

Cystic Fibrosis Center News

Update on Cystic Fibrosis and COVID-19

—Richard Moss, MD

In our Summer 2020 CF Center News, I gave a report on the status of the cystic fibrosis (CF) community as it appeared in what we now would call the early days of a pandemic that shows little sign of quitting, although we have solid evidence of light at the end of the tunnel with the availability of extremely safe and effective SARS-CoV-2 vaccines. Here I will try to bring us up to date, focusing on four topics of particular current interest: frequency and clinical impact of COVID-19 in CF; the vaccines; significance of SARS-CoV-2 variants; and long-haul COVID-19.

COVID in people with CF

According to data from the Cystic Fibrosis Foundation, as of March 18, 2021, there were

1,303 confirmed cases of COVID-19 reported by CFF Center network, including 386 children below 18 years of age. Of these, 210 (16.1%) required hospitalization, 39 of which were in children. However, only 13 patients, all adults, had died (1.0%). Quite similar data have been obtained from a consortium of European CF Centers organized by the European CF Society. As of March 8, 2021, they had reported 1,126 cases (886 confirmed by diagnostic tests), of whom 206 (18.3%) were hospitalized and 13 had died (1.1%). These data suggest that COVID-19 continues to affect people with CF no worse and perhaps less than

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the general population. The CF community has thus continued to respond well to the pandemic, likely because of high adherence to public health measures in reducing exposure to respiratory pathogens. In sharp contrast to our society at large, basic infection-control measures were accepted and ingrained in our CF community long before we ever heard of SARS-CoV-2, and thus the full panoply of measures needed this past year apparently have been very widely adopted and maintained. A serendipitous “side effect” of the pandemic for CF patients documented in the 2020 CFF Patient Registry has been a reduction in non-COVID-19 as well as COVID-19 respiratory illnesses, as reflected in reduced numbers of pulmonary exacerbations, whether defined by hospitalization or use of home IV antibiotics. (This drop in exacerbations is additional to a large, beneficial Trikafta effect seen since its approval in 2019.)

Research into possible protective effects against COVID-19 in people with CF has begun. At present, no firm answers are available, but speculation has arisen on a number of factors that may be relevant. These include, besides social distancing and infection-control public health measures like use of face masks: a younger age distribution than in the general public, less frequent high-risk comorbidities (e.g., obesity, hypertension), certain chronic medications (e.g., azithromycin, dornase alpha), and a variety of potential biological mechanisms such as airway fluid pH or content of molecules affecting SARS-CoV-2 entry into cells (the ACE2 receptor for the virus, certain enzymes called proteases that can affect viral entry).

It should be noted, however, that probable increased risk factors within the CF population may be identified, in that of the 13 American CF patients who have died from COVID-19, eight had received lung transplants and two had advanced lung disease. CF care providers have responded to the pandemic in additional ways, such as adopting a number

of measures to maintain social distancing in the health care setting. These include, besides universal use of protective personal equipment (PPE) for encounters, substituting telehealth for some clinic visits, increasing use of home-based health assessments such as home spirometry and sputum culture collection, and pausing certain clinical research trials. The longer-term duration and impact of these changes in health care practices remains to be seen, but some are likely to stick. Other practices within CF Center facilities and staff have also changed—for example, installation of high-efficiency air filters in clinic rooms; doing fewer aerosol-generating procedures, such as use of nebulized medications; and adding further infection-control measures, such as pre-visit symptom questionnaires and in some situations temperature checks or further diagnostic testing.

Vaccines

The success of COVID-19 vaccine development has been a singular triumph of human ingenuity, focus, and cooperation. It offers a truly inspiring example of our capacity to accomplish great beneficial undertakings together. Although a year of social distancing has indeed been challenging, the ability to discover the way to stop SARS-CoV-2 and use the most advanced biological science to develop and deploy completely new types of vaccines that are very safe and highly effective is amazing. Since December, the Food and Drug Administration (FDA) has approved three vaccines for use under its Emergency Use Authorization power. Two of these, from Pfizer and Moderna, use new mRNA-lipid nanoparticle technology, while the third, from Johnson & Johnson, is also based on advanced but distinct cloned DNA-viral capsid technology. The mRNA vaccines require two doses given three to four weeks apart to produce maximal protective effect, while J&J is a single jab. Because mRNA is less stable than DNA, the mRNA vaccines require cold storage,






somewhat complicating their distribution. But in order to vaccinate the entire world's 7 billion to 8 billion people, many more vaccine sources will be needed. It is a staggering reality that currently 78 different vaccines for COVID-19 are being tested in clinical trials around the world, with 22 in pivotal late-stage trials, and another 75+ vaccines are in preclinical development.

Perhaps the most important fact to keep in mind about the available vaccines is their ability to almost completely prevent serious illness and death from COVID-19. The table shows a summary of design technology (platform), lab and animal studies, and pivotal clinical trial results for the three currently available vaccines in the United States (Moderna, Pfizer, Johnson & Johnson), as well as

two more (from Astra-Zeneca and Novavax) that may be approved by summer. Other COVID-19 vaccines made in China, Russia, Europe, and India are also being used outside the United States.

