

CYSTIC FIBROSIS CENTER NEWS

Fitness Made Simple

BY TAYLOR LEWIS BS, CSCS, CK-FMS, PES, SFG

"As a relatively healthy 54-year-old with cystic fibrosis, there is no doubt in my mind that a lifelong exercise habit has made a huge contribution to my longevity. Most of the research regarding CF and exercise focuses on aerobic activities like jogging or cycling. Certainly, conditioning work like this is important and has been shown to delay decline in lung function. But being strong and moving well has had a dramatic impact on my quality of life, and I think more emphasis should be put on these qualities. Taylor Lewis has designed an exercise program that I have been following for the last six months. He is an amazing coach, and has great ideas on how to make getting strong easy...really. You won't believe that his approach will work because it seems so simple, but trust me, it does. Take his 4-week challenge! You won't be sorry." – Julie Desch, MD, person living with CF

Working out should be fun. You should come away with each workout like you have achieved something, but not at the expense that your body needs multiple days to adequately recover. You do not need to work too hard during your workouts, nor do you need to feel guilty if all you did was get up and move a little. That is what this program is all about: six basic fundamental movements that can help you improve your overall fitness capacity. The concept is based upon completing every movement pattern (push, pull, hinge, squat, core, ground work, diaphragmatic breathing) each day, at an intensity that isn't taxing on your body, so you have efficient recovery in time for your next workout. "Well," you might say, "I thought you weren't supposed to work the same muscles every day?" Yes, but let me ask you a question: How do you get out of bed? What movements do you do to tie your shoes? The answer is: the same movements you do in the gym to get stronger. If you do these movements everyday, why aren't you doing them in every workout at the gym?

Now that I've got you thinking, let's begin.

For the next 4 weeks I am challenging you to try the fitness program below. If it doesn't work I will write a personalized

program based specifically on what you're trying to accomplish. However, if it does work I want you to spread the word so we can help take care of others who are looking to improve their quality of life.

Deal? Perfect I am glad we are on board.

I want you to complete six movements each day at home. It doesn't matter what time you do them, but make sure to get them done every day. If for some reason you miss a day, don't worry. Just hop back on board and keep moving along. Here's how this 4-week program will work each day: You will complete the workout two times through, and each week you will increase each exercises by one repetition. That's all—no bells and whistles, just simple and effective. So let's dive into the exercises and see how they fit together.

DIAPHRAGMATIC BREATHING

You will start on the ground with your feet at 90 degrees and placed on a wall. Squeeze a towel with the inside of your legs and focus on breathing in through your nose and out through your mouth. When you breathe in through your nose, your belly button should rise to the sky. When you exhale through your mouth your belly button should descend towards the floor. If this is hard for you to do put a shoe on your stomach and see if you can make it go up on your inhale and down on your exhale. Complete for 10 breaths.



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



SQUAT

Once you have finished with your breaths, stand up and place your feet hip to shoulder width apart and squat down as low as you can. Come back up pushing down through your heels and squeezing your glutes (butt) at the top. Complete for 5 repetitions.



PUSH UP

Descend back to the ground into a push-up (or plank) position with your hands slightly more than shoulder width apart and hands under your chest. Keep your glutes squeezed. Bend your elbows to lower your whole body down and back up. Complete for 5 repetitions.



PELVIC BRIDGE

Lie on your back and bend your knees. Tighten your stomach. Lift your pelvis by pushing down through your heels and squeezing your glutes at the top position. Then lower your back down to the floor and repeat. Complete for 5 repetitions.



PLANK

Roll back over onto your stomach and place your elbows under your shoulders. Place your feet together, squeeze your glutes and lift up, keeping your body in a straight line from tip of your head to your ankles. Then take five diaphragmatic breaths, breathing in through your nose and exhaling through your mouth. That will complete 1 set. Complete for 5 breaths.



