

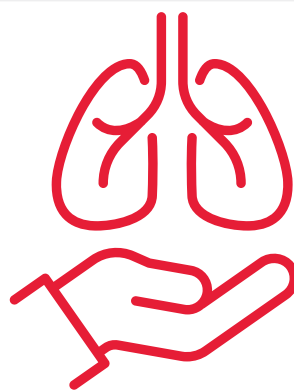
Cystic Fibrosis Center News

Lung Transplantation for Cystic Fibrosis in the Era of CFTR Modulators

—Cissy Si, MD

The availability of highly effective CFTR modulator therapy such as elexacaftor/tezacaftor/ivacaftor (Trikafta) and vanzacaftor/tezacaftor/deutivacaftor (Alyftrek) has been life-changing for many with cystic fibrosis (CF). These medications have improved the course of CF for many people, with increases in lung function, fewer pulmonary exacerbations, and an overall improvement in quality of life. The median life expectancy for someone with CF born after 2020 is now estimated to be 66 years, more than 20 years longer than in the era before modulator therapy.

One encouraging consequence of this progress has been a decrease in the number of people with CF who require lung transplantation, both in the United States and globally. This trend became apparent around the time of the COVID-19 pandemic, when Trikafta became available.



CF now accounts for less than 1% of lung transplant diagnoses performed annually, compared with approximately 10%–12% in prior years. This change has been particularly notable in children, and CF was once the leading indication for pediatric lung

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transplantation. Today, fewer than five children with CF undergo lung transplantation each year. This decline has contributed to a substantial decrease in pediatric lung transplant volumes worldwide.

This encouraging shift, however, does not mean advanced CF lung disease no longer exists. Approximately 10% of people with CF cannot use currently available modulator therapies, either because their CFTR variants are not eligible or because they cannot tolerate the medications. This is particularly relevant in California, where a higher proportion of people with CF have genotypes that are not eligible for the modulator therapies. Additionally, even in people who are modulator eligible, lung disease can still progress.

For these individuals, lung transplantation remains a life-saving treatment option. Signs of declining lung health, such as sustained decline in spirometry, progressive weight loss, increasing frequency of CF exacerbations, or complications such as hemoptysis, are important to recognize, as early referral to a lung transplant center is often preferred. This is especially true for children with CF who are not modulator eligible. It is worth emphasizing that

a referral does not mean lung transplant is imminent or inevitable. Rather, early evaluation gives the lung transplant team, CF team, patient, and family the opportunity to understand all available options and plan thoughtfully if the disease continues to progress.

For people who received a lung transplant years ago and are now eligible for the newer CFTR modulator therapies, there may also be a role for these medications in select circumstances. In particular, they may be considered for people with ongoing CF-related sinus or gastrointestinal disease. The use of these medications post-transplant should be individualized and carefully coordinated between the CF and transplant teams.

In summary, this new era of highly effective CFTR modulator therapy is an exciting time in CF care and has dramatically improved the disease trajectory for many people with CF. However, not everyone is eligible or responds positively. Continued monitoring of lung health and early recognition of disease progression remains important, and if indicated, early referral for lung transplantation remains essential.

“Approximately 10% of people with CF cannot use currently available modulator therapies, either because their CFTR variants are not eligible or because they cannot tolerate the medications. This is particularly relevant in California, where a higher proportion of people with CF have genotypes that are not eligible for the modulator therapies.”

Mental Health Matters: Navigating the Ebbs and Flows of CF

—Diana Naranjo, PhD

Living with cystic fibrosis (CF) involves much more than managing physical health. Treatments, appointments, medications, hospital stays, and the everyday responsibilities of CF care can take time and energy—and sometimes, they can feel overwhelming. It is normal for people with CF and their families to experience a wide range of emotions along the way. Paying attention to emotional well-being is an important part of caring for your overall health.

People with CF and their caregivers may experience periods of stress, worry, sadness, frustration, or feeling burned out. These are all a part of living with a chronic condition. As my mentor said, “They are expected, a normal side effect of living with complexity,” and over the decade of working in this space, I can confirm that there will be ebbs and flows in people’s mental health and ability to cope. Sometimes these feelings are temporary and improve when circumstances change. Other times, anxiety or depression can become more persistent and begin to affect sleep, relationships, motivation, school or work, or the ability to keep up with daily routines and CF treatments. Recognizing when you are struggling—and reaching out for support—is a sign that your mental health deserves the same attention as your physical health.