What is less clear is how well the vaccines shut down transmission—i.e., including asymptomatic or mild infection (early data suggest perhaps 70%–80% reduction) as well as serious disease—and this underlies public health experts' ongoing recommendations for maintaining social distancing and other health measures like wearing masks indoors at least until we have more solid data on transmission control after vaccination and vaccination rates approach what is needed for herd immunity, currently

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Company	Platform	Doses	Non-clinical results	# Who got vaccine	Protection from hospitalization from COVID-19	Protection from COVID severe dz (some at home)	Efficacy against milder COVID
 moderna	mRNA-1273 mRNA in lipid nanoparticle	2	Neutralizing abs; Strong Th1 CD4+, CD8+; protection from challenge (macaques)	~15,000	97% (1 in vaccine arm after 1st dose hospitalized)	97% (30 cases in placebo arm; 0 in vaccine reported but 1 severe per FDA)	94.1%
 Pfizer	BNT162b2 mRNA in lipid nanoparticle	2	Neutralizing abs; Strong Th1 CD4+, CD8+; protection from challenge (macaques)	~18,600	100%	100% (9 cases in placebo arm; 0 in vaccine—1 initially severe but not)	95%
 Johnson & Johnson	JNJ-78436725 non-replicating human adenovirus/DNA	1	Neutralizing abs; Strong Th1 CD4+ > Th2; CD8+; protection from challenge (macaque)	~22,000 US, Latin America, S. Africa	100% (7 deaths; 16 hospitalizations all in placebo)	85% across 3 sites (89% in S. Africa—95% of strains 501Y.V2)	72% US; 66% Latin America; 57% S. Africa (95% B.1.351)
 AstraZeneca	AZD 1222 non-replicating chimp adenovirus-DNA	2	Neutralizing abs; Strong Th1 CD4+ > Th2; CD8+; protection from challenge (macaques)	~8,588	100%	100% (15 in placebo —all hospitalized; 0 in vaccine)	70% overall; 76% 1 dose; S. Africa trial halted for mild
 NOVAVAX	NVX CoV2373 Spike protein/ RBD + Matrix M adjuvant	2	Neutralizing abs; Strong Th1 CD4 > Th2; protection from challenge (macaque)	~9,700 (Phase 3 UK; 2b SA)	100%	100% (but only 1 severe in placebo; 0 in vaccine)	96%; 89% B117 UK; 60% SA (94% B.1.351)

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estimated to require 75%–90% of the population. As of March 19, 74 million Americans had received at least a single vaccine dose, but this still represented only 22% of the population.

While vaccines are currently approved for ages 16 (Pfizer) or 18 (Moderna, J&J) and up, pediatric studies are underway, including a Moderna trial enrolling infants as young as 6 months old. Over 3.2 million children in America have been diagnosed with COVID-19, and while children largely fare much better than adults, at least 266 children have died.

“What has been somewhat surprising over the year of the pandemic is the number of mutations discovered that may affect COVID transmission, infection, or illness severity.”

Variants

Natural selection, the engine of evolution, ensures that some mutations that arise from viral replication errors may increase survival fitness of the virus, and indeed that is the case with SARS-CoV-2. What has been somewhat surprising over the year of the pandemic is the number of mutations discovered that may affect COVID transmission, infection, or illness severity: These have been labeled “variants of concern.” They are identified by sequencing the viral genome and comparing that with the original SARS-CoV-2. The United States is playing catch-up with genome sequencing of clinical COVID-19 samples, but more and more of this is occurring as we realize its importance. It is thought that some of these variants may have arisen in immunocompromised people with prolonged COVID-19 infection and viral shedding, as this would give the virus more time to evolve within its human host. Most, but not all, of these mutations in variants have occurred in the spike protein, which is the handle that the virus uses to grasp hold of a

cell and enter it so it can replicate, and in particular the “receptor binding domain” of the spike that directly engages its ACE2 receptor portal of entry.

The earliest variant of concern, the D614G spike mutation, was identified back in March 2020 and by summer 2020 had become the dominant SARS-CoV-2 strain around the world, based, it is thought, on its increased infectivity. The nomenclature of newer mutations or variants is difficult, so the media often refer to the place where a variant is first identified, such as the “UK variant” termed B.1.1.7 that includes an N501Y spike mutation thought to drive increased transmission, one of eight mutations in that variant’s spike protein and 17 mutations overall. B.1.1.7 shows increased community transmission rate that dovetails with lab data showing increased binding to cells, replication, viral load. We now know from UK studies that B.1.1.7 also increases COVID-19 disease severity and lethality, compared with the original strain. Recently B.1.1.7 has become the dominant strain in the United States. Another variant, B.1.351 or 501Y.V2, first found in South Africa, has 10 spike mutations (21 overall), including N501Y and several other mutations affecting cell binding; a mutation in it of particular interest, E484K, seems, like N501Y, to be involved in resistance to neutralizing antibodies evoked by natural infection or vaccination. A variant from Brazil called P.1 or 501Y.V3 shows 17 spike mutations also including N501Y and E484K. In California, the Cal 20C or B.1.427/B.1.429 variants have spike mutations including one, L452R, that also may be significant. In the New York metro area, hit so hard last spring, fear is growing about a variant called B.1.525 that includes E484K as well as another increased binding spike mutation, S477N, that may increase transmission. As variants of concern have tended to rapidly dominate the regions from which they were first described and quickly spread globally, red flags are being raised

about new surges based on increased transmission, contributing greatly to a sense of urgency about stepping up the pace of vaccinations.

