Winter 2025

Stanford MEDICINE
Children's Health

Cystic Fibrosis Center **News**

Honoring the Life of Carol Conrad, MD

—David Cornfield, MD

I write this note with a heavy heart to share sad of the passing of our dear friend, Carol Conrad, MD.

During the week of Thanksgiving 2024, the stars dimmed in the pediatric pulmonary medicine and lung transplant medicine communities with the passing of a dedicated, intellectually nimble, energetic, unfailingly honest, and fierce patient advocate, Carol K. Conrad, MD. Dr. Conrad touched the lives of countless patients, families, trainees, and colleagues with clarity of thought and expression and careful attention to each person.

Born in Southern California, Carol and her three siblings (David, James, and Elizabeth) were raised in a famously clever and liberal family by her mother, Barbara, and her father, Paul, a three-time Pulitzer Prize winning political cartoonist. Carol forever carried her family's dedication to truth, commitment to justice, humanity, and rapier wit.

A graduate of University of California, Berkeley, Carol received her medical doctor degree from the University of California, Los Angeles and undertook training in pediatrics at Children's Hospital Los Angeles. Dr. Conrad chose to train in pediatric pulmonary medicine at Johns Hopkins and played a central role in demonstrating proof-of-concept for gene therapy in cystic fibrosis.

Carol Conrad came to Stanford in 1995 and worked long, hard, and persistently to build outstanding programs in pulmonary medicine. At Stanford, Dr. Conrad contributed in countless ways, large and small, including bronchoscopy, the pulmonary function laboratory, bronchopulmonary dysplasia,

Continues on page 2…

In this issue

Honoring the Life…continued from page 1

and childhood interstitial lung diseases. Though Dr. Conrad's was rightfully proud of all her work, she was, arguably, most proud of her role as the Director of the Pediatric Lung and Heart-Lung Transplantation Program from 2004 through 2023. Her accomplishments and contributions were recognized and honored by Stanford University School of Medicine with promotion to full professor in 2023, the apex of academic recognition.

Carol was engaged with the world beyond medicine: a devoted aunt and sister, an adventure traveler, an early Burning Man adopter as a fire dancer and house doctor, and physical fitness advocate. Carol's life ended far too soon; she had so much more to learn and teach. In a note written in November 2024, Dr. Conrad stated, "I am proud of the influence I have had on the growth and depth of services provided by the pulmonary division to our patients. My goal is always to maintain clinical excellence and provide compassionate care. I am entering a phase of my career that is extending to increasing resident and fellow teaching, which I enjoy quite a bit."

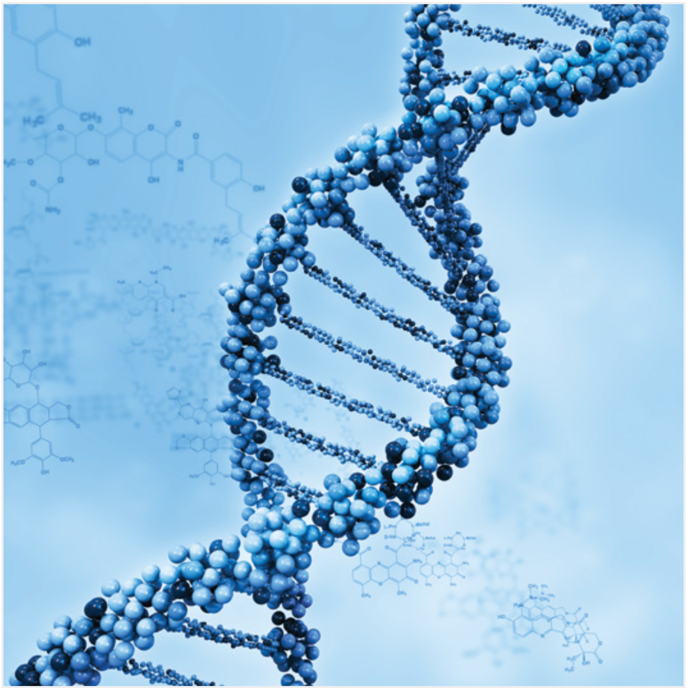
Dr. Conrad's voice will echo forever in the hearts and minds of colleagues, trainees, patients, and families—calling all of us to be our very best selves, to give more, think harder, care prodigiously. May Dr. Conrad's memory always be for a blessing. We will miss Carol with depth and gravity.