One helpful place to start is by checking in with yourself regularly. Ask yourself: How have I been feeling lately? Am I enjoying the things I usually enjoy? Am I feeling more worried, irritable, discouraged, or exhausted than usual? Caregivers can benefit from the same check-in. Supporting someone with CF



can be rewarding, but caregiving also comes with its own emotional demands. Making space for your own needs can help you continue to support the person you care about.

Small strategies can also help protect emotional well-being. Staying connected with supportive friends and family, getting enough rest when possible, spending time doing activities you enjoy, and building moments of relaxation into the day can all make a difference. Even a few minutes spent outside, listening to music, practicing slow breathing, journaling, or talking with someone you trust can provide a mental reset. The goal isn’t to eliminate every difficult emotion; it is to develop ways to cope with those emotions when they arise.

Most important, you do not have to manage mental health concerns alone. Your CF care team is there to support your whole health, including your emotional well-being. If stress, anxiety, sadness, or other concerns are interfering with daily life, consider talking with a member of your CF care team. They can listen, help identify

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Mental Health Matters...continued from page 3

resources, and connect you with additional mental health support when needed. Families and caregivers are encouraged to reach out for support as well.

Mental health can change over time, just

like physical health. Some seasons may feel manageable, while others may be more challenging. Checking in, speaking up when something doesn't feel right, and accepting support when you need it are all meaningful ways to care for yourself.

“You don't need to wait until things feel overwhelming to talk about mental health. Whether you're having a difficult week, adjusting to a change in your health or treatment routine, or simply want additional support, your CF care team is a good place to start the conversation.”

Pediatric CF Center Updates

Congratulations to Our 2026 CF Champion: Jacquelyn Spano, DNP, RN

Cystic Fibrosis Research, Inc. (CFRI) will honor Stanford's Jacquelyn Spano, DNP, RN, with its 2026 CF Champion Award at the A Breath of Fresh Air Gala on October 17, 2026.

Dr. Spano is being recognized for more than 30 years of groundbreaking contributions to cystic fibrosis care, newborn screening, and clinical trials at Stanford. CFRI highlighted her role as the architect of Stanford's CF Newborn Screening Program, as well as her work with international CF teams, including a multi-year collaboration with Rebagliati Hospital in Lima, Peru.



Please join us in celebrating Dr. Spano, our 2026 CF Champion!

Get tickets to the gala: <https://events.handbid.com/lp/cfri-2026-breath-of-fresh-air-gala/tickets>

Growing Skills, Growing Confidence: Your Child's Role in Their CF Care

—Elizabeth Gillespie, MSW, ACSW

As families are heading into a new school year, it comes with new teachers, new class assignments, and new expectations. Throughout the year, your child is able to adjust and adapt to the new responsibilities. Just as your child practices skills to increase their confidence in the classroom, there is much opportunity within the context of their CF needs to cultivate skills and independence. There will always be the irreplaceable role of parent and caregiver as your child develops; however, perhaps take time to think about one way you could support your child's independence with their daily CF care.

While it can seem a little scary to transfer more responsibilities from you, the parent, to your child, it is so important to prepare them for adulthood living with CF. Moreover, no kids are alike in their development or needs as they grow up. You know your child best, so please take these ideas for increasing independence as suggestions to tailor to your personal family as it best works for you.

For our little ones, let's say elementary school age, what are some ways you can involve them in their CF care? Is it having them tell you the names of the medications you are putting in their nebulizer? Maybe it is having them help you put a pill box together at the start of your week while explaining what each medicine does to help them. We know that it may feel like you go on autopilot to complete a lot of these tasks, but investing some extra time to include your child in the day-to-day can help increase their understanding and confidence.

Middle school is such an interesting time, when big concerns can include feeling accepted by your peers and trying to figure out your own identity apart from your parents. As a parent or caregiver, you might start to experience some pushback or resistance from your kid regarding CF care



when you may not have before. That's OK! Take some deep breaths, and try to remember that your kid is trying to find out who they are as an individual. This might be a good time to start to ask your preteen/teen what ways they want to engage in their care to support their autonomy.

