

CF Roundtable®

A NEWSLETTER FOR ADULTS WHO HAVE CYSTIC FIBROSIS

SUMMER 2021

Emergence

By Isabel Stenzel Byrnes

In out-of-the-way places of the heart,
Where your thoughts never think to wander,
This beginning has been quietly forming,
Waiting until you were ready to emerge.
—John O’Donohue

This is the season of emerging. I’m writing this as the summer unfolds: the days are getting longer and warmer, flowers are blooming, the garden is exploding with growth. Many people are vaccinated, so we are making plans, going outside, spending time with friends, and even hugging! We are emerging from our cocoons of safety. It has been a long, dark, and lonely year-and-a-half for many of us with cystic fibrosis who’ve had to take extra precautions during the pandemic. And now that a reintroduction to normal life is beckoning, I’d like to ponder the act of emergence.

Emerging means entering a new world. It takes courage to leave one’s comfort zone and enter the new unknown. We might peer out into

this changed world and see what’s next for us. For some, our homes have been a safe haven. This is a place to return to when we feel threatened or afraid. Emerging can feel shaky—full of trepidation and anxiety. Putting ourselves “out there” can make us vulnerable. Much like our eyes hurt when we emerge from a dark cave and are stunned by the sunlight, sometimes we have to take it slow and adjust before we mobilize.

Emerging will come with risks. These include physical risks in the case of infection rates or threats from the environment, but they also could include relationship risks. We may be tempted to do riskier things, we may be judged by others, or we may reevaluate who is most important in our



ISABEL STENZEL BYRNES

lives. For example, as someone post-transplant, the vaccine is likely not effective, so I’m the only one in my workplace now who does not yet come to the office. I have to explain myself, and it’s hard to stand out and need special accommodation.

Emerging from all kinds of scenarios is a common life experience, but it has greater relevance in the cystic

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EDITOR'S NOTES

Summer is in full swing and, along with that, that heat. This issue we're focusing on alternative therapies that work in conjunction with the western meds from CF clinic. **Sonya Ostensen** writes about her experiences with Reiki, massage, and acupuncture in her quest to find eastern therapies that support her existing CF regimen. She also details her side effects and symptoms following her first few acupuncture visits in her article this issue. Also in our focus topic this summer, Executive Editor **Andrea Eisenman** writes about the myriad therapies she has tried through the years: Reiki, acupuncture, reflexology, Shiatsu, and Swedish massage, to name a few. **Terry Wright** chronicles his journey to becoming an Arkansas Certified Master Gardner and an Arkansas Certified Master Naturalist. He lists the many varieties of herbs, trees, and plants used in his personal garden for helping treat various ailments. If you're wondering where to start with herbal remedies, Terry's list is a fantastic starting point.

This spring we launched our first Scholarship for the Arts and selected our first two winners. You can read about both Rowan O'Bryan and Faith Ettlich's creative pursuits and accomplishments. Be sure to check out the latest research in new treatments for bacteria in CF lungs and more in **Laura Tillman's** expertly collated "From the Internet" column this issue. **Isabel Stenzel Byrnes** writes an in-depth review of *All That Is Gold Does Not Glitter* by Sara Kominsky. Sara's new young adult novel is about Kat, a 12-year-old competitive gymnast with CF. You can read more about Kat in the review.

As a follow-up to a previous 2017 "In The Spotlight" interview, **Andrea Eisenman** talks with Suzanne Joyce about her journey through transplant and her guided meditation yoga classes on Zoom. In **Dr. Xan Nowakowski's** "Pearls of Wisdom" column this issue, they discuss the importance of allowing that some therapies, currently considered alternative, will one day become part of accepted healthcare practice standards. Xan also talks about their use of d-mannose to help prevent chronic urinary and kidney infections. **Cindy Baldwin** details common strategies used to help individuals with cystic fibrosis overcome barriers in getting pregnant in the "Family Matters" column this issue. In our "Ask the Attorney" column, **Beth Sufian** answers readers' questions about unemployment benefits. **Lara Govendo** writes about her decision to not get vaccinated and why she hates having to defend that choice in her "Live Out Loud" column this summer. **David Tarnow** chronicles his introduction to a routine meditation practice and how he has cultivated that intentional awareness through the years. He also discusses his use of autogenic drainage as an effective airway clearance in his "Savoring Serendipity" column this issue. **Mark Tremblay** affirms the benefits, psychologically and mentally, of selecting and using alternative therapies in his column. He details the important role vitamin C plays in his life for helping his immune system fight off oncoming germs.

I hope you enjoy reading this summer issue as much as I did! In the words of Effie Trinket from *Hunger Games*, may the odds be ever in your favor, Sydna.

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Information From The Internet...

Compiled by Laura Tillman

Lung Disease Evident In CF Patients Despite 'Normal' Lung Function

Signs of lung disease were evident in most cystic fibrosis (CF) patients with normal lung function in a small study, and related with a higher number of pulmonary exacerbations and longer antibiotic use. These findings, based on a mix of lung health measures, indicate that such disease can precede changes in pulmonary function, and highlight the importance of early screening to prevent CF progression. A normal FEV1 may wrongly indicate being free of disease and lead to fewer treatments being offered and lower treatment adherence. Researchers analyzed the



LAURA TILLMAN

presence of lung disease in 89 CF patients, ages 4 to 49, with normal FEV1. Lung disease was assessed by CT scans, the number of exacerbations and

chronic infections with *Pseudomonas aeruginosa* in the year prior to the study's start, and via the lung clearance index (LCI), which is considered to reflect abnormalities in the small airways and, when such changes are seen, is associated with early structural lung disease. Almost all the patients with normal pulmonary function demonstrated the presence of lung disease: 86% had elevated lung clearance index (LCI), 92% had structural abnormalities measured by CT Brody score, 21% had chronic *Pseudomonas aeruginosa* (PA) infections, and 19% had at least one major PEx [pulmonary exacerbation] requiring IV antibiotic treatment during the year previous to the assessment.

Based on these results, the researchers found that FEV1 in the normal range is not sensitive enough to identify early lung disease and therefore, it is important to follow patients with normal or slightly decreased FEV1 using

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LOOKING AHEAD

Please consider contributing to **CF Roundtable** by sharing some of the experiences of your life in writing. Read the Focus topics listed below and see if there are any about which you might like to write. In addition, humorous stories, articles on basic life experiences, short stories, artwork, cartoons, and poetry are welcome. We require that all submissions be original and unpublished. With your submission, please include a recent, high-resolution photo of yourself as well as your name and contact information. Email all submissions to: articles@usacfa.org. Or go to our website: www.cfroundtable.com/newsletter.

Summer (August) 2021: Alternative Therapies and CF. (Current issue)

Autumn (November) 2021: Caregiving with CF. How does caring for others affect your physical, mental, and social wellbeing? How do you balance the needs of your own health with the needs of those for whom you care? How has your caregiving work evolved as you have experienced changes with your CF? What resources have you found most helpful for caregiver support?

Winter (February) 2022: CF and Survivor's Guilt. How do you manage your survivor's guilt? How has Trikafta affected your survivor's guilt? What triggers, if any, exacerbate your guilt? If you have had a transplant, how has that impacted any survivor's guilt?

Spring (May) 2022: Aging and CF.



ASK THE ATTORNEY

Some States Stop Unemployment Benefits

By Beth Sufian, J.D.