Genetic Therapy in Cystic Fibrosis: Progress and Possibilities

—Alicia Mirza, MD

Cystic fibrosis (CF) is a genetic condition caused by various mutations in the CFTR gene (cystic fibrosis transmembrane conductance regulator). The CFTR gene (i.e., DNA) makes RNA, which then acts as instructions to make the CFTR protein. This protein regulates the movement of salt and water in and out of cells. When there is a mutation in the CFTR gene, it can ultimately lead to a CF protein that doesn't work the way it should. As a result, thick, sticky mucus builds up in the lungs, digestive system, and other organs, leading to chronic health challenges.

There have been significant advances in CF treatments with the introduction of highly effective modulator therapy (HEMT), such as elexacaftor/tezacaftor/ivacaftor, brand name Trikafta. This class of drugs works on the protein level to make the CF protein work better in



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Genetic Therapy...continued from page 2

certain mutations. While these therapies have been a huge step forward, they do not change the root cause of the disease on the genetic level. We also know that HEMT does not work for everyone. Genetic therapies (sometimes called nucleic acid-based therapies) are the next frontier in CF because they work closer to the root cause of the disease. They have the potential to work for all people with CF and could eventually lead to a cure for the condition.

There are several strategies currently being explored:

1. **Gene addition:** This method involves delivering a healthy copy of the CFTR gene to affected cells using a carrier. This could help cells produce functional protein. There are integrating and nonintegrating forms, which means sometimes it becomes part of the cell permanently and others are not permanent.
2. **Gene editing:** Tools like CRISPR are being studied to directly correct mutations in the CFTR gene, repairing it at its source. Stanford University scientists have done some impressive laboratory work in this area contributing to important advancements in the field.[1] However, translating these findings into safe and effective treatments for humans will require more time and testing.
3. **RNA-based therapy:** These therapies modify the RNA instructions produced by the CFTR gene, correcting errors before the protein is made. At the Stanford CF Center, there is an active Phase 1/2 clinical trial evaluating inhaled mRNA therapy called BEACON enrolling qualified people not responsive to modulator therapy.

Each approach faces challenges, but all have shown potential. In recent years, progress in genetic therapy has gained momentum. One key area of investigation is finding a reliable way to deliver genetic material directly to the lungs to treat CF at its primary site of impact. Early trials have demonstrated the feasibility of these techniques, although achieving consistent and widespread delivery to all affected cells remains a hurdle.

While genetic therapy holds great potential, its widespread availability is still years away. For now, people with CF should continue current treatments, including daily therapies and regular checkups. Genetic therapies are unlikely to replace these approaches in the near future but are still a critical area of research that could transform CF care in the coming decades. If you would like to learn more, the CF Foundation has many excellent resources, including explanatory videos, that can be found at **https://www.cff.org/research-clinical-trials/research-genetic-therapies**.

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[1] Vaidyanathan S, Baik R, Chen L, et al. Targeted replacement of full-length CFTR in human airway stem cells by CRISPR-Cas9 for pan-mutation correction in the endogenous locus. Mol Ther. 2022;30(1):223–237. doi:10.1016/j.ymthe.2021.03.023

CF Research: Amanda’s Journey

Lani Demchak, MBA

As a Stanford clinical research coordinator, I have had the privilege of working with many patients, but Amanda, my very first cystic fibrosis research participant, holds a special place in my heart. Amanda is 45 years old and resides in Santa Rosa, California. Although she isn’t currently a Stanford patient, her involvement in our clinic studies has been incredibly impactful for both her and the CF community. I had the opportunity to sit down with Amanda to hear more about her journey, from her diagnosis to her participation in CF research.

Amanda, can you start by sharing a bit about your background and diagnosis?

I was born and raised in Petaluma, California, to two amazing parents and two older sisters. My sister who is closest in age to me was diagnosed with cystic fibrosis at 20 months old. When I was born three and a half years later, I appeared to be healthy, but doctors tested me for CF as a precaution. At just 3 months old, I was diagnosed with CF as well. I had no symptoms at that time, and my health was good, so they initially thought the test might have been wrong. It wasn’t until I was retested as a preteen that the diagnosis was confirmed. My health issues were mostly related to my sinuses, which led to surgeries at ages 12 and 17. Over time, CF has taken its toll, and I’ve spent many weeks in the hospital dealing with exacerbations. Still, I consider myself fortunate to have maintained fairly good health overall.