While every child is different, this might be a good time for kids to start making a list of questions for the doctors or practice answering the team's questions during a clinic visit. You are always there as a safety net, but this is a great time to start building those muscles for independence!

For our teens who are in high school or getting ready to enter early adulthood, this can be an exciting time to have a dress rehearsal for their adult life! For teens who are able to, getting set up on their own MyChart account and practicing sending messages to the clinic is a great way to get comfortable taking more of a leading role. Or maybe it could be having your child listen in when you need to call the pharmacy. Perhaps increasing independence could even look like encouraging your young person to attend their 504 meetings

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at school so they are aware of the conversations surrounding their education and health. For teens, taking an active role in their own health care is a crucial step to promote confidence for the future. If the idea of this conversation feels daunting,

or you feel like you want to talk more about new ways to involve your child in their CF care, please talk to the clinic! Additionally, there are many resources out there to help give you some ideas for how to share the responsibility of your kid's CF care.

“Take a look at the CF R.I.S.E. website if you haven't already for some great ideas for milestones for your child (<https://www.cfrise.com/cystic-fibrosis-milestones>).”

Adult CF Center Updates

Dr. Yelizaveta Sher Honored with Ed Kinney Award for Service and Dedication to the CF Community



Dr. Sher accepts her award honoring her outstanding contributions to the CF community

Yelizaveta Sher, MD, the embedded psychiatrist with the adult team, is being honored by the Living Breath Foundation with the Ed Kinney Award for Service & Dedication to the Cystic Fibrosis Community.

This award acknowledges her extraordinary contributions to our community over the years. We are so proud and lucky to have Dr. Sher on our team!



Dr. Sher celebrating with supporters at the gala

CFRI's 39th National CF Education Conference

The Cystic Fibrosis Research Institute (CFRI) held its 2026 Annual Conference July 24–26 in Mountain View, California. This conference brought together people with CF, families, clinicians, and researchers for a weekend of learning, connection, and hope.

This year's theme, "A Wave of Progress," captured the momentum building across CF science.

The sessions, including CF and cancer, aging with CF and gene therapy, CF and reproductive health, CFRD, phage therapy, and sleep and mental health impacts, offered something meaningful for everyone in the CF community.

We are proud to share that Stanford was well represented at this year's conference:

Jake Brockmeyer, PharmD, BCPS, BCPPS, presented on drug–drug interactions and other important pharmaceutical considerations, sharing practical guidance on managing complex medication regimens for people with CF, including drug interactions, enzyme and vitamin optimization, and new mental health warnings added to CFTR modulator labels in 2026.

Celeste Riepe, PhD, and Ron Kopito, PhD, shared their research on pharmacogenomics and corrector-resistant CF, working to uncover why certain CFTR variants resist corrector therapies, with the goal of developing next-generation treatments for people with CF who cannot benefit from current options.



Saumel Perez Rodriguez, PhD, and Paul Bollyky, MD, PhD, presented cutting-edge research using phage-based technology to deliver CFTR gene therapy directly to lung cells, exploring a new way to deliver anti-inflammatory treatments directly into lung cells to help reduce the airway damage caused by CF.

Deborah Menet, LCSW, facilitated a support group for parents, caregivers, spouses, partners, and relatives of people with CF, bringing her compassion and clinical expertise to one of the most valued parts of the conference experience.

We are proud of our entire Stanford team for contributing to this important gathering and for sharing their knowledge and research with the broader CF community.

Couldn't make it? Catch up by watching the recordings at <https://www.youtube.com/@cfri.cureCF>.

A Research Study to Advance The CF Therapeutics Pipeline for People Without Modulators

The **REACH** study is an observational study for people with Cystic Fibrosis (CF) who are **not taking a CFTR Modulator Therapy**

Why is This Study Being Done?

- REACH study does not involve testing a drug
- The goal of the REACH study is to collect health information and specimens from people with CF who do not take CFTR modulators
- Researchers hope that these data may help design CF clinical studies and support the development of new treatments for people with CF who do not take CFTR modulators

Who is Eligible to Participate?

Anyone with a confirmed diagnosis of CF, who is 12 years of age or older, and not currently taking CFTR Modulator Therapy

What Will Participants Do?

