CFS Gazette
Convey. Fortify. Support.

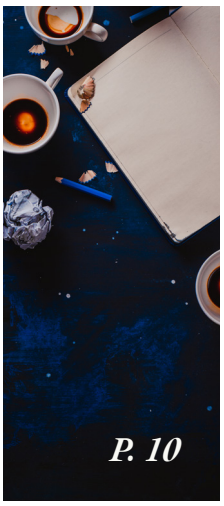
CF Society › Issue #7 › Spring 2019

A CF Center Near You

More accredited CF Care centers are opening nationwide, making care more accessible than ever. An exclusive interview with Mary Lester RRT, RCP on the adult CF center in Los Angeles.

Guest Columnist Alana Kessler MS, RD, CDN, E-RYT - *The Endless Pile*

In This ISSUE



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CFsociety
supporting families with cystic fibrosis

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Happy Early Spring, Folks!

Happy and healthy, that is. How are you all faring? Bundling up for that cold makes you wish for a portable fireplace you can always take with you wherever you go, huh. Well, that's my wish, anyway.

Yeah, it's been a while since our newsletter has been out. This is where the CF Foundation (CFF) comes in. A big shout out to Melody and Piper running the CF Impact Grant Program via the CFF. We at CF Society can't thank them enough for providing us with the CF Impact grant so that we can resume the production of the CFS Gazette. They are simply wonderful. It's been a whirlwind since then and we've finally made it. Again, our hearty thanks to the CFF!

Some of you may have noticed some (welcome) changes to our Gazette. Aside from the new look thanks to our fabulous graphics team, you may have noticed our new feature column regarding CF centers around the U.S. Over time, many people have turned to us in their quest for the right CF center for themselves or their children. They have numerous worried questions and concerns. We have decided to undertake the mission of providing more detailed information regarding centers across the U.S. so that patients can make a more informed choice when searching for a good CF center. Look out for info on additional U.S.-based CF centers in future Gazette issues.

We also feature guest nutritionist, dietician and yoga teacher Alana Kessler who helps us see how nutrition can act as medicine for patients with CF. She offers marvelous insight on everyday food items and how CF bodies work. In addition, M. Wiseman offers us a further look into her family's struggle with CF in the latest chapter of her serial. And feel free to exclaim in appreciation (like I did) for the eye-opening entries that our talented teenagers sent in.

Meanwhile, please stay away from people who like to cough or sneeze in your face. There's no need to take on more bacteria than what we've already got.
Stay safe, stay healthy. Stay sane.

Debbie Spira

Have a question for us?

Email it to
gazette@cfsociety.org

2018'S TOP 10 CF NEWS

Cystic Fibrosis News Today published their list of the Top 10 newsworthy reports of 2018. Each item pertained to advancement in CF medicine and trial studies in the past year. Of course, the approval of Symdeko, the 3-drug combo (tezacaftor[vx-661]/ivacaftor [vx-440] and ivacaftor[kalydeco]) for CF patients with 2 copies of the F508del mutations is a real biggie. Another top tidbit states that children and adults who are given high doses of ibuprofen in studies showed significant slowing of lung function decline and decreased bacterial activity of both pseudomonas and b.cepacia. An aerolized version is in the works so that orally-induced GI and kidney illnesses would be avoided. One top 10 story zeroed in on cinnamaldehyde (CAD), a key component found in cinnamon essential oil that can prevent pseudomonas from creating antibiotic-resistant biofilms. And did you know that AquADEKs-2 does successful work at keeping pulmonary exacerbations away? Fantastic news all around!

https://goo.gl/TU1X6u

MOST CF PATIENTS NOT RECEIVING SUFFICIENT ANTIBIOTICS TO CLEAR LUNG INFECTIONS

In a recent study, patients with CF who achieved appropriate therapeutic blood concentrations showed more significant improvement on their PFTs after treatment. Pulmonary exacerbations are generally treated using a combination of at least two antibiotics. One antibiotic used is time-dependent and must exceed a specific blood concentration in that time frame in order to be effective. Outrageously, these blood concentrations are not usually tracked while patients are being treated. Findings show that dosing regimens alone likely do not predict successful blood serum concentrations. Researchers are now working on creating a new algorithm to determine correct antibiotic dosing.