How did you learn about the research study you participated in?

I first heard about the study through an email newsletter from Emily’s Entourage, an organization dedicated to advancing CF research for patients who are often excluded from current treatments.

Amanda and Jacquelyn Spano, NP, DNP

I was then informed that the Stanford site would soon be recruiting, and I decided to connect. I’m so glad I did—it’s been a life-changing experience!

Can you tell us about your experience during the study?

It was a truly positive experience from start to finish. The staff at Stanford was incredible—they were professional, supportive, and made me feel comfortable throughout the entire six-month trial. They worked with me to schedule appointments that were convenient for my life, all while adhering to the study’s requirements. The sponsor also provided compensation for my time, travel, meals, and even accommodations for my husband, who was my caregiver during the inpatient portion of the study. Overall, I felt extremely well taken care of.

Continues on page 5...

CF Research...continued from page 4

Do you feel your participation made a difference, either for you personally or for the CF community?

Absolutely. It's tough being part of the 10% of CF patients who don't benefit from modulator therapies, but I feel that my participation in this study has allowed me to contribute to research that could make a real difference for myself and others in similar situations. I'm particularly hopeful about mRNA and gene therapy research studies and their potential to transform the future of CF treatment. Participating in this study felt like I was not only helping myself but also being part of something much bigger—something that could ultimately benefit the CF community.

Would you consider participating in future research studies?

Without a doubt! In fact, I'm really hopeful about the possibility of participating more in mRNA clinical trials. It has been incredibly rewarding to work with such a dedicated team of CF professionals. The collaboration between researchers, doctors, and patients is inspiring, and it's been a privilege to be part of a study that could lead to groundbreaking treatments. I'm excited about what the future holds for CF research.

Amanda

What advice would you offer to other CF patients who are considering participating in clinical research studies?

I would strongly encourage anyone who is eligible to participate in research studies. The process may feel daunting at first, but it is so rewarding to know that you are making a difference—not only for yourself but for others who are facing similar challenges. The progress we've made in CF research, thanks to the tireless work of scientists and medical professionals, would not be possible without the active participation of patients. By taking part in these studies, we're not just advancing treatments, we're helping to save lives.

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

Pediatric CF Center Updates

Farewell (and a Big Welcome!) to Debbie Menet, LCSW

The Stanford Cystic Fibrosis Center would like to express our heartfelt gratitude to Debbie Menet, LCSW, for her many years of dedication to the Pediatric CF Center at Stanford Children's. From supporting families through the initial diagnosis to providing ongoing assistance and resources to reduce barriers to care, Debbie has been an invaluable member of our Pediatric CF Center's Care Team.

In September of 2024, Debbie stepped down from her role as the Pediatric CF social worker. Fortunately, Debbie is not venturing far, as she has taken on a new role as one of the Adult CF social workers at Stanford.

Debbie will be deeply missed by all of us at the Pediatric CF Center.

Thank you, Debbie!

With love,
Your Pediatric CF Family

Left to right: TJ, Wendy, Laura, Debbie, Richelle

Helpful tools for needle sticks

There's a new device at Stanford called the Buddy Guard that aims to help with blood draws and immunizations. Similar to the Buzzy® device, this device is placed on the skin and vibrates to distract the patient from the needle stick. The Buddy Guard is integrated with a video game, and the vibrations intensify along with gameplay, providing even better distraction! While the Buddy Guard is currently being used for clinical studies, the next step is to make it available across Stanford clinics.

Buddy Guard

Reference:
Valente, Elizabeth. Stanford Children's Eases Needle Jabs With the Buddy Guard Device. Retrieved August 19, 2024.