BATWINGS

Staying on your stomach, bring your thumbs to your armpits and retract your shoulder blades together and hold for 1 second then descend back down and repeat. Complete for 5 repetitions.

This workout is simple enough to do every day. It won't take you long and it isn't hard, but it will work if done consistently. Remember, each week you will add only one repetition, so by the time you are done with this program you will have increased your repetitions by four each across the board.

WEEK 1

Diaphragmatic Breaths - 10 reps
Squat - 5 reps
Push Ups - 5 reps
Pelvic Bridge - 5 reps
Plank - 5 reps
Batwings - 5 reps
Repeat

WEEK 2

Diaphragmatic Breaths - 11 reps
Squat - 6 reps
Push Ups - 6 reps
Pelvic Bridge - 6 reps
Plank - 6 reps
Batwings - 6 reps
Repeat

WEEK 3

Diaphragmatic Breaths - 12 reps
Squat - 7 reps
Push Ups - 7 reps
Pelvic Bridge - 7 reps
Plank - 7 reps
Batwings - 7 reps
Repeat

WEEK 4

Diaphragmatic Breaths - 13 reps
Squat - 8 reps
Push Ups - 8 reps
Pelvic Bridge - 8 reps
Plank - 8 reps
Batwings - 8 reps
Repeat

Good luck! I would love to hear how the workouts worked for you. Please send me your feedback at tlrlewis@gmail.com.

Hydration Tips for Cystic Fibrosis

BY MICHELLE STROEBE, MS, RD

With its beautiful climate year-round, California is a great place to play outside. Physical activity, including outdoor sports, can be extremely beneficial to people living with cystic fibrosis, helping to improve lung function, muscle building, and overall endurance. Additionally, participation in physical activity helps to regulate appetite naturally and can be helpful in maintaining a healthy weight. The benefits of physical activity and outdoor play depend on staying well hydrated.

Fluid accounts for approximately 60 to 75 percent of our total body weight, as every cell in our body requires fluids for various vital functions. People with CF lose salt and excess fluid through their sweat in greater quantities than the average adult, especially when participating in physical activity. Proper hydration when participating in outdoor activities is the best way to prevent dehydration and its ill effects, some of which include: headache, fatigue, weakness, vomiting, drowsiness, loss of appetite, and constipation. Simply drinking when you are thirsty is not a primary defense method against dehydration, because people with cystic fibrosis have decreased thirst sensation due to excessive loss of sodium. The bodies of those with CF do not store extra water; therefore, one must carefully replace what is lost each day.

Replacing salt and fluids lost through sweat during activity is very important. Your dietitian can help you figure out your specific fluid needs based on your age, activity level, weight, and climate. Be aware that, while plain water is a great source of hydration, electrolyte-containing beverages are best to replace losses when exercising for more than 30 minutes.

Before starting your next activity, take a moment to think about the importance of fueling your workout with proper hydration to avoid dehydration. There are many sports drinks on the market that contain glucose (sugar), salt, and water that are perfectly appropriate. However, if you would like a delicious, healthy alternative to the sports drinks on the market, check out the recipes to the right.



Summer Hydration Recipes

Watermelon Coconut Water

1 cup watermelon, cubed
1 cup coconut water
Fresh lime juice to taste
1/8 teaspoon salt
Blend together

Lemon-Lime Sports Drink

¼ cup of fresh squeezed lime juice
¼ cup fresh squeezed lemon juice
1½ -2 cups filtered water (or coconut water)
1/8 teaspoon of sea salt
1-2 tablespoons sugar/honey/aguave/maple syrup (to taste)
1/8 teaspoon salt
Blend together

Strawberry Recovery Drink

2 cups filtered water
½ cup orange juice
2 teaspoons honey/sugar/aguave (to taste)
¼ teaspoon salt
Approximately 10 medium strawberries

Mix all ingredients in a large container and chill in the fridge for at least 5 hours (overnight is preferred). Strain liquid to remove the berries, or puree if you prefer a thicker drink. Enjoy!