Worries have focused on how some of these variants may decrease vaccine efficacy, based on test tube studies showing reductions of neutralizing antibody capacity in vaccines tested against them. However, data so far are reassuring that the levels of antibody after vaccination still seem adequate to afford protection, both in the test tube when compared with a hypothetical threshold level correlating with protection against illness and, crucially, when rates of serious (hospitalized/fatal) COVID-19 cases are tracked. This protection seems likely to last at least several months if not longer. Also, and very importantly, preliminary evidence indicates that the T-cell response, the other big gun of the immune system, is robust even against the variants in vaccinated people. At this time, performance of individual vaccines against the variants is difficult to compare with others, as, for example, the Pfizer and Moderna mRNA vaccines were field-tested in the United States in spring–summer 2020 before the emergence of these variants of concern, while testing in South Africa and Brazil has mostly involved different vaccines (e.g., Johnson & Johnson, Astra Zeneca, and Novavax) as variants were rapidly rising to dominance.

Currently, the most important point is to get fully vaccinated as soon as possible with whatever vaccine is most available, in order not only to personally protect yourself but also to help your community stave off a potential variant-related surge.

As we learn more about variant escape from vaccine protection, modification of current vaccines to address variants is relatively easy to accomplish. In fact, several such modified vaccines have already entered clinical trials.

We do not yet know if periodic boosting with original or modified vaccines will be necessary to keep COVID-19 controlled, but it would hardly be surprising if this turned out to be the case, similar to how we use periodic vaccination to control seasonal and epidemic influenza.

Long-haul COVID

As time has passed since the onset of the pandemic, it has become increasingly clear that assumptions about COVID-19 being an acute illness that fully resolves after a week or two are erroneous. Beyond the horrific global toll of over 2.7 million dead among 123 million diagnosed with COVID-19, survivors all over the world have yielded mounting reports of sequelae and complications lasting weeks, months, and perhaps longer. The many problems reported have been merged under the general name of long-haul COVID, and there is already a substantial medical literature. Long-haul clinics are being established, and higher-quality information is being generated and distributed. In peer-reviewed published studies, 4%–60% of COVID-19 patients have reported symptoms at least four to six months after the acute illness, with some evidence that the rate runs higher (30%–60%) in those who required hospitalization and especially ICU care than in those with mild acute disease (4%–10%).

“Preliminary evidence indicates that the T-cell response, the other big gun of the immune system, is robust even against the variants in vaccinated people.”

The most frequent symptoms include ongoing fatigue, cognitive changes (“brain fog”), and shortness of breath, but many more varied problems have been noted, such as ongoing

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In Memoriam: Ed Kinney

—Isabel Stenzel Byrnes

The Cystic Fibrosis Center at Stanford has lost one of its longtime saints, Ed Kinney. Ed lost a brief battle with brain cancer and passed away on April 19, 2021 at the age of 78. He is survived by his beloved wife of 52 years, Kay. A native of New Mexico, a proud Stanford alum, a veteran of the Air Force, a lover of Stanford basketball and football tailgates, a finance expert at EF Hutton and Franklin Templeton, and a skilled clarinet player for the Saratoga Community Band, Ed was most recognized for his service to the cystic fibrosis community.

Since his mid-30s, Ed Kinney volunteered every week at the Children’s Hospital at Stanford (aka CHaS), which went on to become Lucile Packard Children’s Hospital Stanford, specifically to hang out with his “CF kids.” He grew up with generations of CF kids, watching them endure loss, cope with cross-infection, thrive with new treatments and transplantation. In the mid-1990s, he extended his volunteer service to the “Big House” and befriended hundreds of CF adults over the years. Ed’s familiar voice and knock on the door brought so many patients laughter, companionship, friendship, and conversation. He made each one of his CF kids feel special, supported, and loved, and he was loved in return by so many. Ed mourned the losses of countless CF friends and also celebrated by their side during their transplants. He even took a beloved CF patient into his home and cared for him through the end of life. Ed befriended and supported so many of the CF Center staff as well. He also volunteered



Ed Kinney

in many capacities with CFRI and received the Dave Stuckert Memorial Volunteer of the Year Award in 2001. Ed served on the Stanford CF Patient Advisory Committee since 2009. He was honored by the Living Breath Foundation with their Volunteerism Award, named in his honor, in 2017.

Only COVID ended his 40-year stint as Stanford Medicine volunteer shortly before his diagnosis. Ed faced his illness and end of life with the teachings of his CF kids: that you live life to the best of your ability, despite your body’s betrayal; you laugh often and choose optimism; and you love deeply and generously. The CF Center at Stanford will never forget Ed Kinney and will be eternally grateful for his long service to the CF community. Ed’s light and love will never die. Per Ed and Kay’s wishes, memorial donations can be made to CFRI (www.cfri.org).