NACFC 2024 Highlights

Lani Demchak, MBA

The 2024 North American Cystic Fibrosis Conference (NACFC) has come to a close! Held at the Boston Convention Center September 26–28, 2024, the event brought together researchers, clinicians, and community members to share the latest advancements in cystic fibrosis care and research. Here are some of the key highlights from the plenary sessions:

Day 1: Challenges and Progress in the Pursuit of Genetic Therapies for Cystic Fibrosis

Daniel Siegwart, MD, from the University of Texas Southwestern Medical Center, discussed how emerging research is tackling biological barriers in the pursuit of genetic therapies, such as overcoming mucus buildup, targeting specific cells, and improving delivery mechanisms for genetic medicines to the lungs. Joe Pilewski, MD, from the University of Pittsburgh, followed with an important presentation on how new research, clinical trials, and community engagement are pivotal to advancing these therapies.

Stanford CF Dinner, Left to right: Diana Naranjo, PhD; Julie Matel, RD; Theresa Kinney, RN; Jake Brockmeyer, PharmD; Laura Banuelos; Debbie Menet, LCSW; Lani Demchak, MBA; Wendy Chen, RN; Teresa Priestly, MSW

Day 2: The Tipping Point: Advancing Research in CFRD

This plenary focused on exciting breakthroughs in research related to cystic fibrosis-related diabetes (CFRD). Rebecca Hull-Meichle, PhD, presented new insights into the CF pancreas, emphasizing the cellular mechanisms involved in CFRD and how these findings could eventually lead to new treatments. Melissa Putman, MD, discussed how the landscape of CFRD is changing in the post-modulator era, covering emerging diabetes technologies, novel treatment strategies, and the evolving needs of an aging CF population.

Day 3: Reproductive Health in Cystic Fibrosis

A dynamic plenary focused on reproductive health in CF included presentations from experts like Molly Pam, an alumna of Stanford University, who addressed community engagement and family-building decisions for those with CF. Raksha Jain, MD, offered a comprehensive overview of fertility and pregnancy challenges for people with CF. Traci Kazmerski, MD, explored the interplay between CF and reproductive health decisions and implications for CF clinical care.

Stanford Faculty, Clinical, and Research Presentations

Several presentations from Stanford faculty, clinical, and research staff highlighted the latest research and clinical advancements in CF care, including the following:

- Tina Conti, BSRC, RRT-NPS, CCRC, presented strategies for reversing the decline in clinical trial enrollment.
- Jake Brockmeyer, PharmD, shared insights on precision dosing of tobramycin in pediatric CF patients.

Continues on page 8...

NACFC 2024...continued from page 7

- Alicia Mirza, MD, presented on evaluating biologic regimens for treatment-resistant allergic bronchopulmonary aspergillosis at physician grand rounds.
- Denise Kwong, PharmD, discussed navigating CFTR modulator challenges.
- Yelizaveta Sher, MD, presented on aging in CF, ethics for mental health practitioners, and strengthening multidisciplinary care.

For a full conference recap, including more highlights and expert insights, check out the summary video available on the Cystic Fibrosis Foundation YouTube channel.

Thank you to everyone who made NACFC 2024 a success! We look forward to seeing you at the next event!

Staff favorites

NACFC is truly an amazing conference—to see the importance of everyone working together for one cause. My favorite part of NACFC is the Program Coordinators Luncheon—I always feel inspired by the efforts of other CF Centers to improve and better our own CF Center, and I get excited to share our successes with other centers.—Wendy C.

Tina Conti, BSRC, RRT-NPS, CCRC

Jake Brockmeyer, PharmD

My favorite experience was hearing a talk by Steph Hansen, a person with CF, share their experience within the CF health care system as a transgender person. They shared insights that really opened my eyes as to how I can support a member of the LGBTQIA+ community in my role as a dietitian at our CF Center. For example, they shared that designating my pronouns or wearing a rainbow flag sticker on my badge (both of which we have available to us) can allow that person to feel supported at our CF Center. I also learned a lot about how nutrition and weight issues impact some folks within the LGBTQIA+ community and how if I understand these issues, I can alter the advice and support I offer. —Julie M.

My favorite experience was speaking at physician grand rounds about the use of asthma biologic therapies in cystic fibrosis. There were hundreds of people in attendance, and they were very interested to learn about our practices here at Stanford.—Alicia M.

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 *Medical Baseline Program*.
- To expedite your clinic visit, please remember to bring your **CF Binder** and the most recent **CF Action Plan** with you to clinic.
- 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.
- 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 with a phone call. **Your CF care team can only communicate with you via MyChart or by phone.** If you/your child has a clinical need/question, please call the **CF RN line at (650) 736-1359**.