https://goo.gl/2K1Rd3

AR-501 MAY BE CF'S NEW BEST FRIEND

AR-501, or gallium citrate, is a solution designed to treat pulmonary bacterial infections. Gallium citrate is a citrate salt that can be intravenously delivered and now an inhaled version will be tested on patient subjects. Remarkably different than other existing antibiotics, AR-501 works by starving bacteria of iron and preventing the processes that depend on iron input from accessing it and further developing the infection. Early data showed how potentially beneficial AR-501 is against the common CF bacterias: Pseudomonas and B. cepacia. Patients are now being recruited (please see sidebar for clinical trial info).

https://goo.gl/HLD8sZ

CF PATIENT DONS HER SCIENTIST HAT

Ella Balasa, a patient with CF, is a microbiology lab scientist who wanted to test the effects of manuka honey on Pseudomonas in real time. Manuka honey has the natural antibiotic methylgyoxal in it, a compound that combats Pseudomonas by making its cells explode and die. First, Ella readied her petri dishes with her Pseudomonas-laden sputum. Then half got honey mixed into the mucus; the other half went without. The hypothesis was that the honey-daubed dishes would cause less bacterial growth to be observed. However, 24 hours later revealed no changes to the petri dishes. Still, this was no official experiment. So if spooning that Manuka makes you feel better, please don't let Ms. Balasa's test stop you. https://goo.gl/cNFqzg

A VACCINE AGAINST PSEUDOMONAS AERUGINOSA?

Scientists are laboring hard to develop a vaccine against one of the most virulent bacterias affecting patients with CF today. Pseudomonas is naturally resistant to a great number of antibiotics. A 2016 study sequenced the genetic material of the bacteria. Using this data, researchers designed a molecule to immunize mice and bring about an immune response against the bacteria- all this before infection even begins. Results show 99.9% eradication of the pseudomonas. They're now working on creating more complete and complex coverage, particularly because pseudomonas adapts and tends to find other ways of infecting a patient.

https://goo.gl/XRHxK9

ORKAMBI NOW APPROVED IN CANADA FOR CERTAIN CHILDREN

O' Canada! Canadian children with the double F508 mutations ranging from ages 2 to 5 years old will now be joining the older children with these mutations in having access to Orkambi. Six consecutive months of study indicated that the drug is well-tolerated. Approval in the U.S. had already been granted in late summer of 2018. Surprisingly, Europe still maintains an undecided position.

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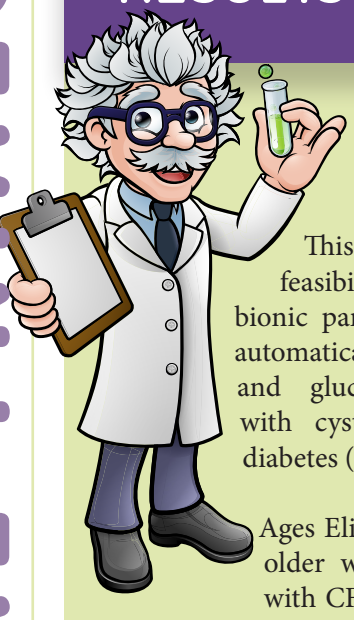
NEW CLINICAL TRIALS

RESULTS ARE IN



Bionic Pancreas

This study will test the feasibility of a wearable bionic pancreas system that automatically delivers insulin and glucagon for adults with cystic fibrosis-related diabetes (CFRD).

Ages Eligible: 18 years and older who are diagnosed with CFRD and use either an insulin pump or multiple daily injections
Location: Boston, Massachusetts

https://goo.gl/k1jrc1

MRT5005 Via Nebulization

This study will evaluate the safety and tolerability of single and multiple escalating doses of MRT5005 administered by nebulization to the respiratory tract of adult subjects with CF. MRT5005 is a new drug designed to restore CFTR function by delivering correct copies of CFTR-encoded mRNA to the lungs.
Ages Eligible: 18 years and older
Multiple locations.

https://goo.gl/8MQNeu

Using Food as Medicine to Manage CF

A Nutritionist's View

Guest Columnist

Alana Kessler, MS, RD, CDN, E-RYT

As a clinician, I have consulted with many patients over the years and have had the opportunity to be inspired and impacted by many. Most recently I had the pleasure of connecting with Brad, who shared with me his hero-like journey with cystic fibrosis. What struck me the most, besides his unbelievably positive outlook on life, was the direct connection between the gut microbiome, lungs, liver, pancreas, kidneys, and nutritional status.