Many people have submitted questions related to unemployment benefits. Some states are ending some categories of unemployment benefits early, which is confusing and causing stress for select individuals with CF who have been receiving unemployment benefits. Nothing in this article is meant to be legal advice and is only information.

If you have questions about laws related to unemployment benefits, Social Security benefits, Medicaid, Medicare, health insurance, employment, and education rights, you may contact the CF Legal Information Hotline at CFLegal@sufianpassamano.com or 1-800-622-0385.

Question: I have been receiving unemployment benefits during the pandemic because it has not been safe for me to return to in-person work and my job cannot be done remotely. I was receiving an additional \$300 per week of federal pandemic unemployment compensation benefit, but just learned that the extra \$300 per week stopped in June. I thought the additional \$300 per week of Federal Pandemic Unemployment Compensation (FPUC) benefits was supposed to continue until September 2021. Why has it ended now?

Answer: FPUC benefits have been a helpful source of assistance during the last year. The rules can be confusing because Congress adopted several laws addressing unemployment compensation during the pandemic: Pandemic Unemployment Assistance (PUA), Pandemic Emergency Unemployment Compensation (PEUC), Mixed Earner Unemployment Compensation (MEUC), and Federal Pandemic Unemployment Compensation (FPUC).

This question deals with Federal

Pandemic Unemployment Compensation, which is perhaps the most familiar and widely used unemployment compensation program. FPUC is a federal supplement offered to states in addition to the usual state unemployment benefit. FPUC was originally a \$600-per-week federal supplement offered to states under the CARES Act. However, the \$600-per-week supplement provided in the CARES Act expired on July 21, 2020. In a consolidated appropriations act, Congress extended the FPUC expiration date from July 21, 2020 through March 14, 2021, but reduced the amount of the federal supplement from \$600 per week to \$300 per week.

In March 2021, Congress adopted the American Rescue Plan Act. This further extended the \$300 per week offer of FPUC to states until September 6, 2021, which is the current expiration date of FPUC.

An important aspect of FPUC is

that the funding of the benefits is offered by the federal government to state unemployment agencies. The states, however, are not obligated to accept the offer of additional federally funded benefits to workers. States may elect not to participate, and states that have elected to participate in the expanded unemployment compensation benefits under FPUC may elect to discontinue participation at any time before the program expires in September 2021.

A small number of states have ended their participation in FPUC in June and others will end their participation in July before the program expiration date in September 2021.

Fortunately, it seems like at least 25 states will continue their participation through the end of the program in September 2021. Consequently, whether a particular worker will continue to receive the \$300 per week federal supplement to unemployment compensation benefits will depend on the state paying the underlying unemployment compensation benefit.

Keep in mind that this question addresses FPUC, but there are other federal pandemic-related unemployment compensation programs (PUA, PEUC, MEUC, etc.). While they all deal generally with unemployment compensation benefits, they all have important differences regarding eligibility and benefits. So make sure that any information you may read about changes in unemployment compensation benefits or eligibility relates to the specific program from which you receive your benefit. A person can usually check their online portal on their state's unemployment website to determine which type of benefits they are receiving.

Question: If my state ends participation in the additional \$300-per-week



BETH SUFIAN

federal unemployment benefit under FPUC, does that mean I will still receive the other pandemic-related unemployment compensation benefits?

Answer: It depends on what your state elects to do regarding its participation in the federal pandemic unemployment compensation programs. But, if your state opts out of the FPUC, it has probably opted out of the other pandemic unemployment compensation programs as well.

The FPUC that provides for the additional \$300 per week is one of three new unemployment compensation programs created in March 2020 by the CARES Act to address COVID-19-related unemployment. The other two programs are the PUA and the PEUC. Each of the three programs is designed to meet different needs, but all provide a benefit in addition to the usual and regular amount of unemployment compensation typically available under pre-pandemic circumstances.

The PEUC is an extension of the eligibility period of the usual and regular state unemployment compensation benefits. PEUC extends unemployment compensation benefits for workers who have qualified for unemployment compensation benefits, but who have exhausted the usual and regular state unemployment compensation benefits. PEUC benefits are funded by the federal government and administered through state unemployment agencies.

When the CARES Act first created the PEUC program, it was set to expire on December 31, 2020. However, like the other federal pandemic unemployment compensation programs, the expiration date was extended to March 14, 2021 by the Consolidated Appropriations Act. The PEUC expiry date was extended again under the American Rescue Plan Act (ARPA) and is now set to expire on September 6, 2021.

The September 6, 2021 expiration date relates to the time period that the

federal government will make funds available to states; it is up to the states to accept the federal funds and make them available to unemployed workers. If a state opts out of participation in the pandemic unemployment programs, then the benefit will not be available in that state.

ARPA not only extended the expiration date of PEUC, but it also increased the number of weeks a person can receive PEUC benefits. Under ARPA, an eligible worker can receive up to 53 weeks of PEUC benefits. Again, even though ARPA extended the number of weeks the federal government will make pandemic unemployment compensation funding available to states under PEUC, the states must choose to accept the federal funding for the PEUC benefits to be available to unemployed workers.

The situation is similar with the PUA. PUA is designed to temporarily assist workers who were typically ineligible for regular state unemployment compensation, such as gig workers, self-employed persons, and independent contractors. The PUA program was also created under the CARES Act, and its expiration date and maximum benefit period were extended by the Consolidated Appropriations Act and ARPA. PUA currently has a maximum benefit period of up to 79 weeks and the program expires on September 6, 2021. However, like the PEUC and FPUC, the PUA benefits are only available to workers if the state is participating in the PUA program.

Question: Which states have opted out of federal pandemic unemployment compensation programs?

Answer: As of June 26, 2021, the following states have ended or plan to end their participation in one or more of the federal pandemic unemployment compensation programs:

June 12, 2021: Alaska, Iowa, Mississippi, and Missouri;

June 19, 2021: Alabama, Idaho,

Indiana, Nebraska, New Hampshire, North Dakota, West Virginia, and Wyoming;

June 26, 2021: Arkansas, Florida, Georgia, Ohio, South Carolina, South Dakota, Texas, and Utah;

June 27, 2021: Montana and Oklahoma;

July 3, 2021: Tennessee;

July 10, 2021: Arizona.

States that continue to participate in the federal pandemic unemployment compensation programs will have federal funding for benefits available through September 6, 2021.

The most up-to-date source of information on unemployment compensation in the state where you live is your state's unemployment compensation agency. Most state agencies have current information and notices on their agency website. ▲

Beth Sufian is 55 and has CF. She is an attorney who focuses her law practice on disability law and is the Treasurer of USACFA. Her contact information is on page 2. You may contact her with your legal questions about CF-related issues at CFLegal@sufianpassamano.com.



In Memory

Paul T. Schnackenberg, 66

Bothell, WA

Died on December 30, 2020

Immediate family members may send in the names of CF adults who have died within the previous year for inclusion in "In Memory." Please send: name, age, address and date of death.

Send to: USACFA, 9450 SW Gemini Drive, PMB43881, Beaverton, OR 97008-7105

E-mail to:
cfroundtable@usacfa.org



FAMILY MATTERS

Using Alternative Remedies To Boost Fertility In Women With CF

By Cindy Baldwin

One of the first things I did when trying to get pregnant was go to the pharmacy and load up on Mucinex (guaifenesin). I'd been in a Facebook group called Cystic Fibrosis Mummies for about a year at that point, and I knew that thick cervical mucus was often an obstacle to women and trans people with CF who wanted to get pregnant—and that, for many patients, guaifenesin successfully thinned cervical mucus enough for conception to occur.