Orkambi and the Advent of Combination CFTR Modulator Therapy

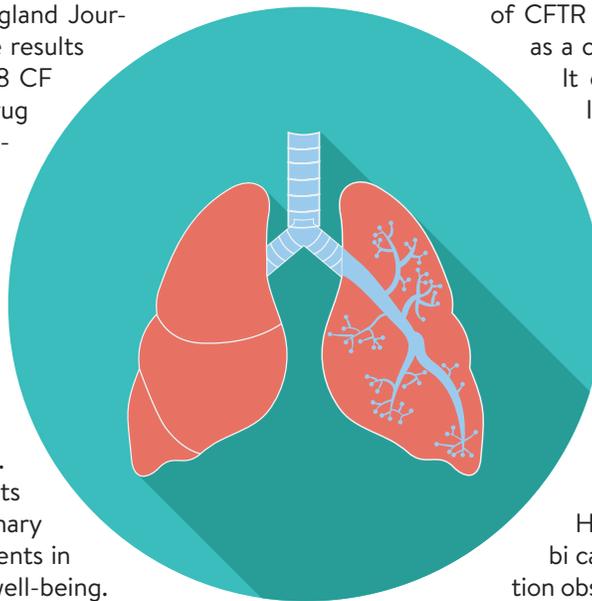
BY RICHARD MOSS, MD

On May 17, 2015, the New England Journal of Medicine published the results of two landmark trials in 1,108 CF patients of the first combination drug therapy aimed at reestablishing function of F508del CFTR. The paper by Claire Wainwright and colleagues reported that a two drug combination of the CFTR modulators lumacaftor and ivacaftor (brand name Orkambi, Vertex Pharmaceuticals) improved lung function, as measured by absolute FEV1 percent predicted, by about 3 percent versus placebo over a 24-week study period. Additionally, Orkambi-treated subjects had a substantial reduction in pulmonary exacerbations and showed improvements in nutritional measures and subjective well-being. Orkambi was well tolerated; although some patients complained of shortness of breath or tightness beginning treatment, very few needed to discontinue it. Follow-up information on Orkambi presented at the European CF meeting in Brussels in June showed the initial benefits of Orkambi are also maintained at least one year. FDA approval of Orkambi, which had been recommended by an expert Advisory Panel convened by the agency earlier in the year, came on July 2. Orkambi costs \$259,000 per patient per year.

What does this mean for the CF community? There are several crucially important aspects of this major advance in CF therapy to consider.

First, this product has only been shown useful in people homozygous for the F508del CFTR mutation (i.e., carrying two copies of this mutation, one inherited from each parent). This genetic cause of CF is the most common, affecting about 50 percent of all people with CF in the world. People with a compound heterozygous form of CF (i.e., one F508del mutation combined with another CF-causing mutation, affecting another roughly 40 percent of people with CF) did not respond in an earlier, smaller, shorter clinical trial of Orkambi and thus were not included in the pivotal trials. (And another, prior trial had shown that lumacaftor alone did not improve clinical status in people with homozygous F508del CF).

Second, the clinical effect of Orkambi on homozygous F508del CF is much more modest than what we've seen as the effect of ivacaftor alone (brand name Kalydeco) on gating mutation CF (the most common gating mutation, G551D, only affects about 4 percent of people with CF). The average lung function improvement in G551D CF over the same 6-month time period is 11 percent, and much bigger impacts on nutritional and other systemic measures have been seen and maintained indefinitely. Kalydeco works as a CFTR potentiator (i.e., boosting the function