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

Annual testing

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

Included in the annuals are the following:

- 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**.

Continues on page 10...

Helpful Tips...continued from page 10

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

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

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

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.

Experience of Care (XoC) Survey

EXPERIENCE OF CARE

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.

Upcoming Events

Great Strides Walks

Sacramento Great Strides: April 26, 2025, at CHP Academy, West Sacramento

San Francisco Great Strides: May 4, 2025, at Little Marina Green Picnic Area

Walnut Creek Great Strides: May 10, 2025, at 1375 Civic Drive

Santa Rosa Great Strides: Sept. 8, 2025, at Howarth Park

Adult CF Center Updates

The Stanford Adult CF Patient & Family Advisory Council needs help from kids with CF! Our logo (which we currently refer to as "the salt shaker") needs a name! The winner will receive a $25 Target gift card and will be featured in a future CF Center newsletter.

Submit your name ideas to kyablonsky@stanfordhealthcare.org; at this link, https://redcap.link/namethesaltshaker; or with this QR code. Deadline is March 31, 2025.

Our Mascot Needs A Name!

ADULT CYSTIC FIBROSIS
PFAC
PATIENT FAMILY ADVISORY COUNCIL

Facts About Salt shaker

They are a seasoned professional and handy in a pinch.
They will always help you if you're in a pickle, although they have a habit of going against the grain.
Favorite music - Rock
Favorite band - Electrolyte Orchestra & Saline Dion.
Plus they are like super into crystals right now.
They love the ocean and support all efforts to preserve and influence its density. (Look it up, salt is awesome!)

Send in your suggestions now!

The winner will be featured in our newsletter!

Contact:
KYablonsky@stanfordhealthcare.org

Name the Salt Shaker Contest

Recipe: Hearty Stew

Ingredients

- 1 pound turkey breast, cut into cubes (or your protein of choice)
- 2 tbsp. whole wheat flour
- 1/4 tsp. salt (optional)
- 1/4 tsp. pepper
- 1/4 tsp. cumin
- 1 1/2 tbsp. olive oil
- 2 cloves garlic, minced
- 2 medium onions, sliced
- 2 stalks celery, sliced
- 1 medium red or green bell pepper, sliced
- 1 medium tomato, finely minced
- 5 cups low-sodium beef or turkey broth, fat removed
- 5 small potatoes, peeled and cubed
- 12 small carrots, cut into large chunks
- 1 1/4 cups green peas

Directions

1. Preheat oven to 375°F.
2. Mix the whole wheat flour with salt, pepper, and cumin. Roll the protein cubes in the mixture. Shake off excess flour.
3. In a large skillet, heat olive oil over medium-high heat. Add protein cubes and sauté until nicely brown, about 7–10 minutes. Place protein in an ovenproof casserole dish.
4. Add minced garlic, onions, celery, and peppers to skillet, and cook until vegetables are tender, about 5 minutes.

5. Stir in tomato and broth. Bring to a boil and pour over protein in casserole dish. Cover dish tightly and bake for 1 hour at 375°F.
6. Remove from oven and stir in potatoes, carrots, and peas. Bake for another 20–25 minutes or until tender.

Nutrition Facts (makes 4 servings)

Cal 450, Fat 9g, Chol 65mg, Sodium 390mg, Carb 56g, Fiber 11g, Sugar 16g, Protein 40g

References:

https://www.cdc.gov/diabetes/pdfs/managing/Tasty_Recipes_for_People_with_Diabetes-508.pdf