Anti-inflammatory Foods for Cystic Fibrosis (CF)

—By Julie Matel, MS, RD, CDE

They contain properties that promote a decrease in inflammatory markers in the body. In fact, anti-inflammatory properties of foods have been studied for some time. For example, following a Mediterranean diet, rich in anti-inflammatory foods such as fish, fruits, vegetables, healthy fats, and whole grains, has been shown in numerous studies to decrease illness and mortality from a number of chronic diseases, including cardiovascular diseases, diabetes, certain cancers, overweight and obesity, gastrointestinal diseases, fatty liver, depression, and cognitive decline in adults. In children, an anti-inflammatory diet is associated with a healthier body weight, improved cardiovascular and respiratory fitness, and less asthma.

We know that part of the disease process in CF involves activation of inflammatory pathways in the lungs and GI tract. Although the benefits from including anti-inflammatory foods into the CF diet have not been studied, incorporating these foods in ways to meet individual nutritional goals may prove beneficial and likely promote overall health and wellness.

Tips for incorporating anti-inflammatory foods

Choose foods that contain healthy fats:

- Extra-virgin olive oil and olives
- Avocados
- Ground flaxseeds and flaxseed oil
- Whole nuts and seeds (almonds, walnuts, pistachios, pumpkin seeds, sesame seeds (including tahini), chia seeds)
- Fish rich in omega-3s, such as wild salmon, mackerel, and sardines

Consider having half of the grains you consume each day be made up of whole grains. Try a variety, including:

- Amaranth
- Brown rice
- Millet
- Quinoa
- Rolled oats
- Whole wheat bread (make sure the first ingredient is whole wheat)

Choose a minimum of five servings of fruits and vegetables per day. Choose a variety of colors, including:

- Blueberries
- Broccoli
- Dark green kale
- Orange squash
- Red beets

Other fruit and veggie tips:

- Choose produce that is local and in season.
- Prepare vegetables in a variety of ways with added healthy fats if you need additional calories for weight gain. For example, toss sweet potatoes in olive oil and roast at 350 degrees F in the oven.
- Minimize fruit juice consumption. Instead, enjoy whole fruit to boost fiber, vitamin, and mineral content.
- Try fermented vegetables like sauerkraut, kimchee, and fermented pickles to provide valuable probiotics for your gut microbiome. In fact, our microbiome plays a large role in regulating inflammation.
- Try full-fat Greek yogurt and fruit topped with nuts for a healthy dessert option. Mix in frozen blueberries for a frozen treat!

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A Research Experience

—The Needham Family

1. **How did you hear about the study?** We received an email alert from the CF Foundation's Clinical Trial tracker that told us the Trikafta study was enrolling at Stanford for ages 2–5. From there, we emailed the Stanford research team to express our interest in enrolling our daughter in the trial.
2. **What were your concerns regarding enrolling your child in a study, especially during a pandemic?** We didn't know what to expect with a clinical trial, having never gone through one before. It was really helpful for us to walk through the study protocol with Sean, our research coordinator, and understand what tests would be performed and how often. Our trial included some days with multiple blood draws, and we weren't sure how our daughter would manage the long visits. In addition, the pandemic added more complexity: Getting COVID tests for all family members prior to visiting, social distancing while in Palo Alto, and being very mindful of exposure were all things on our minds.
3. **What would you share with parents of young children who are considering enrolling their child in a study?** We would absolutely encourage other families to consider enrolling their child in a study. For our 3-year-old, we found the pre-study visit to be a really important time to get to know the research team and learn what to expect. Initially our daughter did not like the ECG or blood pressure cuff—we took home some ECG stickers and played doctor with her stuffed animals. All these little practice sessions really helped the rest of the visits go smoothly. We were so thrilled with how proud our daughter was of herself after she completed her visits, and how empowered



Mimi Needham

she became as she experienced elements of the trial that were challenging for her. The research community at Stanford is incredibly caring, and we always felt in great hands there.

4. **How would you describe your research experience?** It was a very positive experience overall. Since we live outside of the Palo Alto area, we did have to manage the logistics of travel, lodging, time off work, etc., but the research team was extremely helpful. The logistics added an element of stress on top of a new environment, new team, and new experience for our daughter. That said, the process and research team made sure we had support for each stress point, including playgrounds and outdoor areas, consistently friendly staff, and access to answers in real time. We ensured that we planned fun things to do and treats to make the experience a positive one. Now our daughter requests to go back to Stanford on a regular basis and asks how the team is doing, including Ms. Michelle, who was responsible for drawing her blood.

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At Home Sputum Collection Project

—Colleen Dunn, MS, RRT, CCRC

With the FDA approval of the new Vertex drugs (highly effective modulator therapies such as Orkambi, Symdeko, and Trikafta), clinical staff/providers have noticed a significant decrease in the volume of sputum that can be produced during clinic visits. The acquisition of sputum, the laboratory analysis, and appropriate treatment is of primary importance to the care of our cystic fibrosis population.