The range of reasons why someone would come to see an RD (Registered Dietitian) vary, but the common denominator is that food and lifestyle can be adapted and modified to create impactful and long-lasting change physiologically, psychologically, and spiritually.

Although the lungs are the primary organ we think of when discussing CF, the reality is that this disease affects the epithelial cells of both the lungs and the stomach/lumen (the latter the inner space or cavity of tubular organs like the intestines). CF causes an excess of phlegm and mucus to accumulate in both of these organs and effects functionality.

The production of phlegm in the lungs inhibits oxygen uptake into the bloodstream, and in the stomach/lumen affects their proficiency to digest and absorb all the nutrients from food. For this reason, individuals

with CF find it hard to maintain weight, keep energy up, and stay properly hydrated. Immunity decreases as well, creating an opportunity for bacteria to enter the system.

From a Chinese medicine perspective, we are comprised of two different types of chi (i.e., life energy) to function. One is the chi we are born with and it is stored in the kidney. The other is the "postnatal chi," and this is the energy we continually make as our lives progress. It is made from air taken though the lungs and food taken through the stomach.

The combination of air and food is how we literally live. Since CF affects the lungs and the stomach, there is a deficiency in the amount of postnatal chi produced. Because of this, more of the "limited supply chi" from the kidneys that we are born with is used up earlier than normal. One of the symptoms of depleting kidney chi is fluid deficiency.

Since fluid is cooling for the body, when there is lack of it, heat accumulates to create a salt imbalance and essential electrolytes are lost through extracellular tissues and fluids like sweat and phlegm. This presents as problematic as other manifestations can arise. These include life-threatening lung infections, and obstructions of the pancreas that can stop natural enzymes from helping the body break down and absorb food, leading to fat and nutrient malabsorption. These malfunctions inhibit the liver's functionality, causing a CF-related form of diabetes and insulin resistance.

Antibiotics and anti-inflammatory medications are typically prescribed to help clear mucus from the lungs; however, these medications can have potential effects on the overall balance of the gastrointestinal (GI) microbiome. This is supported by the 2016 Pediatric Pulmonology article "The CF Gastrointestinal Microbiome: Structure and Clinical Impact" that notes: " A growing body of evidence suggests that GI microbiome in people with CF is altered, and that these dysbiosis contribute to disease manifestations in many organs, both within and beyond the GI tract." As the article continues: "The GI microbiome is shaped by host diet, immunity, and other physicochemical characteristics of the GI tract, and perturbations such as antibiotics treatments can lead to persistent changes in microbial constituency and function. These GI microbes also play a critical roles in hosts nutrition and health."

If there is no other choice but to take antibiotics, make sure that you consume probiotics as well, either before or after taking the medications, to maintain an optimal ratio of gut bacteria.

So, how can we use food as medicine?

Food combining for gut health

The basic rule is to eat protein alone or with green/ non–starchy vegetables.
Fats can be eaten with green or non–starchy vegetables and/or starches
Starches can be eaten with green vegetables and/or fats
Eat small, frequent meals using this food combining guide. Meals should be either fat-based or protein-based but not combined together. This is an excellent method for glucose control as well.

Bitters

Take bitters before meals. Bitters help trigger the release of digestive and pancreatic enzymes, specifically bile, which are essential for digesting fats that have essential metabolic functions for health and wellness.

According to an article published in 2014 in the Journal of Pediatric Gastroenterology and Nutrition, "About 90 percent of patients with CF in the US have pancreatic insufficiency and are at risk for fat malabsorption and fat soluble vitamin deficiency."

Improving these secretions are crucial in weight management because, even if the calories are

increased, if the ability to absorb the nutrients aren't available than desired outcomes won't be achieved. Bitters are also lung and kidney strengtheners, and are especially good at clearing infections with a lot of phlegm and inflammation as well as chronic infection. Some of the best options are alfalfa, dark leafy greens, asparagus, celery, peel of citrus fruits, radishes, scallions, apple cider vinegar. Bitter herbs are especially good, and include dandelion leaf and root, chamomile, echinacea.

Pungent and sour foods

These foods help to disperse mucus and stimulate digestion. Examples are garlic and cayenne. But its important to remember that spices can have both a warming and a cooling effect. When there is inflammation, cooling spices like peppermint and radishes are beneficial; whereas when there is a pathogen or a cold that needs to be burned out, warming spices like cinnamon, ginger, black pepper, anise, horseradish, mustard greens, hot peppers, and fennel can be helpful.