I turned out to be one of the rare people for whom guaifenesin has zero effect, but that wasn't the last alternative therapy I tried in my quest to overcome the obstacles CF placed on my path to becoming a mother. Over the years of my fertility journey, I tried special brands of sperm-friendly lubricant, herbal preparations that promised to even out my irregular cycles, and even drinking a small cup of grapefruit juice a day, which *did* successfully thin my cervical mucus. (Grapefruit interacts with all Vertex modulators, so please talk to your doctor if you're on a modulator therapy before trying anything involving grapefruit!)

I became a self-titled expert in fertility, reading book after book about the complex processes necessary to lead to conception. I learned to chart my cycles with a dizzying amount of detail, until I was able to pinpoint specific fertility problems I was having long before my doctors could.

These days, Cystic Fibrosis Mummies on Facebook has grown to

include over a thousand members, and other Facebook groups like Moms With Cystic Fibrosis have also arisen to give space to women and nonbinary people with CF who have children or are trying to have children. Although many things have changed in the decade since I loaded up my shopping cart with Mucinex, there's still a lively conversation among women with CF about alternative therapies that can help a CF patient conceive.

In this article, I'll share a few of the commonly recommended strategies that have helped some people

with CF overcome problems such as overly thick cervical mucus and successfully get pregnant. Please know that I am not a doctor and nothing in this column should be taken as medical advice; rather, see these suggestions as something that you could potentially explore with your CF care provider or gynecologist.

1. Guaifenesin to thin cervical mucus.

As I mentioned, this is one of the oldest and most-trusted alternative therapies for thinning cervical mucus in people with CF. Guaifenesin, an expectorant, helps to thin secretions throughout the body, and many patients have noticed a positive difference in the texture of their cervical mucus. Guaifenesin is sold under the brand names Mucinex and Robitussin, as well as generic labels. When purchasing, make sure to get a preparation that includes

only guaifenesin, as other ingredients in cold medicines (such as dextromethorphan) may suppress coughing and make it harder to clear your lungs.

2. Use a fertility-friendly lubricant.

For conception to happen, cervical mucus has to be the right consistency to allow sperm to survive long enough to reach an egg. In many CF patients, cervical mucus is less like egg whites and more like rubber cement, which can provide very effective birth control! There are several brands of lubricant on the market that simulate the texture of fertile cervical mucus, without including ingredients that would be toxic to sperm. Some brands include Pre-Seed, Conceive Plus, and Yes Baby. (Note that the method to use these for

I learned to chart my cycles with a dizzying amount of detail, until I was able to pinpoint specific fertility problems I was having long before my doctors could.



CINDY BALDWIN

conception is different than using a normal lubricant to make sex more comfortable; be sure to read the directions fully.)

3. Get to know your menstrual cycle.

For many people with CF, cervical mucus is the big fertility hurdle and menstrual cycles are normal. For others, however, CF can cause menstrual irregularities. Before I started on Kalydeco in 2012, it was common for me to have four periods a year at most, and not at all uncommon for me to go nine months or more without a period if I got sick. Learning to chart your menstrual cycle using morning temperature checks as well as signs such as cervical position and cervical mucus consistency can give you a wealth of information about what might be affecting your menstrual cycle. In learning to chart my own cycles, I realized that I was low in both estrogen and progesterone—something that helped me pinpoint where conception was going wrong *and* helped later, when I had to take progesterone supplementation during my pregnancy. The book *Taking Charge of Your Fertility* is a comprehensive overview into how to use

charting to your advantage; there are also many apps and websites that can help you figure out how to get started.

4. Use a menstrual cup after sex to increase the likelihood of conception.

One of the most common old wives' tales about upping the chances of pregnancy is that after sex, a woman should lay for a specified amount of time with her legs up against the wall. Thanks to modern technology, there's a much easier version of this trick! Some CF patients swear by inserting a menstrual cup immediately after sex and keeping it in for a few hours, which helps keep sperm close to the cervix for as long as possible.

5. Try supplements to regulate your cycles.

For some patients who struggle with irregular menstrual cycles, herbal supplements might help to support normal menstrual function. Two popular herbal remedies for irregular cycles are red raspberry leaf (available in tea form or capsules) and vitex/chasteberry (available in capsules). Although many cases of irregular menstruation will require more medical intervention, herbal preparations can help regulate

cycles in some cases.

For many women and trans people with CF who struggle with infertility, conception will take a skilled fertility doctor and medical interventions such as Clomid, IUI, or IVF. But if you're just getting started on your fertility journey and want to maximize your chances as much as you can, these alternative therapies can be immensely helpful in overcoming some of the common issues with CF and fertility.

In the end, I personally wasn't able to conceive until I started Kalydeco shortly after its release. Still, I saw interventions like the ones I've shared here help many people with CF conceive despite the unique challenges that CF brings to fertility! As always, please make sure that your medical team is aware of any supplements you're using. ▲

Cindy Baldwin is 32 years old and has CF. She lives near Portland, Oregon, with her husband and daughter. Cindy is the author of several middle grade books published by HarperCollins, including The Stars of Whistling Ridge, which released in June 2021.

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other clinical parameters...to early identify and treat all changes with the aim to prevent or reverse disease progression. <https://tinyurl.com/yhwardav>

P. Aeruginosa, Other Bacteria Appear To Support Each Other In CF Lungs

Two bacterial species known to be frequent sources of lung infection in people with cystic fibrosis—*Pseudomonas aeruginosa* and *Staphylococcus aureus*—can feed each other with a nutrient called purine that both need to thrive. One way these bacteria can interact is via nutrient exchange. Some bacteria are unable to make a particular metabolite,

or nutrient that provides nourishment essential for their growth, and they need to obtain it from the surrounding environment. The researchers found that *P. aeruginosa* lacking the ability to make purine — a molecule used to build other, more complex molecules that are essential for life — thrived when placed with purine-producing *S. aureus*, indicating that *P. aeruginosa* used the purine provided by *S. aureus* to grow. Previous studies have shown that chronic lung infections in CF are associated with biofilms, the communities of bacteria that attach tightly to each other and to surfaces, and that these biofilms are rich

in exogenous DNA (DNA originating outside the organism). Such exogenous DNA may be sourced from dead microbial cells or from host innate immune components. Researchers wondered whether the growth of purine-deficient *P. aeruginosa* could also be rescued by exogenous DNA that is released by *S. aureus*. They found that *S. aureus* indeed releases exogenous DNA through cell lysis (cell breakdown), but the amount was not enough to completely rescue the growth of purine-deficient *P. aeruginosa*. Next, the researchers performed a similar set of experiments, but this time

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PEARLS OF WISDOM

Everything's Alternative Until It Isn't: CF Care Beyond Allopathic Medicine

By Xan Nowakowski, Ph.D., M.P.H.

Growing up in the 1990s, I always knew on some level that being “alternative” was cool. But it wasn't until I became a medical sociologist that I realized how subjective the “alternative” label really is. In healthcare, something called “medical authority” determines what gets commonly regarded as valid treatment. This is basically a system of power and control in which people regarded as medical experts get to decide what does and does not count as legitimate care.