During the pandemic, we had the opportunity to create new ways to improve the care of our patients. Out of the desire to continue excellent care and obtain sputum from as many patients as possible, we developed the At Home Sputum Collection project. All CF patients who are older than 6 years of age can participate in this study. After providing consent, you will be given the appropriate supplies to collect and ship your sputum to the CF research office prior to your next CF appointment. We have found, and most patients tell us, that they are able to produce most often in the morning during morning therapy and/or during their morning shower. Therefore, we are asking all patients to collect their sputum in the morning. For our younger patients, or those who are struggling with sputum acquisition, one of the members of the research team—Sean Ryan, RRT, or Colleen Dunn, RRT (our respiratory therapists)—can set up a virtual coaching session with you or your child. This session will provide one-on-one real-time coaching during a modified sputum induction. Once you collect your sputum, you will follow the instructions found inside the shipping box. You will receive collection

process/shipping requirements reminder calls from either Cathy Hernandez or Alyssa Remulla from the research office. If you are interested in a coaching session, please let Cathy or Alyssa know.

This sputum sample will be sent to the Stanford Clinical Lab for analysis, and the results should be available before your upcoming visit. This clinical sample is charged to your insurance provider as usual. Before we take your sample to the lab, if there is a sufficient amount of sputum in your provided sample, a member of the research team will take a small sample of your sputum to Dr. Milla's lab for our various research projects.

The process of getting consent from the entire Stanford CF Center patient population is a rather large undertaking, so we have begun a virtual consenting process, which we hope will help us get the entire CF Center population consented more efficiently. We are hopeful that once all eligible patients are consented, we will start to regularly receive many more samples. However, please do NOT send in a boxed sputum sample if you have not yet signed an informed consent. If this collection of sputum at home is successful, we are hoping to transition away from our research-based collection project and make it a clinic-based initiative. That means that your clinical CF team will manage the collection of your sputum before your clinic visits. We believe, and hope, that this will ultimately become a new standard procedure. Be on the lookout for a research team member to contact you to get your consent soon.

Cystic Fibrosis Parent Advisory Council

—By Kirsten McGowan

Keeping CF Families Entertained (and Safe) during the COVID-19 Pandemic

Cooking	<ul style="list-style-type: none"> Plant some flowers or a garden Learn paper folding (origami, paper airplanes, newspaper hats) Build a fairy garden Science experiment - mix drops of food coloring to water and see what new color is made Sidewalk chalk Play dress up and put on a play or make up a dance Write letters or draw pictures to friends/family they cannot visit in person Family Game/Puzzle Night Build a tower out of playing cards - see who can build the tallest Learn new jokes and tell them to your family FaceTime/Zoom friends and family Family Movie Night
Fitness/Activity	CF Meds Practice
<ul style="list-style-type: none"> Make a grocery list together to get your kid(s) excited about mealtime Bake dessert or a treat (cookies, brownies, cupcakes, banana bread, muffins, etc.) Younger kids can assist making meals Older kids can be responsible for preparing 1 meal/week for the family Sign up for an online cooking class Pack a picnic and go to a park to enjoy it! 	<ul style="list-style-type: none"> Learn what each medicine is for and how to say it Get their own meds ready for each meal/snack Set up treatment (plug in equipment, put on vest, put in hoses, etc.) Assemble their nebulizer and add meds Sterilize their nebulizer sets Practice good hand hygiene
Fun Activities	Learn/Assign New Chores
<ul style="list-style-type: none"> Gonoodle.com (FREE activity/fitness/dancing videos for kids - requires a login/password setup) Do a family workout together (https://www.youtube.com/watch?v=5if4cjO5nxo) Have a stair running race Dribble a basketball up and down the sidewalk (or around the block) Ride bicycles/scooters Setup an obstacle course around your house and have an American Ninja Warrior competition Play catch Find an empty tennis/basketball court and bring your own racket/ball/bat (have kids makeup their own game, doesn't have to be actual tennis) 	<ul style="list-style-type: none"> Picking up/organizing toys Make beds Fold laundry Dusting Vacuuming Mopping floor Loading/unloading dishwasher or washing dishes Walking the dog Cleaning bathrooms Yardwork (mowing lawn, raking, watering plants) Wash the car
<ul style="list-style-type: none"> Artforkidshub (YouTube Channel) Go on an indoor scavenger hunt with clues Decorate a cardboard box (racecar, spaceship, castle, etc.) Repurpose cardboard for toys (ramps, forts, stuffed animal hideouts, etc.) Build a tent/fort with sheets/chairs and read or have a sleepover in it Backyard camping (pitch a tent and sleep outside, make s'mores, etc.) Plant some flowers or a garden Learn paper folding (origami, paper airplanes, newspaper hats) 	

Tips to Maximize Post-COVID-19 Vaccination Recovery

—By Taylor E. Lewis, MA, CSCS, CMT, PRT, PES and Nicole Ezcurra, MS, CCC-SLP

As vaccinations are increasing across the United States, it's important to talk about the steps you can take to optimize your recovery before and after receiving the COVID-19 vaccine. There is still much to be learned about the COVID-19 vaccines, but at this moment we do know that the COVID-19 vaccines have the potential to impact you physically for a few days post-vaccination. I've heard of side effects ranging from feeling "totally fine" to "I had high fevers and felt exhausted for up to a week after." It varies from person to person. Nonetheless, when you're already combating a chronic disease, receiving a vaccination with potential side effects can be nerve-racking. Fortunately, there are steps you can take to help retain all the progress you have made thus far in your health and exercise journey.