Garlic and onions are considered medicinal for their antimicrobial properties and antioxidants. Be sure to crush garlic and let it sit for 10 minutes before consuming it to optimize its healing potential by releasing the oil that contains allicin.

Sour foods stimulate digestion and make fats and proteins easier to digest. Drinking a glass of warm water with lemon or starting a meal with a fermented food like a pickle or sauerkraut can be beneficial. Other sour foods include; limes, olives, sour apples, leeks, blackberries, raspberries, olives and tomatoes.

Increase fiber, favor low glycemic index foods

Fiber helps to slow down the release of glucose into the bloodstream, directly supporting a reduction in blood sugar, and offers protection against the insulin resistance and osteoporosis that can occur due to dysbiosis, electrolyte imbalance, and de-mineralization.

A low carbohydrate diet is not indicated, but reduce simple concentrated sugars like high-fructose corn syrup, agave, brown rice syrup, cane sugar and artificial sweeteners. Raw honey can be used as a replacement for sweeteners, but should be eaten with other foods or in very small quantities to decrease the incidence of a spike in blood sugar. Eating whole

Food Type	Benefits	Food Sources
Bitters	Helps trigger the release of enzymes, aiding in weight management. Strengthens lungs and kidneys.Clears infections.	
Pungent & Sour	Disperses mucus, stimulates digestion. Good for fighting infections. Animicrobial & contains antioxidants.	
Fiber	Slows down the release of glucose, resulting in a reduction in blood sugar. Protects against insulin resistance and osteoporosis.	
Fatty Acids	Combats oxidative stress with anti-inflammatory omega-3's & DHA	
Probiotics	Good basteria aids digestion and protects from food-borne pathogens. Having sufficient good bacteria can decrease lung infections.	

foods that contain sugars, such as fruits and grains, do not contribute to de-mineralization because of the beneficial dietary properties of fiber, vitamins, minerals, fats, and proteins.

Good choices include 100% stone-ground whole wheat or pumpernickel bread, oatmeal (rolled or steel-cut), oat bran, muesli, pasta, converted rice, barley, bulgar, sweet potato, corn, yams, lima/butter beans, peas, legumes and lentils, most fruits, non-starchy vegetables, carrots, and avocados.

Beneficial fatty acids

High quality fish oil, either from seafood or a supplement, contains the anti-inflammatory omega-3's EPA & DHA to combat oxidative stress. Examples of supplements are krill oil and cod liver oil. These oils are very high in fat soluble vitamins A, D, E, and K and must be consumed with a fatty meal and enzymes for proper absorption.

Omega-6 fatty acids from vegetable and seed oils (safflower, sunflower, corn, grapeseed, peanut, etc.) that are found in the standard American diet are inflammatory and must be reduced. Attempt to achieve a balanced ratio of omega-3:omega-6 fatty acid in the diet of 1:2–1:4

Probiotics

As mentioned earlier, antibiotics can disturb the microbial balance by killing off both bad and good bacteria. It is the good bacteria that helps to digest food and protect us from food–borne pathogens and toxins. A lack of beneficial gut bacteria can cause diarrhea, gas, reflux, poor digestion and bloating, and may also lead to increased lung infections.

Food–based probiotics are found in fermented foods. Examples are cultured dairy (yogurt and kefir), sauerkraut, kimchi, kombucha, fermented grains and meats. They should be packaged as "live," "raw" or "probiotic."
If supplementation is indicated, be sure to purchase a probiotic that has at least 10 different strains of bacteria, with at least 20 CFU's per pill. The bottle should indicate its potency is guaranteed until the expiration date. Some probiotics contain prebiotics in them. Prebiotics are fibers from complex carbohydrates and are excellent for the probiotics to feed on.

As a whole, ensuring proper digestion and absorption of nutrition is essential for individuals with cystic fibrosis. A high-calorie, high-protein diet from good quality sources is key. Special attention to hydration, salt balance, fat, and extra vitamins — including chelated zinc, magnesium and D3 — are indicated to support overall health and continued vibrancy.