Participants will be in the study for up to 12 months. This includes 4 study visits at research site.

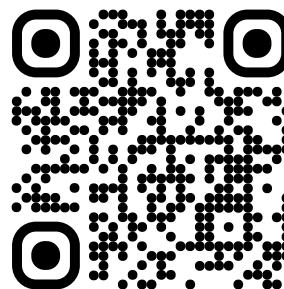
The **main study** includes:

- Blood collection at visits 1, 2 and 4
- Spirometry, questionnaires, height and weight measurements at all visits
- Every month at home, participants will complete home spirometry and fill out electronic questionnaires

Participants at selected study sites may also take part in additional procedures:

- Mucociliary Clearance Scan (to take images of your lungs) at visits 1 and 2
- Multiple Breath Washout (procedure to test how well your lungs can clear gas in the air) at all visits
- Additional blood collection to test immune responses at visits 1, 2 and 4

Visit REACH Study website to learn more:



<https://www.reachcfstudy.com/>

If You're Interested in This Research Study or Want More Information, Please Contact:

Name: Lani Demchak Phone: (650) 725-1087 or lldemchak@stanford.edu

Healthy Pasta With Butternut Squash and Sausage

Enjoy the flavors of fall with this comforting pasta dish! Tender butternut squash, browned Italian chicken sausage, spinach, onion, and Parmesan cheese come together for a delicious and wholesome meal. Simple, flavorful, and perfect for a cozy weeknight dinner.

Prep time: **5 min.** | Cook time: **30 min.**

Calories: **429 kcal per serving** | Servings: **4**

Ingredients

- 8 oz. pasta, measured uncooked
- 12 oz. chicken sausage, such as hot Italian, fully cooked, sliced
- Olive oil spray
- 1 medium onion, chopped
- 2 cups butternut squash, cubed
- 1 tsp. kosher salt
- 1 tsp. garlic powder
- 1/2 tsp. paprika
- 1/2 tsp. coriander
- Nutmeg, pinch
- 6 oz. spinach
- 1/2 cup chicken broth
- 1/2 cup Parmesan cheese
- 2 tbsp. fresh parsley for garnish

Instructions

1. Start by cooking your pasta in salted water. Be sure to follow the directions on how long to cook your specific pasta shape.
2. Reserve some of the cooking liquid for later to help bring the dish together.
3. Slice your chicken sausage, and add it to the pot with olive oil spray.



4. Sauté over medium heat for 5 minutes or until browned. Remove from the pot once browned. If using raw sausage, cook until fully cooked.
5. Add one chopped onion to the pot along with the cubed squash and spices. Sauté for 10 minutes until tender, not mushy.
6. Add spinach and the broth to wilt the spinach.
7. Add the cooked pasta back to the pot.
8. Stir in the Parmesan cheese. You can add some reserved pasta water (1/4 cup at a time) to help bring the dish together, or omit altogether.
9. Garnish with fresh parsley. Add salt and pepper to taste. Enjoy!

Nutrition

Serving: **2 cups** | Calories: **429kcal**
 Carbohydrates: **57g** | Protein: **32g** | Fat: **10g**
 Saturated Fat: **3g** | Polyunsaturated Fat: **1g**
 Monounsaturated Fat: **1g** | Cholesterol: **9mg**
 Sodium: **1533mg** | Potassium: **689mg**
 Fiber: **5g** | Sugar: **5g** | Vitamin A: **11716 IU**
 Vitamin C: **32mg** | Calcium: **247mg** | Iron: **3mg**
 Weight Watchers: **11 points**.

CF PFAC 2026 Financial Planning Resource

Are you interested in becoming more financially literate? Have you thought about your financial future? It's never too late to start planning, especially for people with cystic fibrosis.

The Stanford Adult CF Patient & Family Advisory Committee has got you! We did some homework to identify some resources for you to take control of your financial future. Here are some options for you:

- People with CF planning for retirement?
YES! This is the year 2026! Check out this [Retirement Calculator](#).
- The United Way [Planning for Your Future](#) site has lots of great information on financial basics like different types of accounts, how to live on your own, how to plan for retirement, how to afford a family, and more!