Before we get into the recovery component of this article, it's important to start off by saying that the first thing you should always do is talk with your health care team about setting up a short-term plan post-vaccination. Planning is the key to any type of recovery, and your health care team knows your medical history best.

Now, on to the exercise component of recovery. Due to the fact that everyone reacts to vaccinations differently, everyone's recovery program will be individualized as well. When it comes to exercising, there are a few key areas to consider before and/or after the vaccination. First, decide if you do want to exercise on the morning of your vaccination. This will vary based on the time of your vaccination, family or career obligations, health, etc., but if you decide that you will exercise, then take a moment to intentionally think about what type of exercise (e.g., cardio,

strength training, high intensity, stretching) may be most beneficial for you prior to getting the shot. Ideally, which exercise doesn't already leave you drained and exhausted before you get the vaccine? Next, if you have decided that you will exercise the day of, determine the intensity of the exercise. If you are the type that likes to dial up the intensity, think about reducing that intensity to around 50%. This is because when you exercise, the body shifts blood to the muscles to meet the demand that is being placed on them. However, when you then receive the vaccine, a foreign substance is introduced into the body, and it is the body's number one goal to fight off any threats, therefore shifting its focus from sending blood to the muscles for recovery to focusing primarily on fighting off the foreign substances from the vaccine; as a result, your body will be overworking. Reducing your intensity during exercise will allow the body to maximize its protective mechanisms in the introduction of the vaccine.

Lastly, this could be a great opportunity for you to shift your focus from your exercise programs and instead reflect on the prime areas of recovery, such as sleep, diet, and hydration intake. Recovery between trainings is just as important as the energy you put into your training regimen. Your body needs the time to build itself back up. To do this efficiently, adequate amounts of water, food, and sleep are essential for the recovery process. Take a step back and spend some time tracking how much sleep you are getting, your water intake throughout the day, and if there are any gaps in your nutritional

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Pediatric CF Center Update

—Mary Helmers, RN

Mask changes

Since construction is completed here for both Lucile Packard Children's Hospital Stanford and Stanford Hospital, patients have switched back to wearing the yellow masks (please note that these masks may also be blue or white in color). Patients should wear them to and from all clinics/ the hospital and when you walk outside the medical center. They should fit snugly around the nose and mouth. Patients can also wear the Vogmask (a microfiber, high-filter mask with vents).

COVID-19 updates

We hope all our patients and families are doing well and staying safe. We want our families to know that we are here to answer all your concerns and any questions you may have. Feel free to call the CF RN phone line at (650) 736-1359, or if you feel you need some additional support during these uncertain times.

We started seeing patients back in clinic on May 4, 2020, and visits have gone well. Your CF team—provider, RN, RT, social worker, dietitian, and/or pharmacist—are now all accessible in person during your clinic visit. We continue to enforce the rule that only one family member may accompany their child to the visit. NO siblings or additional family members are allowed in clinic at this time. Upon request, some providers are offering telehealth visits.

Everyone who enters the building and or hospital will be screened at the entrance before coming up to clinic.

We encourage all our patients who are 16 years and older to receive the COVID vaccine when you qualify in the county where you reside. Currently the Pfizer vaccine is for ages 16 and older; the Moderna and Johnson & Johnson

vaccines are for ages 18 and older. You can go to the My Turn Vaccine website to check eligibility and where to get the vaccine in your area (<https://myturn.ca.gov/>). We encourage you to refer to the Centers for Disease Control and Prevention (CDC) website, www.cdc.gov, for the most up-to-date information and the Cystic Fibrosis Foundation website, www.cff.org.

Helpful tips

PG&E: Did you know that you can get assistance with your PG&E bill? PG&E forms for medical equipment and devices can be found on the PG&E website under Medical Baseline Allowance Application for Medical Baseline Enrollment and Recertification. All you need to do is print the form, fill it out including all your medical devices (e.g., nebulizer/compressor; if you use oxygen, CPAP, or BIPAP), and bring the form with you to your next CF clinic visit; your provider will sign it, and you'll mail the form to PG&E.

CF Clinic Prep form (patient update): Do you drive away from clinic thinking, "Oh no, I forgot to ask a question"? You can now fill out this form ahead of time and bring it to your clinic appointment. It was designed to help you get all your questions answered. This is not mandatory, but a tool to assist you in jogging your memory in preparation for your clinic visit.

MyChart (secure electronic correspondence): If you have not signed up already, please sign up for MyChart at your next clinic visit. MyChart is a secure way to communicate with your provider and CF care team. The CF care team cannot respond to patient or parent emails, since email is 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 or your child has a clinical need or question, please call the CF RN line at **(650) 736-1359**. It takes only a minute to sign up—one of the front desk staff will be happy to assist you.

