park
  - **San Francisco Great Strides**: May 11, 2024, at Little Marina Green Picnic Area

Spotlight on Child Life Specialists at Lucile Packard Children's Hospital Stanford

What can your child life specialist offer?

- **Building coping techniques**
  - Child life specialists can help provide children with strategies for coping with their hospitalization and assist with understanding pain.
  - The video You Are the Boss of Your Brain: Learning How Pain Works helps everyone understand how pain works and what everyone can to do to help a child have more control over their pain, their brain, their body, and their experience.
- **Education and support**
  - Consultations—Parents may consult with child life specialists when they have concerns related to their child's adjustment to illness/hospitalization, parenting in the hospital, and other related concerns. Both patients and siblings can receive education and support regarding the reason for admission, diagnosis, and ongoing treatment as needed. They can prepare patients and siblings for what they will experience at the hospital and what they will see, explain how medical equipment is helping, and suggest ways they can each be involved with the hospitalization.

  - Educational resources—The Family Resource Library offers patients and families educational resources about health care, specific diagnoses, and parenting.
- **Recreational opportunities**
  - Patients, siblings, and parents are encouraged to participate in Preschool, Forever Young Zone, and Family Resource Center programming to help adjust to the hospital. They can even borrow activities for in-room use.

Call the Child Life and Integrative Therapies Department at (650) 497-8336 for more information and support.

> "Both patients and siblings can receive education and support regarding the reason for admission, diagnosis, and ongoing treatment as needed."

References
https://www.stanfordchildrens.org/en/patient-family-resources/child-life/education

Current Research

Active Studies

Name	Brief description	Criteria	Contact(s)
Beacon A Phase 1 Single Dose Escalation Study Evaluating the Safety and Tolerability of VX-522 (Vertex 522-001)	Phase 1 clinical trial of inhaled mRNA gene therapy in people with CFTR genotype not responsive to modulator therapy. Will be recruiting for multiple ascending dose (MAD) cohort- TBD	• 18-65 years old • CFTR variant non-responsive to modulators	Lani
BEGIN-OB-19 A Prospective Study in Infants and Young Children (BEGIN)	Prospective longitudinal study to observe the effects of administration of either ivacaftor or elexacaftor/tezacaftor/ivacaftor (elex/tez/iva) on growth.	• <6 years old • CFTR variant eligible for HEMT • Not currently on ivacaftor or ETI	Amanda
CMTX-P1-CT002 A Phase 1b/2a Study to Evaluate the Safety of CMTX-101	Phase 1b/2a clinical trial to determine the safety and tolerability of IV administered CMTX-101 along with standard of care treatment	• 18+ years old • CF and P. aeruginosa+	Amanda
NBSA Collection of Gene Mutation for Laboratory Quality Assurance: Newborn Screening Accuracy Project	Study collecting blood samples from patients with rare CF mutations to ensure that newborn screening tests are accurate in all ages	• Diagnosed with rare CFTR variant	Tina
NICE-CF A Multi-Center Study of Non-Invasive Colorectal Cancer Evaluation in Cystic Fibrosis	Colorectal cancer screening study comparing stool-based testing to colonoscopy	• 18+ years old • CF patients eligible for colonoscopy	Elvi
RESPIR-102 A Phase 1b Study of Aersolized RSP-1502	Phase 1b clinical trial to evaluate the safety, tolerability, and efficacy of tobramycin plus CaEDTA for chronic Pseudomonas aeruginosa lung infection administered via nebulizer	• 18+ years old • CF and P. aeruginosa on inhaled tobramycin	Amanda
SILP Multisite Qualification Studies Using the Slow Inhalation, Large Particle (SILP) Mucociliary Clearance Measurement Method	Observational study of the ability of study sites to follow experimental procedures and collect research quality data using a new standard operating procedure for the performance of mucociliary clearance scans	• 18-60 years old • 1 healthy control and 2 patients with CF • Non-smoking	Tina
WEARABLE RESPIRATORY Innovative Respiratory Condition Monitoring	This study is to better understand the best way to monitor the health of people with respiratory conditions	• 12+ years old • CF with history of more than one pulmonary exacerbation in the preceding year	Lani

Cystic Fibrosis Center at Stanford

Pediatric providers at Lucile Packard Children's Hospital Stanford

Pediatric Center Director: Carlos Milla, MD
Providers: Sumit Bhargava, MD; MyMy Buu, MD; Lori Lee, MD; Carol Conrad, MD; David Cornfield, MD; Michael Tracy, MD; Jacquelyn Spano, DNP, RN, CPNP; Cissy Si, MD; Nick Avdimiretz, MD
Clinic Scheduling ..... (650) 724-4788
Clinic and Prescription Refill Fax ..... (650) 497-8791
Office Assistant/Patient Services Coordinator:
Laura Banuelos ..... (650) 498-2655
Nurse Coordinator: Wendy Chin, RN ..... (650) 736-1359
CF Clinic Nurse: Liz Beken, RN ..... (650) 736-1359
Respiratory Therapist: Samuil Kovalchuk, RT ..... (650) 724-0206
Nutritionist, Dietitian:
Julie Matel, MS, RD, CDE ..... (650) 736-2128
Social Worker: Debbie Menet, LCSW ..... (650) 796-5304
Newborn Screening Coordinator:
Jacquelyn Spano, DNP, CPNP-AC/PC, CCRC..... (650) 721-1132
Clinical Pharmacist:
Jake Brockmeyer, PharmD, BCPS ..... (650) 505-9419
Clinical Psychologist: Diana Naranjo, PhD