If you're interested in learning more about how medical authority works, I highly recommend the work of Dr. Peter Conrad, especially his book *The Medicalization of Society*. For today's article, all you really need to know is that deeming things “alternative” is a form of “boundary work.” This term also comes from sociology; it describes how people intentionally set up divisions between different things. Sometimes this is useful, of course—like labeling household cleaning chemicals as hazardous materials that should not be ingested. But sometimes it can have harmful consequences too.

Adults living with CF often understand well that what works for one of our peers may not work at all for our own care, and vice versa. This explains why there are so many different antibiotics out there that may be effective against the same bacteria—or not, depending on the person and a host of specific factors. It also explains why some of us take different pancreatic

enzymes than others or get wildly different results from the same enzyme formulary. And, at one point, none of these therapies were part of medical research or care at all!

Think about the medications you take for your own CF or the medications your loved ones take to stay well. Were all of these available when you were born? I suspect not! Regardless of whether you have CF yourself, you have likely benefited at some point in your life from a treatment that would have been considered completely

fringe—or even inconceivable—in the past. If you've gotten a vaccine for COVID-19 this spring, that's a perfect example! So when I think about “alternative” medicine, I make space for the idea that some of these therapies will one day be part of commonly accepted scientific wisdom and healthcare practice standards. My position on “alternative” treatments is thus that everything is alternative until it isn't.

I got to have one of these experiences of “alternative” therapies becoming accepted in mainstream biomedical

science and the associated “allopathic” model of medical care just a couple years ago. My particular presentation of CF—remember, each of us can be quite different from one another—has often involved recurrent infections in the bladder and kidneys. Ever since my pre-teen years I would get several bladder infections each

month that would often migrate up into my kidneys, causing damage to the membranes and a lot of pain in both areas. This cycle left me with chronic kidney disease and a host of other physical issues by my early 20s. It also impacted my mental health adversely, even leading to thoughts of suicide.

Just being on oral antibiotics constantly didn't seem like an upgrade, given I would basically have been trading pelvic and flank pain for worse GI issues and more destruction of my joints. And because I wasn't open to being on narcotic pain relievers constantly, pretty much my only option for treating the acute pain was phenazopyridine, a drug that can help with pain from urinary tract infections. Phenazopyridine definitely works, but

You have likely benefited at some point in your life from a treatment that would have been considered completely fringe—or even inconceivable—in the past.



XAN NOWAKOWSKI

at a significant cost as the drug itself can be quite rough on the kidneys.

So often I did what a lot of us do and just kind of toughed things out. You get used to living with that kind of pain, somewhat. Eventually things got bad enough that I needed surgery to remove scar tissue from my bladder. I learned to prevent some of the worst damage and scarring by taking antihistamines when I'd have infections; this at least prevented the immune cells in the membranes from attacking the rest of the tissue. But the infections kept happening, and I kept suffering.

Then one day when I was discussing all of this on my Facebook page, something I would often do in the spirit of education and awareness, a colleague asked if I had ever tried using something called d-mannose to prevent infections in the urinary and renal systems. I had to Google it; this was the first time anyone had mentioned d-mannose to me as a possible therapeutic option. This colleague said they had been skeptical about it until happening upon a significant evidence basis suggesting it may help with UTI prevention.

Finding anecdotal evidence online about the possible utility of d-mannose was quite easy. I also learned the basics of how it seems to work. D-mannose is a sugar alcohol that binds to *E. coli* bacteria, sort of like fiber can bind to fat in the digestive tract. Because d-mannose and *E. coli* have such an affinity for each other, the presence of d-mannose in urinary fluids can help these bacteria exit the system instead of sticking around and colonizing the tissue. And because it is not an antibiotic but rather something that could already be present in ambient quantities in food, there are few safety concerns with d-mannose.

So, I looked into the clinical literature to see if I could find anything there to discuss with my providers. Sure enough, I not only found some recent general studies indicating that d-mannose could be helpful but I also

found some specific literature about exploratory use of d-mannose for respiratory health among people with CF! D-mannose began as an “alternative” therapy for UTIs, made its way into the clinical urology literature, and then caught the attention of specialists in other areas of allopathic medicine. I found it unsurprising that clinicians who work with people predisposed to recurrent bacterial infections beyond the urinary system would be among the first to take interest in its potential applications beyond urology.

I consulted with my clinic about potentially incorporating d-mannose into my daily medication regimen. After I reviewed both the scientific literature and some particularly helpful educational resources from more lay-oriented sources with my CF care providers, they agreed that this would be a good approach to try for controlling my recurrent urinary and renal infections. I purchased some d-mannose caplets from a corporate nutritional supplier and began taking them daily. Not expecting much, I felt completely shocked when, within just a couple of days, I stopped having any ambient discomfort in my bladder.

I kept careful track of what I experienced over the next few weeks and presented my data to my clinic team at my next well visit. We observed clear evidence of a dose-response relationship and temporal association between me taking d-mannose a couple times daily and experiencing near-complete remission with my chronic bladder and kidney infections! I was even able to present observational data about increasing my d-mannose dosage during times when I experienced early symptoms of acute infection, and subsequently feeling the discomfort subside within a couple of days.

Two years out from this initial experience, I do feel I have sufficient experiential data to consider d-mannose an important element of my daily

care. This journey has been an eye-opening exercise engaging my own skills as an epidemiologist and medical educator. It has also given me more of a vocabulary to describe how so-called “alternative” therapies can easily become commonly accepted practice within allopathic medicine.

The beauty of evidence-based care is that there are always opportunities to develop and embrace evidence for new and exciting treatments that offer better quality of life. We see this happening constantly in the wide and diverse world of CF care. Getting to be part of the evolving science on infection control has been a fantastic experience—both because it has been an exciting intellectual challenge and because my own physical comfort has improved vastly in the process!

So today’s “pearl of wisdom” is to keep an open mind about what may lie just beyond the horizon of current clinical evidence, and to collaborate proactively with your care team on leaning into exploration of emerging therapies from the “alternative” world. Today’s complementary therapy may be tomorrow’s standard care. And that process of innovation happens more efficiently and effectively when those of us living with chronic conditions like CF get educated and activated about helping our care teams contribute to thoughtful research about emerging therapies. ▲

Dr. Alexandra “Xan” Nowakowski is 37 years old and has CF. Xan is a director of CF Roundtable, in addition to being a medical sociologist and public health program evaluator. They currently serve as an Assistant Professor in the Geriatrics and Behavioral Sciences and Social Medicine departments at Florida State University College of Medicine. They also founded the Write Where It Hurts project (www.writewhereithurts.net) on scholarship engaging lessons from lived experience of illness and trauma with their spouse, Dr. J Sumerau. You can find their contact information on page 2.



SAVORING SERENDIPITY

The Peace Within

By David Tarnow

Living with CF is something that many of us have had to gradually learn to accept at some point in our lives in order to continue moving forward with life despite the numerous obstacles and setbacks. For me, having been diagnosed at the age of three, one might think that by now I have found peace with my reality. The truth is, however, I, like many others, am not always willing to accept this fact. Nonetheless, over the years through the process of self-discovery, I have found tremendous benefit in seeking out not only professional medical help, but also long-standing wisdom contained within countless spiritual texts from cultures all around the world in an attempt to deepen my understanding of life, its purpose, and the meaning of suffering.

Anyone who knows me well also knows that I tend to overthink everything. Recently, I have come to realize that this tendency is perpetuated by my good fortune of having too much time to think—ruminating and reflecting on what was and what could have been. I often find myself bursting into tears at the most innocuous stimuli, largely, in my estimation, due to unresolved traumas past. Part of my personality is to seek deep understanding and connection with people, places, and events. In doing so, however, I often find that this results in an endless “dog chasing its own tail” scenario. To simply be present, and mindful is an act that often proves, without discipline and intention, not so simple.