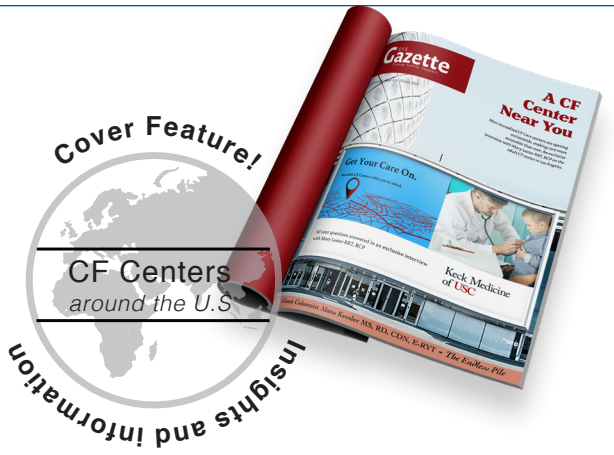
***

Alana Kessler, MS, RD, CDN, E-RYT, *is a registered dietitian, nutritionist, weight management expert, and an accredited member of the CDR (Commission on Dietetic Registration) and the American Dietetic Association. She is also a yoga and meditation teacher, Ayurveda specialist, and the founder of the New York City-based fully integrated mind, body, and spirit urban sanctuary, BE WELL. Alana's BE WELL ARC System and Method Mapping technique is a holistic multidisciplinary approach to health and wellness that blends Eastern and clinical Western diet and lifestyle support to effect long-lasting behavior change.*

A graduate of NYU with a BA and MS in clinical nutrition, Alana is dedicated to helping others learn how to nourish themselves, create balance, and understand their true nature through nutrition, yoga, and inner wellness. She leads Yin Yoga workshops and trainings as well as wellness retreats at international locations. For more information, visit her website at bewellbyak.com.

CF Center Spotlight

Exclusive Interview with Mary Lester RRT, RCP



Tell me about your team. Who are they? What are their specialties? And can you give us some insight on the pulmonologist heading your team?

Our team is very unique when compared to other CF teams in the US. We have a dedicated staff that devote their full time to the care of CF patients. Our dietician, social worker, and my position, RT, are all fulltime positions that care for patients' outpatient and inpatient when they are admitted to the hospital. Dr. Adupa Rao has been the Director of this Adult Program since 2005. He has been integral in the recruitment of the CF Care Team members, and is currently recruiting for a Pulmonologist to partner with as a co-director of this Center. He was awarded a $1,000,000 grant from the Anton Yelchin Foundation that is to be used for the betterment of the clinic experience here at USC Keck Hospital.

Do the doctors give strict regimens and guidelines that patients must follow? Do they accept their CF patients' and their family's input on how to manage their CF self-care?

We are involved in a national project that is sponsored by the CFF, C3N, which bases the projects that are involved with in the: co-production of health decisions, CF Center policy changes through the Patient Advisory Board, and close monitoring with the patient of important health data that is collected during a clinic visit.

What new medications are you now discussing for use with your patients?

We have very robust pharmacy involvement at our Center. Our fulltime Pharm.D., Dr. Joshua Wang, sees patients regularly while training Pharmacy Pharm.D. residents along with pharmacy students. They are very involved in the review of the patient's medications, they follow their lab results very carefully, and they make sure that patients that are eligible for the genetic modifiers are on the medication they qualify for: Kalydeco, Orkambi and Symdeco.

Your center is located in California. From where do your patients travel from to come to your CF Center?

Some of our patients are local to the LA area, but many travel great distances to get here. We have patients that we follow that live in Mexico, Hawaii, and distances in California up to 4 hours away.

Which pediatric CF centers are referring adult patients to you? Also, please give us some info about the pediatric CF center program affiliated with Keck Hospital.

The primary Pediatric CF program that transitions their patients to Keck is Children's Hospital of LA, (called) CHLA. We are essentially "one" program as far as the CFF Center grant is concerned, but our locations are 6 miles apart. We work closely with the staff on patient transition communication and education day presentations. There are several Pediatric CF programs in the area that we receive patients from: Children's Hospital of Orange County, Long Beach Memorial- and many of our patients come to LA for college or to pursue acting careers. We typically get 10-12 transition-in-to patients a year.

What equipment do you promote that especially help CF'ers in their pulmonary self-care? Which devices are the top most effective in mucus clearance?

This is where I come in! As the RT (Respiratory Therapist) on the Team, my purpose is to help patients preserve their lung function. Together, the patient and I discuss airway clearance methods that are available to them, trial the equipment or breathing techniques in clinic, and determine which method works best for their lifestyle- and most importantly, which method is the most effective in helping them keep their lungs healthy.