Current and Upcoming Research

Active Studies

Name	Brief description	Criteria	Contact(s)
BEACON A Phase 1/2 Single Dose Escalation Study Evaluating the Safety and Tolerability of VX-522	Phase 1/2 clinical trial of inhaled mRNA gene therapy in people with CFTR genotype not responsive to modulator therapy. Currently, recruiting for multiple ascending dose (MAD) cohort	• 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 either ivacaftor (Kalydeco) or elexacaftor/tezacaftor/ivacaftor (Trikafta) on growth	• <6 years old • Eligible for modulators • Not currently on either med	Tina
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*$^+$	Lani
NBSA Newborn Screening Accuracy Project	Study collecting blood samples from patients with rare CF mutations to ensure newborn screening tests are accurate in all ages	• Diagnosed with rare CFTR variant	Tina
PROMISE **Study to evaluate the effects of ETI**	Post approval, real-world, observational study to understand the effects of elexacaftor/tezacaftor/ivacaftor (ETI) in clinical use	• >6 years old • >=1 copy of F508del	Jackie
ReCode A Phase 1/2 Multiple Dose Escalation Study Evaluating the Safety and Tolerability of RCT2100	Phase 1/2 clinical trial of inhaled mRNA gene therapy in people with CFTR genotype not responsive to modulator therapy	• 18-65 years old • CFTR variant non-responsive to modulators	Lani
RESPIR-102 A Phase 1b/2a Study of Aerosolized RSP-1502	Phase 1b/2a clinical trial to evaluate the safety, tolerability, and efficacy of tobramycin plus CaEDTA in ascending doses administered via nebulizer	• 18+ years old • CF and P. *aeruginosa*$^+$	Lani
SILP Slow Inhalation, Large Particle (SILP) Mucociliary Clearance Measurement Method	Observational study using a new standard operating procedure for the performance of mucociliary clearance scans	• 18-60 years old • 2 patients with CF • Non-smoking	Tina

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 ReCode Study

Who can participate?
We are looking for people 18–65 years old with cystic fibrosis who are not eligible or not able to tolerate CFTR modulators.

What is involved?

If you are eligible, you will receive multiple doses of the investigational treatment, RCT2100, inhaled through a nebulizer for four weeks.

How long is the study?

Your participation will last up to eight months.

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

Philanthropy Corner with Lucile Packard Foundation for Children's Health

Stanford MEDICINE Children's Health

Lucile Packard Foundation

You can support research at the Cystic Fibrosis Center at Stanford

The Cystic Fibrosis Center is actively exploring multiple research projects to address the most urgent needs of the cystic fibrosis community. As you know, lung complications remain the most serious challenge for children with CF, and the team is focused on identifying the most effective ways to control infections and detect lung disease earlier. The CF Center is also leading innovative research in CF treatments in utero and working to address mucus clearance, especially for CF patients who don't respond to modulators. All of these research initiatives have the potential to make a tremendous impact for all CF families. If you would like to learn more about how you can make a difference through philanthropy, please reach out to us. Together, we can create a brighter future for families navigating CF.

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

Cystic Fibrosis Center at Stanford

Pediatric providers at Lucile Packard Children's Hospital Stanford

Pediatric Center director: Carlos Milla, MD

Providers: Sumit Bhargava, MD; MyMy Buu, MD; David Cornfield, MD; Lori Lee, MD; Michael Tracy, MD; Jacquelyn Spano, DNP, RN, CPNP; Cissy Si, MD

Clinic scheduling:..(650) 498-2655

Clinic and prescription refill fax:.............................. (650) 497-8791

Laura Banuelos Office Assistant/ Patient Services Coordinator:...............................(650) 498-2655

Nurse Coordinator—Wendy Chin, RN:..................... (650) 736-1359

CF Clinic Nurse—Liz Beken, RN:............................... (650) 736-1359

Respiratory Therapist—Samuil Kovalchuk, RT:........(650) 724-0206

Nutritionist, Dietitian— Julie Matel, MS, RD, CDE:..(650) 736-2128

Social Worker—:..(650) 796-5304

Newborn Screening Coordinator— Jacquelyn Spano, DNP, RN, CPNP: ....(650) 721-1132

Clinical Pharmacist— Jake Brockmeyer, PharmD, BCPS:.........................(650) 505-9419

Clinical Psychologist—Diana Naranjo, PhD

For urgent issues:

Monday – Friday, 8 a.m. – 4 p.m.: Call the CF nurse at .... (650) 736-1359

After hours and weekends: Call the main hospital and ask for the on-call pulmonology doctor.................................. (650) 497-8000

Pediatric providers at Emeryville

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

CF Clinic scheduling:..(844) 724-4140

Clinic and prescription refill fax:..............................(510) 457-4236

Nurse coordinator—Neetu Perumpel, MSN, RN:....(650) 724-8414

Respiratory Therapist—Lorraine MacPhee, RT; Carol Journey, RT:... (510) 587-9631

Nutritionist, Dietitian— Mikaela Burns, CRD, MPH:.....................................(510) 806-3659