of CFTR already placed in the cell membrane as a chloride and bicarbonate ion channel). It costs \$311,000 per patient per year. It is currently FDA-approved for nine further mutations sharing gating defects with G551D (including R117H) down to age 2 years. Almost everyone with severe gating mutation CF responds to Kalydeco, while only about 25 to 50 percent of F508del homozygous CF people clearly respond to Orkambi. This means that some people prescribed Orkambi may not show improvement in lung function, at least over the initial months of treatment. However, it does not mean that Orkambi cannot reduce the decline in lung function observed over years to decades in people with CF, which could come from a continuous effect on the lungs and/or simply by reducing exacerbation rates over time. The evidence for or against that critical outcome will not be known for a long time, and the methods to evaluate it are necessarily less rigorous than randomized, double-blind, placebo-controlled trials like those reported by Wainwright et al. Only time will tell. In the meantime clinicians and patients may be drawn into conflicts with medical insurance plan payers over the benefit-cost merits of Orkambi.

Precision medicine, the current favorite of both academy and industry, looks so far to be carrying a budget-busting price to society, as drugs are targeted in a new way to extremely well-defined and smaller groups of people within known disease entities.

Therefore, third, can more effective ways to fix F508del CF be found? Currently Vertex is conducting late phase clinical trials of a lumacaftor successor molecule called VX-661 given in combination with ivacaftor. VX-661 is similar in action to lumacaftor as a CFTR corrector (meaning a drug capable of improving the cell's ability to produce and direct CFTR to the cell membrane by binding to CFTR during its synthesis) but it has some advantages, in particular regarding fewer drug-drug interactions that include allowing a lower ivacaftor dose. But a significant potential hurdle was identified last year when two groups independently found that ivacaftor has a two-edged interaction with lumacaftor (and probably VX-661), in that the good effect of boosting chloride channel function of CFTR on the cell membrane is to some degree counterbalanced by a bad ivacaftor effect on the stability

Orkambi story continued from page 4

of lumacaftor's improvement of CFTR packaging and transport from where it is made deep within the cell to the cell surface. Most scientists and CF clinicians, however, expect the addition of a second corrector (or another type of drug) in a triple drug combination with a corrector and potentiator, rather than a simple "upgrade" of a single corrector, will be needed to make the next big jump in efficacy. Trials of triple-combo therapy can be expected as early as next year.

This brings us to the final aspect of the new molecular era of CF therapy, a socioeconomic and ethical quandary of a new order of magnitude. Orkambi, like Kalydeco, is extraordinarily expensive. It is one thing for third party payers to cover the \$311,000 per patient annual cost of Kalydeco for fewer than 5 to 7 percent of CF patients and another for them to cover the \$259,000 per patient annual cost of Orkambi for 50 percent of CF patients. What will the next generation, say VX-661/Kalydeco, or a triple combo, cost? Price correction through market mechanisms (i.e., competition) may well eventually come, but not in the near future, and with uncertain impact. How will the health care system bear this

cost? Is there a role for providers, patients and government in this equation, or is it simply a battle in the marketplace between drug producers, distributors and payers? Who will ensure equitable access, and how? Precision medicine, the current favorite of both academy and industry, looks so far to be carrying a budget-busting price to society, as drugs are targeted in a new way to extremely well-defined and smaller groups of people within known disease entities. It seems fundamentally unsustainable. Here, in health economics and social justice as in science and medicine, CF, for better or worse, seems again to be leading the way.

Further reading:

Davis PB. Another beginning for cystic fibrosis therapy. New England Journal of Medicine, 2015 July 16, volume 373 (number 3), pages 274-6.

Ferkol T, Quinton P. Precision medicine: at what price. American Journal of Respiratory and Critical Care Medicine, 2015 Jul 24, Epublication ahead of print.

The Cystic Fibrosis Parent Advisory Council BY KIRSTEN MCGOWEN

Cystic Fibrosis Parent Advisory Council: What Do You Need? We Can Help!

The CF Parent Advisory Council seeks to address the needs of all families seen at the Pediatric CF Clinic at Lucile Packard Children's Hospital Stanford. We have some exciting changes to report, which are happening within both the CF Clinic and the Council.