- CFRI produced a great podcast a few years ago: [Financial Planning & Cystic Fibrosis: Preparing for the Future](#). The speaker is a Stanford CF dad and financial planner, who gives tons of great advice on how to master personal finance.
- This short video from the CF Foundation ([Navigating CF: Financial Planning](#)) is a great starting point for thinking about balancing costs of CF with your other financial goals.

Did you know?? Your very own nurse coordinator Kristel Fallon is a nerd for finances! She recommends breaking down your personal financial management into three important categories:

1. Budgeting
2. Managing Debt
3. Saving

Here are Kristel's Finance Book Club recommendations!

- *I Will Teach You to Be Rich: No Guilt. No Excuses. Just a 6-Week Program That Works*, by Ramit Sethi
- *The Simple Path to Wealth: Your Road Map to Financial Independence and a Rich, Free Life*, by J. L. Collins

Current Research Studies at Our CF Center

Our team is actively conducting research across several exciting studies. If you or your child may be eligible, please reach out to the contact listed—we would love to tell you more.

Name	Brief description	Contact(s)
GDC-6988 (Genentech)	A Phase 1c open-label study evaluating an inhaled therapy for patients with muco-obstructive disease. Open to patients 18 and older with a CF diagnosis.	Jackie
NBSA Newborn Screening Accuracy Project	Collecting blood samples from patients with rare CF mutations to improve the accuracy of newborn screening tests.	Tina
REACH-OB-23	A longitudinal observational study collecting research-quality CF outcome data for patients 12 and older whose CFTR variant does not respond to modulators.	Lani
ReCode	A Phase 1/2 clinical trial of an inhaled mRNA gene therapy for patients ages 18–65 whose CFTR variant is not responsive to modulator therapy.	Lani
STOP PEDS	A randomized controlled trial comparing two approaches for treating pulmonary exacerbations in children with CF ages 6–18.	Tina

Cystic Fibrosis Center at Stanford

Pediatric providers at Lucile Packard Children's Hospital Stanford

Pediatric Center director: Carlos Milla, MD

Providers: MyMy Buu, MD; David Cornfield, MD; Lori Lee, 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, dietitians—

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

Linh Nguyen, MS, RD:..... (650) 736-6141

Social Worker :..... (650) 512-4438

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 pulmonary doctor..... (650) 497-8000

Pediatric providers at Emeryville

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

CF Clinic scheduling:..... (650) 724-8414

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

Nurse Coordinator—Anika Merryman, RN :..... (650) 724-8414

Respiratory Therapists—Lorraine MacPhee, RT:..... (510) 587-9631

Carol Journey, RT: (925) 239-2907

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..... (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, RCP: (415) 600-3424

Registered Dietitian—Elena Zidaru, RD:..... (415) 237-3671

Social Worker—Scott Plymale, LSW, PhD:..... (415) 237-1252

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, CCRC:..... (650) 498-8701

Lani Demchak, MBA: (650) 725-1087

Monica Elazar, DDS: (650) 723-5193

Cathy Hernandez: (650) 724-3474

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

Summer Scamper 2026—a Runaway Success!

Our Pulmonary and CF Center team had a wonderful time at the 2026 Summer Scamper, joining thousands of participants in celebrating community, pediatric care, and the research that makes a difference in the lives of children and families.

This year's event raised an incredible \$929,247—surpassing its fundraising goal and adding to a legacy of generosity that has now totaled nearly \$8 million for children's health since 2011. That is the power of a community showing up year after year.

Our CF team ran an active booth at the Family Festival, connecting with families and sharing what is happening in CF care and research right here at Stanford. A special thank-you to Wendy Chin, RN; Laura Banuelos; Liz Beken, RN; and MyMy Buu, MD, and the entire Emeryville CF team for representing our center with such

energy and heart. It was a joy to be part of such an exciting and meaningful event.

A heartfelt thank-you to everyone who walked, volunteered, donated, and cheered us on. Every step and every dollar bring us closer to a healthier future for our patients and families.

To learn about Summer Scamper and future events, visit the Summer Scamper website (<https://www.summerscamper.org/>).



Liz Beken, RN, Wendy Chen, RN, Laura Banuelos

Newsletter Contact Information

Editor: Lani Demchak, MBA

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](#).