I promote exercise and believe that my healthiest patients are the ones that participate in a regular exercise routine. I was a member of the CFF Pulmonary Guidelines Committee and was privileged to be involved in forming the guidelines for airway clearance therapies which state: no form of airway clearance therapy proves to be more beneficial than another. This work was done in 2007 and still holds true in 2018.

I gave a Symposia talk at the North American CF Conference in Denver this past October 2018: Methods for Clearing the Airway: What the Science is Telling Us. Research was done looking at the airway clearance methods used in the US, Canada and the UK, and the results were very interesting. In the U.S., 75% of those living with CF use vest therapy, in Canada only 4% use the vest, and in the UK only 2% use vest therapy. Canada and the UK are dictated by their state medical systems, and because vest therapy has not been proven to be more effective than other forms of airway clearance, these countries prescribe breathing techniques, positive expiratory devices (e.g. PEP and AeroBika), and they have life expectancy outcomes that match, and even exceed the U.S. My approach to airway clearance therapies is that my patients here at USC are exposed to all forms: breathing techniques, PEP devices, vest devices, and exercise plans, so they have a well-rounded repertoire of airway clearance options.

Regarding exercise, better lung function is well correlated with exercise.

Is there any particular exercise(s) that your center's physical therapists particularly recommend?

Here at USC we recommend that our patients see one of our outpatient Physical Therapist(s) for a yearly exercise evaluation and exercise plan. Not everyone is at the same physical fitness level so each exercise prescription needs to be tailored to the individual patient and their level of physical fitness and state of their lung disease.

The CF Center is located on the third floor of the Keck Medical Center of USC, in Los Angeles CA.

The devoted team of the CF Center at the Keck Medical Center of USC. (Left) Mary Lester, RRT, RCP

Patients and their families sometimes have concerns that pop up after hours or during weekends/holidays. How accessible are the doctors and other members of the team?

Our facility is unusual in the aspect of afterhours care. We do not have an emergency room since we are affiliated with the LA County Hospital, which has the largest emergency room in the country. The problem with being seen at LAC hospital is that the transfer to Keck Hospital can take hours. We try to fit sick patients in to the clinic schedule whenever possible, and patients can talk to an on-call Pulmonary Fellow 24/7, and can (then) be admitted to the hospital if necessary.

CF can eventually cause a patient to reach the point where lung transplant may be suggested. To which facilities do you direct them to pursue transplantation?

We have a lung transplant program here at USC and many of our patients are referred to this program. Certain insurance policies dictate which transplant program the patient is referred to, and state insurance (Medicare, Medicaid) are only accepted at certain transplant centers. If our patients aren't accepted at USC for transplant, many are referred to other California Programs: UCLA, Stanford, San Diego.

Patients are sometimes very frustrated regarding cultural misunderstandings seen among CF center staff members as well as hospital personnel. What can you tell us about cultural awareness at the CF center and hospital?

Keck Hospital is very aware of cultural diversities, not only in the patient population, but amongst staff members as well. We are required to participate in diversity training which involves: cultural diversity, religious diversity and sexual diversity.

If you could convey one vital piece of advice to our readers with CF, what would you say?

Work with your Care Team to stay as healthy as possible. With all of the genetic modifiers that are available to patients, and the triple/combo on the horizon, it is imperative that patients stay as healthy as possible because (Ed. as they likely already know) these medications DO NOT regenerate lung tissue or restore the damage already caused by their CF lung disease.

Finally, can you give us a great story regarding a CF patient who struggled immensely and yet achieved great health and strength after following Keck protocols that were specifically designed for him/her?

One particular patient comes to mind. In 2014, the year I started at USC, Lisa came to USC from Tennessee to move back to California to be closer to her family. She became ill and was admitted to the hospital for the first time in her 40 years of living with CF. She worked fulltime and had a very active lifestyle. She was placed on oxygen during her admission and her FEV1 was 30%. She was shocked that her lung function was so low and that she now needed oxygen to use at home. We worked together very closely to get her transitioned to the idea that the use of oxygen was going to be permanent. Together we fine-tuned her airway clearance therapies to get her the most therapeutic results, along with the ability to continue to lead her very busy, full life. She like(s) to travel, so we often collaborate on O2 availability on planes, trains and automobiles. The co-production of care has helped her to stabilize her lung disease over the past 4 years. She participates in videoconferences with pharmaceutical sales force training, (and) often video conferences in to the North American CF Meeting to inspire Care Team members from North America with her resilient, positive attitude about living with CF.