For urgent issues:

Monday to Friday, 8 a.m. to 4 p.m.
Call the CF Clinic Nurse ..... (650) 736-1359
After hours and weekends: Call the main hospital and ask for the on-call pulmonology doctor ..... (650) 497-8000

Pediatric providers at Stanford Medicine Children's Health Specialty Services – Emeryville

Providers: Karen Hardy, MD; Eric Zee, MD; Manisha Newaskar, MD; Rachna Wadia, MD
CF Clinic Scheduling ..... (844) 724-4140
Clinic and Prescription Refill Fax ..... (510) 457-4236
Nurse Coordinator: Neetu Perumpel, MSN, RN ... (650) 724-8414
Respiratory Therapist: Lorraine MacPhee, RT ..... (510) 587-9631
Nutritionist, Dietitian: Mikaela Burns, CRD, MPH ..... (510) 806-3659
Social Worker: Teresa Priestley, MSW ..... (925) 357-0733

For urgent issues:

Monday to Friday, 8 a.m. to 4 p.m.
Call the CF Clinic Nurse ..... (650) 724-8414
After hours and weekends: Call the main hospital and ask for the on-call pulmonary doctor ..... (844) 724-4140

Adult providers at Stanford Health Care

Adult Center Director: Paul Mohabir, MD
Associate Center Director: Alicia Mirza, MD
Pulmonologists (MDs): Laveena Chhatwani, MD; Alicia Mirza, MD; Paul Mohabir, MD
Director of Psychiatric and Psychological Services: Liza Sher, MD
Infectious Disease Consultant: Joanna Nelson, MD
Advanced Practice Providers: Meredith Wiltse, NP
Clinical Pharmacist: Denise Kwong, PharmD
Adult Clinic Scheduler/Patient Care Coordinator:
Patricia Morales ..... (650) 723-0798
Adult CF Center Fax ..... (650) 723-3106
Nurse Coordinators: Theresa Kinney, RN and Kristel Fallon, RN ..... (650) 498-6840
Respiratory Therapy: Erica Collins, RCP IV; Jenny Kwok, RCP IV; Jennifer Mori, RCP; Gauri Pendharkar, RCP (CF RT Coordinator) ..... (650) 736-8892
Registered Dietitian:
Marion Seabaugh, MPH, RD, CNSC, CCTD ..... (650) 529-5952
Social Work: Meg Dvorak, LCSW ..... (650) 518-9976
Social Work: Kate Yablonsky, MSW ..... (650) 444- 6512
Routine issues/concerns during business hours (Monday–Friday, 8:00 a.m.–4:30 p.m.)
- CF Nurse Coordinator Line ..... (650) 498-6840
- Voicemails will be answered within 24–48 business hours, or sooner based on clinical priority.
- Alternatively, you can utilize MyHealth messaging for NON-URGENT NEEDS ONLY. MyHealth messages are NOT checked after hours or on the weekends

Urgent issues/concerns DURING business hours (Monday–Friday, 8:00 a.m.–5:00 p.m.)
Chest Clinic Call Center ..... (650) 725-7061
• A message will be generated and sent to the CF Team ASAP
Urgent Issues/concerns AFTER business hours:
Chest Clinic Call Center ..... (650) 725-7061
- A message will be generated and sent to the covering CF provider ASAP.
- MyHealth messages are NOT checked after hours, weekends, or holidays.

Adult providers at CPMC

Adult Center Director: Ryan Dougherty, MD
Associate Center Director: Vinayak Jha, MD
Provider: Christopher Brown, MD; Carolyn C. Hruschka, ANP-BC
Adult Clinic Scheduling ..... (415) 923-3421
Adult CF Center Fax ..... (415) 243-8666
Nurse Coordinator:
Carolyn C. Hruschka, ANP-BC ..... (415) 923-3421
Respiratory Therapy:
Bryan Ellis, RCP; Arthur Pundt, RCP..... (415) 600-3424
Registered Dietitian: Elena Zidaru, RD..... (415) 923-3997
Social Work: Amy Greenberg, LSW..... (650) 518-9976
Mental Health Coordinator:
Amy Greenberg, LSW ..... (415) 923-3854

For urgent issues:

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

Research

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

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

Other Research Opportunities

GEMS-CF: Mental Health Screening Tool Study

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

Know of currently enrolling studies? Send the information to us at **cfresearch@lists.stanford.edu**, 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**. Follow us on Facebook: **Cystic Fibrosis Center at Stanford**.