1. A Psychologist Is Available for CF Patients, Families and Caregivers

Diana Naranjo, PhD, will be providing support for CF families. She has expertise in caring for children and adolescents with chronic illnesses and speaks both English and Spanish. If you are interested please ask your physician for information on how to schedule an appointment at your next clinic visit.

2. Complementary Alternative Medicines and CF

These days we are flooded with options for alternative medicine, which can range from exercise, dietary supplements, breathing exercises, stress-relief techniques, acupuncture and even essential oils. It can be hard to know what's useful or safe, especially when related to CF. If you have questions regarding specific alternative medicines or curious to learn more about it, John Mark, MD, is here to help you navigate and educate what might be best for your family. Consult with your team if you have questions about alternative medicines or schedule an appointment with Dr. Mark directly.

3. New Educational Material for CF Binders is here!

The Parent Advisory Council has developed some new educational material for the CF binders. We recently completed an informational sheet regarding Spirometry and Pulmonary Function Testing (PFT). It contains great info on what spirometry data tells you: what does an FVC measure? What does FEV1 mean? Look for these to be distributed at clinic in the upcoming weeks. We are also working on handouts for Nutrition and Infection Control in Public (CF travel tips, places to avoid, how to be prepared).

4. Recipes, Recipes, Recipes

We post a NEW recipe on our Facebook page each week! Recently it was Raspberry Crumble Bars and Blueberry Bonanza Smoothies – YUM! Not on social media? Check out the Stanford CF Center website for a collection of all posted recipes: <http://med.stanford.edu/cfcenter/services/Nutrition.html>

If you have input for the CF Parent Advisory Council, please email Kirsten McGowan, Co-Lead Parent, at kmcgowan@stanfordchildrens.org

New Staff Members:

New Pediatric Staff Member



Wendy Valencia graduated from Everest College in 2009 in Medical Assisting (MA). She worked for Lucile Packard Children's Hospital Stanford for two years as a medical assistant in the Pediatric Pulmonary/CF Clinic and as the temporary Patient Service Coordinator for six months while her co-worker was out on maternity leave. Wendy became very interested in learning more about CF, and in July was given the opportunity to work with the research team. She is very excited to begin her new career.

Wendy has two children Andrea (6) and Andrew (2) and loves spending time with them, especially Sunday dinners at home with her entire family.

New Adult Staff Member



Julian Liang is originally from Princeton Junction, NJ, and lived there until she left for college in Philadelphia, PA. She completed a dual degree program at the University of Pennsylvania in 2011 and received her Bachelors in Nursing and Bachelors in Economics (Wharton School, concentrating in Healthcare Management and Policy). After graduating, Julian moved to Atlanta, GA, and started her nursing career as an inpatient cardiac nurse. In 2014, she ventured into travel nursing and worked as a cardiovascular travel nurse in Tacoma, WA, and in San Francisco, CA. While she was in San Francisco, Julian worked at UCSF Medical Center on a cardiac, vascular, and thoracic surgery unit, which sparked her interest in working with pulmonary patients. She's also a part-time student at UCSF studying for her Masters of Healthcare Informatics.

Although she doesn't have a personal experience with CF, Julian is passionate about working with individuals with genetic disorders as her younger sister has Down syndrome. She loves living in the Bay Area and is excited to be working as a nurse coordinator at the Chest Clinic along with Ronni Wetmore and the rest of the Stanford team.

Pediatric CF Center Update BY MARY HELMERS, RN

HELPFUL REMINDERS

Parents and patients, please remember to carry your CF Passport in your wallet. Last November we sent the passports to you by mail. If for any reason you do not have one or need a replacement, please ask for one when you come to your next clinic appointment. We now have them in English and Spanish.

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

PRESCRIPTIONS: Just a reminder that your prescription request can take up to 72 hours to be processed. This has always been our policy, however, we strive to turn them around sooner. Please keep in mind that even after we send the scrip to the pharmacy, it may still take another 48 to 72 hours for the pharmacy to process (especially mail-order pharmacies). It is important for you to stay on top of your refills and request them at least one week before you are due to run out.