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

Prescriptions: Just a reminder that your prescription request can take up to 72 hours to be processed. This has always been our policy; however, we strive to turn them around sooner. Please keep in mind that even after we send the scrip to the pharmacy, it can still take another 48–

72 hours for the pharmacy to process (especially mail order pharmacies). It is important for you to stay on top of your refills and request them at least one week before you are due to run out.

Requesting refills: Call your pharmacy first to find out if you have refills. If you have a refill, then they will process. Your pharmacy should call us if you have no refills.

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

New Pediatric Staff



Murielle Hanania, RN, BSN

I was born and raised in Millbrae, California, and attended the University of San Francisco, where I received my Bachelor of Science in Nursing. I have eight years of nursing experience and recently came from the Pediatric Intensive Care Unit at Packard Children's Hospital. I am very passionate and driven about providing patient-and-family-centered care. I look forward to forming strong relationships with patients and their families. I thrive on life experiences and love to travel to discover new places. Long hikes bring me joy and peace. On my time off, I take my golden retriever Bo to Fort Funston's dog beach for some fun in the sun. I look forward to meeting all the CF families and joining the team to provide excellent care.

A Research...continued from page 8

5. **Are there any other thoughts you'd like to share?** Participating in the trial was a formative experience for our family and made even better knowing we're advancing the health of many other children like our daughter. It makes the impact of travel, balancing life and emotions, and the risk of exposure worth it. We didn't just participate in the study, we incorporated it into our lives and ensured that it was intertwined with experiences we'll never forget, like spending time at Half Moon Bay, visiting some of the incredible playgrounds in Palo Alto, and having slumber parties in the hotel room.

Current Research Studies

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

RARE: Rare CFTR Mutation cell collection protocol (currently for people who have two copies of rare mutations).

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

Immune Response Study: Study examining the immune response to viral infection and/or vaccinations (anyone with CF can participate).

At Home Sputum Collection: See page 9 for detailed information on this project.

Upcoming: Vertex 445-111, Part B: Phase 3 study for children 2–5 years of age with F508/F508 and minimum function mutations looking at the safety and tolerability of Trikafta.

Upcoming STRC Tele-Coaching: This study is looking at medical adherence. We hope to determine if tele-coaching sessions are useful and whether these sessions are effective to enhance medical adherence. People with CF who are between 14 and 24 years of age will be eligible.

Tips to Maximize...continued from page 11

intake throughout the day. These three areas are key components to helping you build a stronger foundation for your overall physical fitness capacity.

Of course, there is no one-size-fits-all to optimizing recovery after receiving the COVID-19 vaccine. The biggest takeaway is to listen to your body. Get one last workout in before your vaccination, and then focus on what will help improve your health and fitness goals outside of exercising.

Update on Cystic...continued from page 5

loss of smell/taste, headache, tachycardia, sleep disturbance, anxiety, and depression. Objective tests such as lung, heart, and brain imaging techniques have uncovered evidence of unhealed and often otherwise undetected damage. Some studies that have separately localized virus- and immune response-related pathology suggest that the reason some people have long-lasting damage may have to do with their body's inflammatory response rather than direct viral tissue damage. While men are at higher risk for more severe acute COVID, some evidence suggests that women are at higher risk for long-haul COVID. The implications of this emerging vast cohort of chronically ill people post-COVID are enormous. They add one more utterly compelling reason to do what you can to avoid exposure to the virus, encourage fact-based behavior by your fellow citizens—and get your vaccine as soon as possible!

Anti-inflammatory...continued from page 7

Use these herbs and spices frequently for their anti-inflammatory properties:

- Turmeric
- Basil
- Parsley
- Rosemary
- Cilantro
- Oregano
- Cloves
- Garlic
- Ginger
- Cumin
- Cinnamon
- Coriander
- Paprika

References

Gotsis, E, et al. *Health Benefits of the Mediterranean Diet: An Update of Research Over the Last 5 Years*. *Angiology* 66 (4); 2015.

Patinella, S., Romey, H., McClafferty, H., Deutsch, J., Mascarenhas, M. *The Anti-Inflammatory Family Cookbook*. Simon & Schuster, 2021.

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;

Elizabeth Burgener, MD; Carol Conrad, MD; David Cornfield, MD;

Michael Tracy, MD; Jacquelyn Spano (Zirbes), DNP, RN, CPNP

Clinic Scheduling(650) 724-4788

Clinic and Prescription Refill Fax(650) 497-8791

Office assistant/ Patient Services Coordinator: Laura Banuelos

.....(650) 498-2655

Nurse Coordinator: Mary Helmers.....(650) 736-1359

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

Respiratory Therapist: Jessica King.....(650) 724-0206

Nutritionist, Dietitian: Julie Matel(650) 736-2128

Social Worker: Teresa Priestley(650) 736-1905

Newborn Screening Coordinator: Jacquelyn Spano (Zirbes)

.....(650) 721-1132

PharmD: Russell Wise(650) 724-4788

Clinical Psychologist: Diana Naranjo, PhD

For urgent issues:

Monday to Friday, 8 a.m. to 4 p.m.