When thinking about alternative therapies and CF, there are many that come to mind. Like other adults with CF, I have found myself at various points in my healthcare journey desiring more solutions, more options, and better alternatives than what the traditional western medical establishment has been able to provide. Taking up the initiative to heal, fix, and treat

myself has always been a road down which I have always been willing to travel with survival and longevity hanging in the balance.

While I continue and always have believed that you are your own best advocate, sometimes the added stress and anxiety of trying to fix yourself can become too big of a burden to bear. When you are fighting for your life, taking on the roles and responsibilities of many other specialized professionals who have far more resources, education, experience—not to mention the fact that they are getting paid to do so—can be overwhelming.

This brings me to the form of alternative therapy which I have found most beneficial: meditation. My first real exposure to the practice of meditation came about 20 years ago when I was in the 8th grade. I attended a Catholic school where a beloved religious studies teacher decided that rather than following the prescribed curriculum and teaching from a textbook, he would, instead, teach us how to meditate. I can remember sitting in the classroom, some students taking this more seriously than others, being guided to close our eyes, quiet our minds, and try to bring our conscious awareness to the inflow and outflow of our breath. When our minds were bombarded with thoughts, as they inevitably were, we were told to imagine them as one might watch an airplane pass by as it flies overhead. Observe and acknowledge their presence, but do not become attached to them. Let them come and go like the waves

“I have fallen both in and out of the practice of meditation and mindfulness but always find it beneficial when I have made time to include them into my daily life.”



DAVID TARNOW

rolling up and back down the beach. If anything, at the time it was a great opportunity to take a nap for those who were so inclined, but for others including myself, I found the whole process surprisingly relaxing. It certainly was better than having to read from a textbook. Through these guided meditations, I slowly began to understand how to bring my awareness to different parts of my body: fingers, toes, neck, etc. and recognize whether any tension or unusual sensation was present. With the addition of controlled breathing, deep breaths in and out in a deliberate manner, we learned that even if there was pain or discomfort in our bodies, there was a way to release our attachment from it. By not focusing our conscious awareness on these sensations we relinquished them of their power to cause suffering. I began to feel that maybe there was something to this.

I didn't quite understand the benefits or reasons behind the practice initially, but as I continued on into high school, group meditations became a regular part of annual class retreats when reflection and introspection was encouraged.

It wasn't until several years later, during the second semester of my junior year in college that the practice of meditation came back into focus for me personally. While attending a Mardi Gras parade in New Orleans in 2009, I and seven other innocent bystanders fell victim to an indiscriminate shooting by two young men who were tasked to do this as part of a gang initiation. I suffered an abdominal gunshot wound and afterwards, as part of the healing process, I decided to rekindle a sincere routine of meditation to help me heal from the trauma in both body and mind. I read Deepak Chopra's book, *Quantum Healing*,

during my recovery and I would regularly listen to guided meditations online. I found these very helpful as they aided me in mentally visualizing the healing taking place in my body, which I so desperately hoped for.

Subsequently, during my senior year, I elected to take a course on eastern religions. As part of the required reading for the class my professor had us read, *The Miracle of Mindfulness*, by Thich Nhat Hahn. Thich Nhat Hahn is a Vietnamese Zen Buddhist monk who has written many books on the art and practice of mindfulness. I remember being very positively impacted by the message of this book and once again was reminded of the power of bringing my awareness and attention to the present moment through purposeful and intentional breathing. In the years since, I have fallen both in and out of the practice of meditation and mindfulness but always find it beneficial when I have made time to include them into my daily life. There are many different forms of meditation and every individual should seek out that which resonates with him/her. Today, there are many books, apps, and resources available for anyone desiring to learn and benefit from this practice.

One lesser-known form of airway clearance, which I have been exposed to as a result of my meditation experience, is autogenic drainage. This organized, intentional, and controlled form of breath work has been something that I have found great benefit from at times for clearing secretions when other forms of airway clearance such as positive expiratory pressure like the Flutter, Acapella, or Aerobika are not feasible due to increased friability in my lungs which can lead to frequent episodes of hemoptysis. If you have experience with meditation

this particular form of airway clearance may come easier as it does require discipline and controlled technique which may not come easy for the inexperienced.

In sum, it is my hope that the CF community at large, including traditional and non-traditional medical providers, can take it upon themselves to be open to and encourage all methods of care and treatment for those who suffer from this awful disease. Which brings me to the final alternative practice which everyone can benefit from—gratitude. In my short lifetime, the process of drug development and the evolution of care for CF has come a long way and we all stand to benefit. Personally, I am beyond grateful for the hard work and dedication that all who are working towards a cure have put into this most noble of causes.

For me, alternative therapies have always been “on the table”—so to speak—with regard to my CF care and overall wellness. As an individual who has only recently had the opportunity to benefit from CFTR modulators, traditional CF care has always seemed somewhat lacking to me. When faced with loss, in this case with regard to health and all that that implies, I have never taken no for an answer nor believed that the only remedies are those that are prescribed by a physician. In some ways, this may have overcomplicated things for me mentally, but in other ways it has added layers of beauty and understanding for which I am ever so grateful. ▲

Dave Tarnow is 32 years old and has CF. He lives in Erie, Colorado. Dave is the founder of “Dave’s Cycle for a Cure,” which inspired the national Cystic Fibrosis Foundation event now known as “CF Cycle for Life.” You may contact him at dtarnow@usacfa.org.

fibrosis experience. In the simplest of ways, many of us have emerged from the MRI machine or the OR relieved that *that* was over. I remember emerging from so many long hospital stays, with wobbly knees and weakened muscles, inhaling the fresh air outside the hospital with great appreciation. It felt so good to be free again, but I'd have to learn to return to normal activity. It meant returning to school or disclosing to others about why I had been gone for so long. And, after my transplant, I remember emerging from the protected indoors and taking off my mask outdoors for the first time and inhaling. I felt both scared and mischievous, like a little child courting trouble. It was just a breath, but my first as an immunocompromised person. I felt both bold and terrified, together. I was overwhelmed with gratitude at this miracle.

Those with CF who've had a transformation in their health, either with a modifier drug or transplantation, serve as a symbol for emergence. It has been thrilling to witness some of my CF friends skyrocket into health after years of unpredictable disease. One friend is backpacking like crazy, untethered from treatments. One was traveling the world (before COVID-19 hit). One had a baby. One went back to graduate school. Our futures, opportunities, and newfound health offer tremendous hope and possibility. We need to find our next plan and purpose.

Emerging can lead to psychological transformation as well. The word itself implies having a new start or a new perspective. After a difficult experience, we can emerge with increased confidence and self-awareness that makes us capable of facing another challenge. I remember so many times as a child, after I was discharged from the hospital, I was more determined than ever to stay out of the hospital. I'd start jogging on my wobbly legs and try my best to keep my lungs clear. *This time it'll be different*, I'd think, with a fierce spark of motiva-

“ Emerging can feel shaky—full of trepidation and anxiety. Putting ourselves “out there” can make us vulnerable. ”

tion to fight my CF.