Mary Lester *has been a Respiratory Therapist (RT) for 40 years. Most of her career she spent at Medical University of South Carolina (MUSC) in Charleston, South Carolina. From 1999 to 2014, she worked with both children and adults living with CF at MUSC. In 2014, she was recruited by the USC CF Center in Los Angeles to join their team. They had never had an RT on their Team, so they were very excited about her joining the team. Mary's career in the world of CF has been very rewarding. She has worked on a national level with the CF Foundation. She is presently a mentor for respiratory therapists just entering the field of CF healthcare. Mary also co-leads a task force on the acquisition of nebulizer kits and the durability of compressor machines. She has two children who are currently attending college.*

Keck Medical Center of USC
Keck Medicine of USC

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Type: Adult Program
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The ENDLESS PILE

CHAPTER 5

By: M. Wiseman

Brown bags. Brown boxes. Brown pill bottles.
Brown brown BROWN EVERYWHERE.

Clutching an industrial garbage bag, and suited up in comfortable socks, tight kerchief, and latex- free bright purple surgical gloves, Sarah surveyed the cluttered space. Eight years ago, this space had been a charming family room. But, from a neat and tiny little bin tucked into the corner, an endlessly cluttered corner had grown. And grown. And grown.

In perfect correlation to her frustration.

"One bag at a time" she told herself.

Boxes of unused supplies had moved in, made themselves comfortable, and were squatting for an indefinite period of time in what had once been her sanctuary: Alcohol swabs. Expired enzymes. Sharps containers that, if stacked, would reach the ceiling and then continue on up. Latex gloves size XL, totally unusable. Tubes, tubes and more tubes. Expensive equipment someone else could probably use.

Some time ago, maybe three years ago, maybe four, she'd attempted to make some real sense of the chaos, in the form of plastic Sterilite shelves, over the door shoe storage, and other such nonsense. The evidence lay buried and covered. The mess had only grown out of control.

Quite frankly, she felt like those kids at the end of the eponymous kids book "Cat in the Hat', bemoaning: "This mess is so big and so deep and so tall. We cannot pick it up. There is no way at all."

From upstairs, she could hear thumps as David roamed around his room, navigating a magnificent model city made of blocks that took up the entire center of his room; her darling little boy who had taken over her heart...and her life...and her home.

"Hey, Max," Sarah called to her elder son, curled up on the couch with a 600- page thick autobiography that looked as dull as it most certainly must be. "A little help?"

"Mmmm," was the enthusiastic response.

With a sigh, and a grunt of exertion that was, perhaps, a little more exaggerated than absolutely necessary, Sarah waded into the disaster and squatted down.

"One bag at a time" she told herself. "One easy peasy bag at a time. Here goes!" Personal pep-talk complete, she ripped open a brown pharmacy bag

that had, for some reason, never been open, and dug right in. Some vitamin bottles rolled out. She squinted at the expiration dates.
She sorted. She stacked. She tossed. She sighed.

For the next two hours, Sarah studiously worked her way from the inside out, creating piles for miles, and stuffing her contractor bag to its absolute breaking point. Sweat glued several hair tendrils to her forehead, but at last, her hard work was becoming evident --in the form of her divine cornflower blue carpet, peaking through in between the layers of detritus.

From a neat and tiny little bin tucked into the corner, an endlessly cluttered corner had grown.

Bottle by bottle, pack by pack, she carefully arranged the Sterilite drawers. With her teeth, she popped the cap off a permanent marker. It squeaked in protest as she proudly labeled each one.

"Wonn-er how wong -is wiwll -ast me" she mumbled to herself from around the cap.

But, alas she had spoken too soon. Just then the thud of a visitor's feet sounded up the porch stairs, followed by the squeaking of the screen doors hinges and a confident rapping at the door.

"I'll get it!!" howled Max, stumbling off the couch and turning his book face down onto a cushion.

Sarah sighed to herself, rubbing her tormented knees and then removing her gloves with a satisfying snap. Her sweaty hands were wrinkled and white from being cooped up so long.

"Mom! Delivery!!"

Naturally. Sarah creaked to her feet and wobbled to the front door.
"Hiya Jim," she said, "crazy weather, huh."
"Yep, crazy weather," Jim agreed, completing their usual riveting small talk. Sarah scrawled her autograph crookedly across the yellow form and rescued the heavy cardboard box from Max's stubborn, determined, but precarious grasp.