Social Worker—Teresa Priestley, MSW:....................(925) 357-0733

For urgent issues:

Monday – Friday, 8 a.m. – 4 p.m. Call the CF nurse at ....(650) 724-8414

After hours and weekends: Call the main hospital and ask for the on-call pulmonary doctor..........................(844) 724-4140

Adult providers at Stanford

Adult Center director: Paul Mohabir, MD

Associate Center director: Alicia Mirza, MD

Pulmonologists (MDs): Laveena Chhatwani, MD; Alicia Mirza, MD; Paul Mohabir, MD

Director of Psychiatric and Psychological Services: Liza Sher, MD

Infectious Disease Consultant: Joanna Nelson, MD

Advanced Practice Providers: Meredith Wiltse, NP

Clinical Pharmacist: Denise Kwong, PharmD

Adult Clinic Scheduler/Patient Care Coordinator: Patricia Morales .... (650) 723-0798

Adult CF Center Fax:.. (650) 723-3106

Nurse Coordinators: Theresa Kinney, RN and Kristel Fallon, BSN, RN ....(650) 498-6840

Respiratory Therapy: Jenny Kwok, RCP IV; Jennifer Mori, RRT; Gauri Pendharkar, RCP, CPFT (CF RT Coordinator) ....(650) 736-8892

Registered Dietitian: Emily Yelenich, MS, RD......... (650) 529-5952

Social Worker: Debbie Menet, LCSW....................... (650) 518-9976

Kate Yablonsky, LCSW:...(650) 444- 6512

Routine Issues/Concerns during Business hours

- **CF Nurse Coordinator Line:**.................................(650) 498-6840
- **Voicemail will be answered within 24-48 business hours, or sooner based on clinical priority.**
- **Alternatively, you can utilize MyHealth messaging for NON-URGENT NEEDS ONLY. MyHealth messages are NOT checked after hours or on the weekends.**

Urgent Issues/Concerns DURING Business Hours

Chest Clinic Call Center: ....(650) 725-7061

- **A message will be generated and sent to the CF Team ASAP**

Urgent Issues/concerns AFTER Business Hours:

- **Chest Clinic Call Center:**..(650) 725-7061
- **A message will be generated and sent to the covering CF provider ASAP.**
- **MyHealth messages are NOT checked after hours, weekends, or holidays.**

Adult providers at CPMC

Adult center director: Ryan Dougherty, MD

Associate center director: Vinayak Jha, MD

Providers: Christopher Brown, MD; Carolyn C. Hruschka, ANP-BC

Adult clinic scheduling:.. (415) 923-3421

Adult CF Center fax: ....(415) 243-8666

Nurse Coordinator— Carolyn C. Hruschka, ANP-BC:.............................. (415) 923-3421

Respiratory Therapy—Bryan Ellis, RCP; Arthur Pundt, RC: .... (415) 600-3424

Registered Dietitian—Elena Zidaru, RD: ....(415) 923-3997

Social Worker—Amy Greenberg, LSW: .... (650) 518-9976

Mental Health Coordinator— Amy Greenberg, LSW: ....(415) 923-3854

For urgent issues:

Monday – Friday, 9 a.m. – 5 p.m. Call nurse coordinator .... (415) 923-3421

Evenings/weekends: Call and ask for the on-call pulmonary provider...................................... (415) 923-3421

Research

Tina Conti, BSRC, RRT-NPS:....................................(650) 498-8701

Lani Demchak, MBA: .... (650) 725-1087

Monica Elazar, DDS: ....(650) 723-5193

Cathy Hernandez, AD:.. (650) 724-3474

Jacquelyn Spano, DNP, CPNP-AC/PC, CCRC: ....(650) 721-1132

CF Center at Stanford
770 Welch Road, Suite 350
Palo Alto, CA 94304

Dr. Carol Conrad with her patient Doris Diaz after her double lung transplant in 2014

To continue Dr. Conrad's profound impact, the Carol Conrad Memorial Fund has been established to support critical research in lung transplantation and cystic fibrosis at Stanford. Your generosity will help carry forward her mission and advance the care and science she devoted her life to.

Donate at https://my.supportlpch.org/fundraiser/5997327.

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