And what can emergence do for spiritual transformation? Of course, there are many examples of spiritual transformation in religion. When Noah emerged from the Ark after surviving the flood and found dry land, he built an altar to make an offering to the Lord. God blessed Noah and told him to repopulate the Earth. When Jesus emerged from 40 days and nights in the wilderness, where he was tempted by the Devil, he was ready to begin his ministry. When Buddha emerged from his protected and opulent palace, he was stunned to witness all the suffering and struggle in the outside world. He pledged to study meditation, the ancient doctrines, and achieve Enlightenment.

As we emerge from this strange time of the pandemic, we have the choice to be changed inside. We might have a renewed appreciation of our friends and family, of access to food and toilet paper, of a hug, of a restaurant meal, of essential workers, of vaccine research. We might shift our priorities and decide what really matters. Some of this is made evident by the “resignation boom” seen in our country. We also might reevaluate how we spend our time and decide the slower pace of sheltering life is healthier than the busy pre-pandemic rat race. Perhaps we might even have spiritual intentions to emerge from this pandemic with greater faith or stronger spiritual practices. With all that's on the news, maybe we pledge to be kinder, more compassionate, and non-violent toward others. I know I have a new commitment to surrender my fears of the unknown to my higher power.

As we remember the 600,000 Americans who have died from this pandemic, including at least 11 people with cystic fibrosis (as of March 2021, per cff.org), we feel lucky to have the chance to reenter the world again. Dr. Elisabeth Kübler-Ross became a profound believer in life after death after studying dying people for decades. She believed that in this life, our bodies are a chrysalis, and, after death, the soul emerges from this shell and becomes a butterfly. It is free to roam and fly, unencumbered by the body. And so, I'd like to believe that the victims of the pandemic, too, have their own chance to emerge into a better place.

I acknowledge and truly respect my CF peers who actually did not have the luxury to seclude themselves during the pandemic. Those include essential workers and healthcare providers living with CF. While I have worked safely from home, as a grief counselor I have been a front-line worker in a different sense—in mental health. I am changed forever by the suffering I have witnessed. It sure puts CF into perspective. I am deeply grateful for my CF community that has spared me from burnout, depression, and isolation. I emerge slowly from this pandemic with a renewed intention to enjoy life, to work less, to cross more things off my bucket list, to strengthen my body, to love more fully and to not take my relationships for granted. I hope you, too, can ponder what will change for you after your post-pandemic emergence. ▲

Isa Stenzel Byrnes is 49 years old and has CF. She lives in Redwood City, California. She is 17 years post-lung transplant.

Recipients Of The Arts Scholarship Announced

The U.S. Adult CF Association (USACFA) is pleased to announce the recipients of the Scholarship for the Arts, offered in memory of Helen M. Eisenman. We offer this arts scholarship in Helen's memory—she was a Holocaust survivor with a passion for the arts. A talented photographer, she eventually earned a reputation as the “Doyenne of Subtitles” within the film industry for her skills in subtitling films in multiple languages. She made many sacrifices over the years so that her daughter, Andrea, who has cystic fibrosis, could live as long as possible. Helen always encouraged Andrea to be creative, read books, appreciate museums, and listen to music.

In our evaluation, we look for students who demonstrate tremendous artistic creativity, originality and achievement, community involvement, and a powerful understanding of how their CF—matched with their creative endeavors—places them in a unique situation to impact the world through their art. The scholarship is open to anyone seeking a degree, from an associate to a doctoral degree, in the creative arts: fine arts, computer graphics, design, music, choral, photography, filmmaking, creative writing, and poetry, to name a few.

We are pleased to announce **Rowan O'Bryan** and **Faith Ettlich** as the recipients of this year's arts scholarships. They will each be awarded \$5,000.

Congratulations to both!

Rowan O'Bryan is an accomplished young woman who prominently features her disability, and what that looks like, through the medium of digital and film



ROWAN O'BRYAN

photography. Rowan is currently a student at UCLA, where she is pursuing a degree in fine arts as well as a double minor in both American Sign Language and disabilities studies. Rowan volunteers with various CF organizations. Through her art, she aims to advocate, fundraise, support, and inspire people with intersecting disabilities who face additional barriers and isolation.

Faith Ettlich is a homeschooled high school senior attending Gordon College in Massachusetts this fall, pursuing a degree in piano performance. In addition to her

artistic pursuits, she's active in musical theatre, Tae Kwon Do, swim team, church youth groups, and the American Red Cross. Faith has extensive experience volunteering throughout her local communi-



FAITH ETLICH

ty, from various CF organizations to art organizations and other governmental entities. Faith hopes to one day accompany ballet companies, musicals, classical choirs, or other smaller music venues.

Scholarships are offered in the spring semester each year. More information, including the application and relevant deadlines, can be found on our website. For questions about future scholarships or anything related to the application process, please contact us at scholarships@usacfa.org. ▲



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FOCUS TOPIC

ALTERNATIVE THERAPIES AND CF

An Open Mind To Alternative Medicine

By Sonya Ostensen

I have always gravitated toward alternative therapies to add to my repertoire of CF care. For years, I often felt like a lab rat in some bad science experiment. The clinicians in my CF team in Columbus, Ohio, were amazing, competent, and caring. However, back in the 70s and 80s, and even the early 90s, cystic fibrosis treatment options were limited. For 30-plus years I took a lot of the same medications and nebulizer treatments day in and day out. Years and years of heavy antibiotic doses and steroid treatments take a toll on the body—inflamed joints, damaged veins, kidney damage, early tooth decay, and tinnitus to name a few. Don't get me wrong, I realize I would not be writing this article right now if it were not for those doctors and the science of western medicine. However, the eastern medical approach to treating disease was captivating as I have discovered additional treatments that could possibly prolong the next “clean out” and help my body best deal with medication side effects.

Eastern medicine takes a whole-body approach to treating illness. Having originated out of Asia, it focuses on balancing the entire body. Alternative therapy treats the body, mind, and spirit, all of which make up an individual's life force or qi (a/k/a chi). Both eastern and western medicine have evolved for thousands of years. The western medicine approach was developed by the Greeks and incorporates a scientific, evidence-based diagnosis that focuses on treating the symptoms. Both philosophies have their merits and, since their paths often cross, it only seems natural to try

to incorporate therapeutic treatments from each spectrum.

The first alternative therapy I tried, and still love to this day, is massage therapy. It is my go-to when it comes to sore coughing muscles. There is a seemingly vast array of types of massages. I have found that deep tissue massages are too much for my body. The result



SONYA OSTENSEN

ends up agitating whatever inflamed muscle group I have, which is painful and causes my body to tense up rather than relax. Personally, I favor the Swedish massage, which has the right mixture of gentle pressure to work out the kinks.

Reiki is another therapy that has yielded positive results with helping body fatigue and pulled muscles. I will never forget my one and only profes-

sional Reiki session. I was super stressed from work and physically exhausted from constant coughing fits throughout the day and night—basically on the verge of yet another hospitalization. The Reiki specialist never touched my body. Instead, she held her hands over me as I lay on a massage table and moved them above my body to administer healing energy. She went from chakra to chakra: there are seven total, starting from the root at the base of your spine and continuing to the crown of your head. With my eyes closed I could feel calming waves of sensation run through my core. I will never forget the coolest and strangest feeling as she went over my left lung, creating a deep inner vibration within the individual lobes. It just so happens that my left lung is in the poorest condition and was often where infections usually began. Afterward, we sat down and discussed what I had felt versus what she had felt during the session. She told me that all my chakras were on fire...awesome! I thought, yeah, baby, I still got my mojo; and then she explained this was not good and that my entire body was inflamed. Regardless of being metaphorically on fire, I walked out of there feeling energized, refreshed, peaceful, and, this may sound hokey, but I swear I had a euphoric glow (of course that could be due to the chakra fire thing). Overall, I would try Reiki again despite insurance not covering the therapy. Unfortunately, when I got around to booking another appointment, the facility no longer offered Reiki. I have yet to take the time to seek out another recommended Reiki master, but all in due time.