Call the CF Clinic Nurse(650) 736-1359

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

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

Providers: Karen Hardy, MD; Eric Zee, MD;

Manisha Newaskar, MD; and Rachna Wadia, MD

CF Clinic Scheduling.....(650) 724-8414

Clinic and Prescription Refill Fax(510) 457-4236

Nurse Coordinator: DJ Kaley, RN.....(650) 724-8414

Respiratory Therapist: Lorraine MacPhee (Tues–Fri)

.....(510) 587-9631

Nutritionist, Dietitian: Ayah El-Beshbeeshy (Tues & Thurs)

.....(510) 457-4232

Social Worker: Teresa Priestley(510) 362-7504

For urgent issues:

Monday to Friday, 8 a.m. to 4 p.m.

Call the CF Clinic Nurse(650) 724-8414

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

Adult providers at Stanford Health Care

Adult Center Director: Paul Mohabir, MD

Associate Center Director: Laveena Chhatwani, MD

Providers: Jennifer Cannon, NP; Elika Rad, NP; Meredith Wiltse, NP

Adult Clinic Scheduling.....(650) 498-6840

Adult CF Center Fax(650) 723-3106

Nurse Coordinators: Theresa Kinney, RN

and Kristel Fallon, RN.....(650) 498-6840

Respiratory Therapy: Gauri Pendharkar, RCP

and Sheldon Porter, CRT, RRT, BSRT(650) 736-8892

Registered Dietitian: Michelle Stroebe, MS, RD ... (650) 529-5952

Social Work: Meg Dvorak, LCSW.....(650) 518-9976

Social Work: Kate Yablonsky, MSW(650) 444- 6512

Mental Health Coordinator: Liza Sher, MD

Routine issues/concerns during business hours, 8 a.m. to 5 p.m.

CF Nurse Coordinator Line(650) 498-6840

- Please leave a voicemail if no answer. These calls will be answered within 24-48 business hours

- Alternatively, you can utilize MyHealth messaging. These messages will be answered within 24-48 business hours. This is NOT to be used for urgent issues. MyHealth is NOT checked on the weekends

Urgent issues/concerns during business hours, 8 a.m. to 5 p.m.

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

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

Urgent issues/concerns after business hours:

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

- Nurse triage is available 4:30 p.m. – 7:30 a.m. A message will be generated and sent to the CF Team ASAP

Adult providers at Sutter Health CPMC

Adult Center Director: Ryan Dougherty, MD

Associate Center Director: Vinayak Jha, MD

Provider: Carolyn C. Hruschka, ANP-BC

Adult Clinic Scheduling.....(415) 923-3421

Adult CF Center Fax(415) 243-8666

Program Coordinator: Carolyn C. Hruschka, ANP-BC

.....(415) 923-3421

Respiratory Therapy: Bryan Ellis, RCP; Arthur Pundt, RCP

.....(415) 600-3424

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

Social Work: Amy Greenberg, LSW(650) 518-9976

Mental Health Coordinator: Amy Greenberg, LSW

.....(415) 923-3854

For urgent issues:

Monday to Friday, 9 a.m. – 5 p.m.

Call the nurse coordinator(415) 923-3421

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

Research

Colleen Dunn, Zoe Davies, Alyssa Remulla, Sean Ryan, Jackie Zirbes

.....(650) 736-0388

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

Living—How a study on rabbits revealed the secret to living a longer life

—Kelli Harding

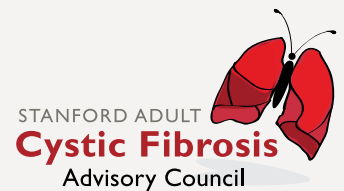
In 1978, a rabbit revealed the answer to living a longer life. That year, researchers ran a simple experiment with rabbits to show the link between high cholesterol and heart health. The results surprised everyone. While the genetically similar rabbits all ate the same high-fat diet, one group appeared protected from a heart attack or stroke.

Dr. Robert Nerem, the lead scientist on the study, recalled wondering what explained the difference. It remained a mystery until the team noticed that one of the lab researchers wasn't just feeding the rabbits. She was petting and talking to them. Dr. Nerem explained, "She couldn't help it. It's just how she was." They repeated the experiment and got the same shocking results. The difference was kindness and company. Four decades later, ample scientific studies have shown that kindness and connection

are critical to health and cellular aging. Love and tender loving care alter gene expression through microscopic epigenetic changes. Telomeres—the DNA "caps" that help determine how long we live—extend or shorten in response to stress and our connections to others, as first reported in the 2004 Proceedings of the National Academy of Sciences. Positive relationships lower stress, cortisol, inflammation, pain, and blood pressure. They boost immune functioning, mood, and recovery after injury. Supportive relationships can also help people with serious disease and cancer live longer.

"I think our CF group should know that they are not alone. There are people out there that understand that everyone does better with kindness and love."

—Shawn Taylor, member, Adult CF Advisory Council



Newsletter Contact Information

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

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