Helpful hints for requesting refills:

- Call your pharmacy first to find out if you have refills
- If you have a refill...Great! Then they will process
- Your pharmacy should call us if you have no refills

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

ANNUALS: Our goal is to complete all annual testing on or around your child's birthday. Included in the annuals are your child's lab work including oral glucose tolerance test (6 years of age and older), CXR, bone density scan (12 years of age and older), full PFTs, Baseline Audiogram (starting at age 6). Please let us know if you have not had any of these tests done with your annuals.

WEAR YOUR MASK: We ask all CF patients to wear masks when coming to or from the clinic or hospital and/or walking outdoors as Stanford Medical Center construction is ongoing. Available at our front desk or from any CF team member, these turquoise-colored masks have smaller filters, which allow for more protection. They should fit snugly around the nose and mouth.

Lastly, with all the exciting research being done in CF, new drug advances for CF patients are genotype specific. We need to have copies of all our CF Center patients' Genotype/Sweat Chloride test results. If you have a copy of your original result, please bring it with you to your next clinic appointment. If your child had these tests done at an outside lab or another CF Center, please contact that provider and ask them to fax results to (650) 497-8791 ATTN: Mary Helmers, RN, Pediatric CF Coordinator. We will have patients re-genotyped if there is no documentation on file. Thank you for your help with this task.

Adult Cystic Fibrosis Center Update

BY RONNI AW WETMORE, RN, MS

WELCOME

Meredith Wiltse, ARNP, joined the Adult CF Team and the Pre and Post Lung Transplant Team in March. Meredith is a welcome addition to Stanford, with an interesting background. Look for her biography in the next CF newsletter. Julian Liang, RN, BSN, BSE, joined the CF Team as Co-Coordinator of the Adult CF Center. Julian comes to Stanford from the East Coast where she worked as an in-patient Cardiology nurse. The CF team is happy to have Julian with us. Please read her biography in this issue.

CYSTIC FIBROSIS NURSE COORDINATOR NOTES

We are happy to have two full time CF Coordinators. This enables us to answer phone messages, refill orders and complete medication Prior Authorizations in timely manner. We also now have a Coordinator available by phone from 8am until 5:30pm, Monday through Friday. Please allow a minimum of 48 hours for prescription refills, and 72 hours if your prescription will require a prior authorization. We make every effort to answer all phone calls and messages daily, but no later than end of the next business day.

If you need to schedule a CF Clinic appointment, please call Dulce Moreno at (650) 736-5400.

ORKAMBI UPDATE

Orkambi is the newest prescription medication approved by the FDA for the treatment of CF patients age 12 years and older and is targeted towards those who have two copies of the F508Delta mutation in their CFTR gene. This medication is a combination of ivacaftor and lumacaftor, and is dispensed in pill form. The Stanford Adult CF Team is excited about the availability of this medication, which has shown good promise in decreasing CF exacerbations and increasing lung function. We have reviewed our records and have sent letters to those patients in our adult program who are eligible for this medication. We are currently meeting with those eligible patients on an individual basis to discuss requirements necessary to receive this medication as well as possible medication interactions and the monitoring of ongoing lab tests that will be required.

Current Research Studies

CURRENT STUDIES:

- Vertex 661 Open Label extension** – For F508/F508 patients, looking at video endoscopy – Enrollment closed
- OPTIMIZE** – For treatment of newly acquired Pseudomonas PTC study – Enrolling early now for Stop mutations
- Lung CT study** – Enrolling now, young children
- Vertex 809-11B** – Safety study in children with F508/F508 – Enrollment closed
- ProQR study** – Enrolling now for F508/F508 adult patients
- Prospect** – Enrolling this summer, Observational study for healthy normal people and CF patients
- SHIP** – Use of Hypertonic saline in children - Enrolling children now
- Vertex 661-108** – 661 in combination with Ivacaftor – Enrolling now (for limited number of genotypes)
- CF Pulmonary Exacerbation study** – recruiting adults and pediatric patients