Acupuncture, another alternative

therapy, has always fascinated me. A lot of my peers could not understand why I would want to subject myself to more needles; however, needles do not bother me and are just another tool in life needed to survive, and acupuncture needles are so tiny you can barely feel them. I finally found a highly recommended acupuncturist and started treatments this past April. Dr. Peter Shaw is a seasoned Chinese acupuncture doctor located in Melbourne, Florida. As we sat down in his peaceful office to go over my paperwork, we began to discuss my ailments. My main complaints for the day included achy sore joints, sinusitis, and peri-menopausal symptoms. He asked to feel my pulse and took

body's energy systems known as meridians. There are 12 principal meridians that circulate throughout the body. Each meridian carries the energy life force or qi and relates to an organ or group of organs. He described the meridian systems by using the ocean's currents as a metaphor. The currents continually circulate nutrients, shape land, balance ecosystems, affect weather patterns, and are the Earth's main sustenance to life. Just like the ocean's currents, the meridian systems in the body also circulate to keep us balanced and nourished promoting optimum health function. When the ocean currents are interrupted there are great consequences that affect the health of our planet's ecosystems. The same is

fatigued and spacey as I walked out of the clinic equipped with a four-day supply of Chinese herbs to aid with digestion, along with instructions to drink large quantities of water and avoid all the things I love like coffee, spicy foods, and alcohol.

After four days of taking the herbs 15 minutes before each meal and avoiding everything as instructed except coffee (my family's safety would have been endangered), I noticed a massive difference. My stomach did not bloat immediately after eating, gas decreased, and bowel movements became more regular. On the sixth night however, I experienced sharp cramping and constipation. Dr. Shaw said my body was trying to move the built-up toxins out of the large intestine.

During the second acupuncture session (one week after the first appointment) I had 12 needles that targeted digestion flow and achy joints. He placed one needle in the left forearm, one in the right hand, and more in the top of my feet to stimulate the whole-body meridians. Halfway through, Dr. Shaw came in and realized I had a migraine. He placed a needle in my temple and the migraine instantly disappeared. I was given more Chinese herbs (stronger dose) to take for four days before each meal for digestion flow. This time I felt very tired and spacey, but also my joints were noticeably more irritated. I reasoned that it was probably sensitivity due to deteriorated tendons from years of quinolone antibiotics. However, it took longer than I suspected to recover my energy and my joints felt worse, as opposed to better. I decided to cancel the next week's appointment to take a break with the intention of going back on the fourth week. However, life happened with the end of my daughter's school year and now there is little time to spend half a day doing an

Continued on page 21

“ Dr. Shaw, who has never treated or met me, knew in just a few minutes what my symptoms were simply by feeling my pulse! I was blown away. ”

my hand, placing it on a small pillow on his desk. Dr. Shaw closed his eyes while feeling my pulse and turned his head almost as if he were listening to a secret. Then he asked if I had been having a lot of stomach pain. Eureka! Yes, I have been having a massive amount of digestion issues. For the previous four months I was experiencing a lot of bloating and gas, along with inconsistent bowel movements—constipation one day and the opposite the next. That is when it dawned on me how out of touch I had been with my body recently. Dr. Shaw, who has never treated or met me, knew in just a few minutes what my symptoms were simply by feeling my pulse! I was blown away.

Dr. Shaw began to explain that acupuncture works by unblocking the

true when our energy channels become blocked possibly due to bad living habits (diet, lack of exercise, and addictions, to name a few), trauma, or stress, which cause an imbalance resulting in disease, in turn affecting our spiritual, physical, and/or mental health.

My first acupuncture session included nine different needles in my legs, feet, and right hand that targeted the digestion meridian channels. Dr. Shaw would come in about every 15 minutes, feel my pulse and either adjust a previously placed needle or add more. I could not feel any of the needles initially go in, but there were crazy sensations that reminded me of an electric wave traveling to different parts of my body as he adjusted the needles to the accurate point on each meridian. The session lasted over an hour. I felt



Natural Herbs And Remedies As Alternative Medicine In Caring For My Cystic Fibrosis

By Terry Gene Wright

Medical Waiver: none of the plants and herbs in the article below is intended to replace recommended treatment from your CF physician or care clinic. Please consult with your doctor before adding any herbal and therapeutic remedies to your existing regimen.

As I reflect on my health journey throughout my life, I am amazed that I will turn 59 on August 16, 2021. But I'm all the more astonished and grateful considering that I was not diagnosed with cystic fibrosis (CF) until the age of 54. This means that I went almost five-and-a-half decades without access to the appropriate western medicine and treatments that are often so desperately needed for CF care.

It took an extreme and devastating health crisis (that went unnamed for decades) in my life to help me fully embrace something that my grandmother, the late Clara Bolden, had instilled in me from an early age—herbs can contribute to good health and better quality of life and wellbeing. My first memory of being in a garden or around plants was at the age of 13 when I assisted my grandmother, who ran our family's own chicken yard and garden located by the original Little Rock Airport. At that young age, not only did I assist with my grandmother's chicken farming and gardening endeavors, I also became an integral part of ensuring her garden's continued growth and success.

Following my 1981 graduation from Little Rock's Hall high school and the unfortunate death of my beloved grandmother—which led to the abandonment of her longstanding home, chicken



TERRY GENE WRIGHT

farm, and garden—my health began to worsen (including having difficulty breathing and severe stomach pains), but my love and passion for herbs, gardening, and horticulture continued to blossom all the more. These two extremes in my life would soon expand to new heights and intersect in ways I couldn't even begin to imagine.

In my 20s, I was determined not to let my grandmother's land go barren. I started to plant an array of herbs and plants to which my adopted mentor, Curtis Johnson, introduced me. I also quickly learned how even just the smell of certain herbs would calm my anxiety. Needless to say, it didn't take long for me to recognize that I had a God-

given gift and a unique green thumb. I felt like I was on the same growing field as the herbs, plants, and the very land itself. I knew I had so much more to learn, which I continued to do faithfully over the next two decades.

In 2010, I was hospitalized yet again for the typical double pneumonia, sinusitis, bronchitis, and an array of other medical issues. However, during this particular stay, I received a phone call that would change the course of my herbal studies for the better. I received an opportunity to interview for a program to study for and become an Arkansas Certified Master Gardener. I gladly interviewed right from my hospital bed, which became my temporary home and office for over a month. Following my discharge, I learned that I was accepted into the program, which further cultivated my longstanding passion for gardening.

I earned the title of Arkansas Certified Master Gardener in 2010 after completing all of the required coursework and extensive training. The following year, I also became an Arkansas Certified Master Naturalist. Now, it was time for me to step up not only my herbal game but my health, which continued to experience its share of ups and down with surgeries, pain, suffering, and unforeseen events. Although I did not yet have the answers as to the root of my health issues, I did know that my expertise in plants and herbs would help me in alleviating some of the symptoms from my recurring and thus far undiagnosed medical issues. As such, my garden of roughly 150 trees, plants, and herbs spread across multiple garden beds and became my medicinal haven and edible landscape.