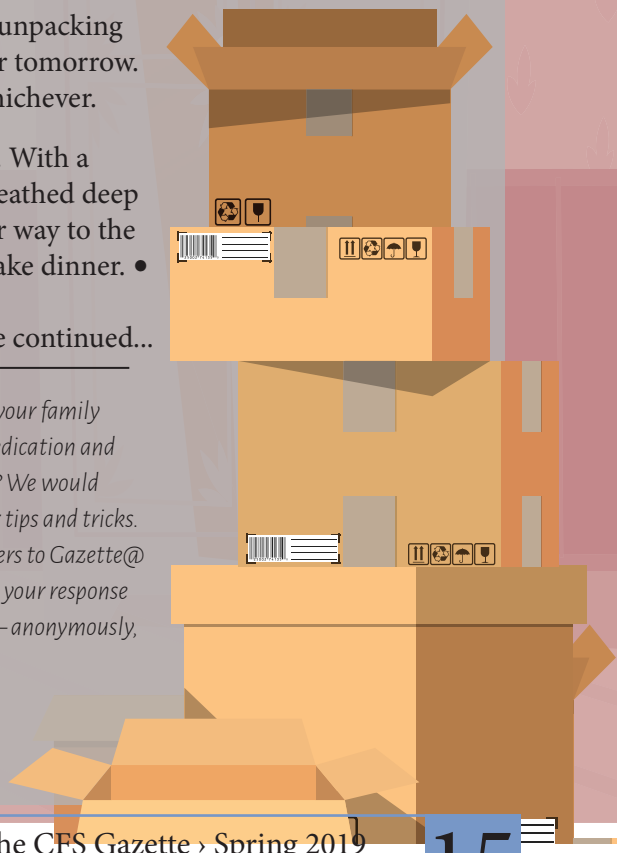
Closing the door, she glanced through the kitchen doorway at the stove. Somehow, it was past 7 o'clock. Noodles for dinner again. Naturally.

With a sigh, Sarah lugged the box to the family room, ripped open the tape and peered inside. No refrigerates. Good. The unpacking could wait for tomorrow. Or never. Whichever.

Such was life. With a shrug, she breathed deep and made her way to the kitchen to make dinner. •

To be continued...

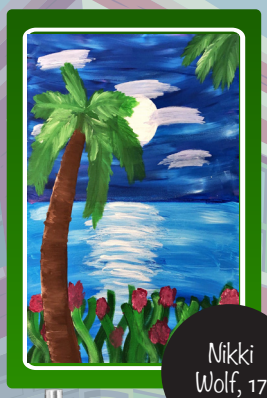
How do you and your family organize your medication and medical supplies? We would love to learn your tips and tricks. Email your answers to Gazette@cfsociety.org, and your response may be featured – anonymously, if you wish - in the next edition of the CFS Gazette.



YOUR CORNER

Nikki Wolf, 17

Anynonmous, 19



Nikki Wolf, 17

Unfinished

Elusive
Wisps of words
Floating high
Out of reach

And as I try
To grasp
Those thoughts
And dreams

Reality calls
And tugs
Persistently
On my sleeve

And fills my day
With smiles
And laughter
And messes
And meaning

And I let
Those puffs
Evaporate
In the warmth
And love

Of my family
Of my life
Of my spirit
Of my essence

Mom of a CF'er

If all illness could stand still
For only a moment
I would run against the wind
Without a care in the world
I would laugh my eyes dry
And I would never breath in
I would wonder what to do
With all my empty time
And I would be so grateful
For being given a chance to live
While all illness stood still
If for only a moment

Anynonmous, 17

COMIC CORNER

Life is short. If you can't laugh at yourself, call me, I will.

Ban pre-shredded cheese. Make America grate again.

In search of fresh vegetable puns. Lettuce know.

Big shout out to my fingers. I can always count on them.

A teacher asked her students to use the word "beans" in a sentence. "My father grows beans," said one girl. "My mother cooks beans," said a boy. A third student spoke up, "We are all human beans."

Q: What did the banana say to the doctor?
A: "I'm not peeling well."

I went down the street to a 24-hour grocery store. When I got there, the guy was locking the front door. I said, "Hey, the sign says you're open 24 hours!" He said, "Right, but not in a row!"

Q: What did one eye say to the other eye?
A: Between you and me, there's something that smells.

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