UPCOMING STUDIES:

- Vertex 809-109** – Lung clearance index in children 6-12 years with the F508/F508 mutations. (Blinded study with Vertex 809 and 770 combination therapy)
- Celtaxsys** – Anti-inflammatory study
- Alcreata** – Feeding tube study
- Elctro-Flo500 Home use study** – Device study enrolling Winter 2015
- Nivalis** – Upcoming Winter 2015

CF Center at Stanford
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Stanford Adult Cystic Fibrosis Advisory Council



The adult advisory council is busy working on several exciting projects which include: peer-to-peer mentoring for individuals seeking one-on-one support; the Return to Clinic Form, developed by the council to help streamline the clinic check-in process; and lastly, collecting real life stories that will be rewritten (to protect confidentiality) and then utilized to help clinic staff learn from these individual experiences. If you are interested in participating on the council, we are always looking for new members and would love to have you join us. For more information please go to <http://cfcenter.stanford.edu/acfac/>

CYSTIC FIBROSIS CENTER AT STANFORD

Pediatric Providers at Lucile Packard Children's Hospital Stanford: Carlos Milla, MD, Pediatric CF Center Director; Sumit Bhargava, MD; My My Buu, MD; Carol Conrad, MD; David Cornfield, MD; Susan Gage, MD; Richard Moss, MD; Terry Robinson, MD; Nanci Yuan, MD; and Jacquelyn Zirbes, DNP, RN, CPNP

Clinic Scheduling (650) 724-4788
Clinic and Prescription Refill FAX (650) 497-8791
Erica Oliva, Patient Services Coordinator (650) 498-2655
Mary Helmers, Nurse Coordinator (650) 736-1359
Liz Beken, CF Clinic Nurse (650) 736-1359
Kristin Shelton, Respiratory Therapist (650) 724-0206
Julie Matel, Nutritionist, Dietitian (650) 736-2128
Sruthi Veeravalli, Social Work (650) 736-1905
Jacquelyn Zirbes, Newborn Screening Coordinator (650) 721-1132

FOR URGENT ISSUES:

Monday-Friday, 8 am to 4 pm, contact RN Coordinator (650) 736-1359
All other times, for children's needs, call (650) 497-8000 (Lucile Packard Children's Hospital main number)

ADULT PROVIDERS AT STANFORD:

Paul Mohabir, MD, Adult CF Center Director; David Weill, MD; Gundeep Dhillon, MD; Jennifer Cannon, NP, Kelly Johnson, NP, Megan Kneemiller, NP, Elika Rad, NP, Laura Starr, NP, Meredith Wiltse, NP

Clinic Scheduling (650) 736-5400
Adult CF Center FAX (650) 723-3106
Ronni Wetmore, RN, MS Nurse Coordinator (650) 498-6840
Julian Liang, RN, BSN, BSE Nurse Coordinator (650) 498-6840
Carol Power, Respiratory Therapist (650) 736-8892
Michelle Stroebe, Registered Dietitian (650) 721-6666
Meg Dvorak, Social Work (650) 518-9976

URGENT ISSUES:

Monday-Friday, 8 am to 5 pm: call nurse coordinator
Monday-Sunday 5pm to 7am: (650) 723-4000 and ask for the Pulmonary Fellow on-call
Saturday-Sunday 7am to 5pm: (650) 723-4000 and ask for the Adult CF Ghost Pager

REFILL REQUESTS:

Please submit your request to your pharmacy and allow 2 weeks advance notice. For urgent requests, call the coordinator line or send a message via MyHealth.

RESEARCH:

Colleen Dunn, Zoe Davies, Sean Ryan, Wendy Valencia (650) 736-0388

Visit our website at <http://cfcenter.stanford.edu> for more information about our center and CF.

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

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