Continued on page 21

THROUGH THE LOOKING GLASS

Vrksasana

Magnificent tree
reaching upward toward the sky
grounding me

Miraculous breath
flowing throughout my body
sustaining me

Mind, body, spirit
seeking balance and wholeness
strengthening me

-R. Petras, 2000



PHOTO BY STEPHEN BOYER

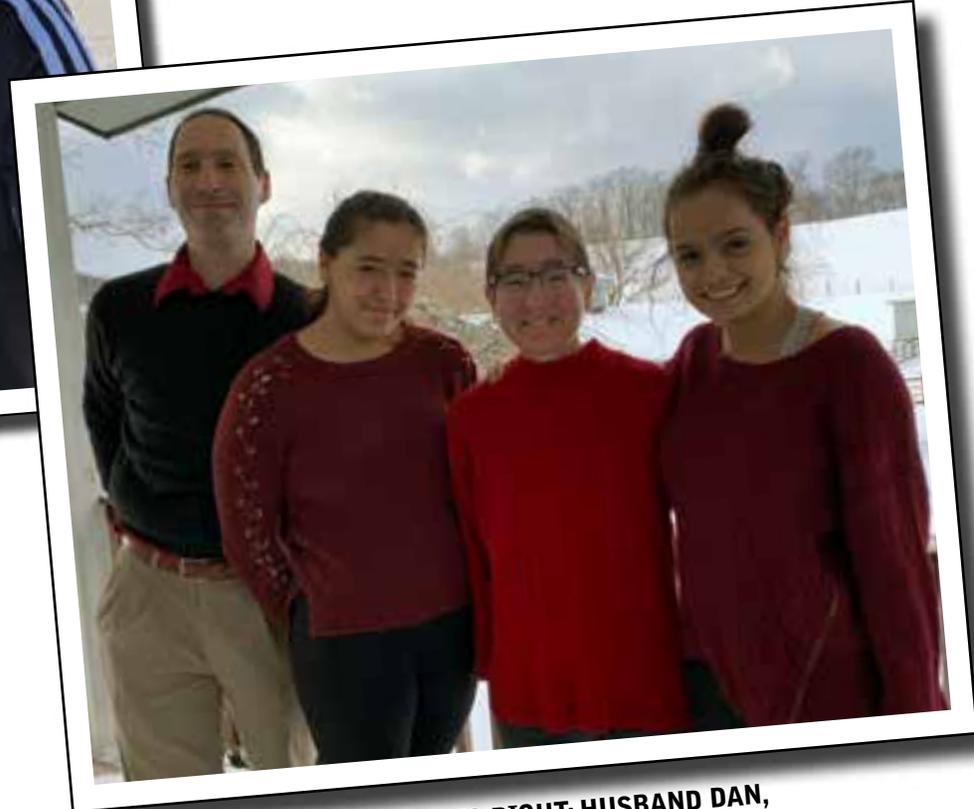
FROM OUR FAMILY PHOTO ALBUM...



ANDREA EISENMAN AND HER DOG, WILLIE, SIT AT THE BEACH IN HAMPTON BAYS.



SUZANNE JOYCE AND JADE SHARE THE COUCH.



THE KOMINSKY FAMILY, LEFT TO RIGHT: HUSBAND DAN, DAUGHTER SOLANA , SARA, AND DAUGHTER CECELIA.



NEW GRANDPARENTS, JOHN AND JEANIE HANLEY, ON CLOUD NINE WITH THEIR TWO-WEEK-OLD GRANDDAUGHTER AMELIA MARIE HENDRICKSON.



TERRY AND MICHELE WRIGHT ARE STRIPPING HOREHOUND (MARRUBIUM VULGARE), A BITTER PERENNIAL HERB OF THE MINT FAMILY HARVESTED FROM THEIR LAND, TO MAKE A COUGH TINCTURE.

KURT, MAISLYN, AND SONYA OSTENSEN ENJOYING A SUMMER ADVENTURE IN DOMINICAL, COSTA RICA.





BOOK REVIEW

All That Is Gold Does Not Glitter

By Sara Kominsky

Reviewed by Isabel Stenzel
Byrnes

Sara Kominsky, 49, with CF and two bilateral lung transplants, has contributed another lovely piece of art to the CF literature genre. Her book is written as a novel and targets both tweens and teens. In a very short and easy-to-read book, Sara captures every aspect imaginable of living with CF.

Kat, the protagonist, is a 12-year-old girl with CF who is also a competitive gymnast. She loves her sport and is exceptionally good at it. Yet, she also endures what all of us with CF endure: a long and detailed regimen of caring for her respiratory, nutritional, hydration, and sleep needs. She is unusually driven and somewhat unrealistically independent in her healthcare management. She is hyper-educated about her disease thanks to Google and has a great medical team. She has supportive, yet stressed-out, parents and a younger brother with advanced CF. She distracts herself with a focus and passion for gymnastics, which helps her feel good about herself because she can identify as not just a CF patient.

Sara captures the reality of a modern-day family coping with CF. She describes siblings having to be six feet apart and wearing masks. She captures the parents' dynamic of managing two children with CF. The book does not shy away from tackling heavier topics, like the fear of mortality, that kids with CF endure. Kat grieves a recent diagnosis of CFRD and lives with anxiety about getting sicker or losing her brother. Despite being a high achiever, she also lives with the possibility of losing her ability to be a gymnast.

I appreciated the creative affirmations that Kat tells herself to keep her-

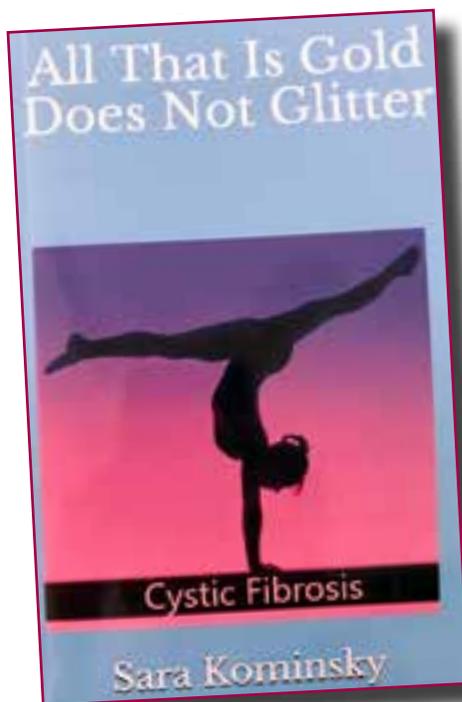
self motivated and driven. She refers to a favorite poem that helps her see herself as carrying the poise of a puma, the might of a mountain lion, the confidence of a cougar, the perseverance of a panther, and the courage of a catamount. The use of a metaphor that aligns Kat's determination to persevere—whether on the beam and bars and even behind the nebulizer mask—to these elegant and valiant felines, is beautifully realized.

Another impressive aspect of this novel is that Kat is open with her friends and her fellow gymnasts about having CF. There is little shame or discomfort about others learning about Kat's special needs. I hope this accurately reflects what many 12-year-olds

are dealing with these days.

This is an excellent book for educating young readers about cystic fibrosis. There is a comprehensive glossary at the back of the book, and she sprinkles educational facts about the progress of CF research and care before each chapter. She includes characters who are facing other issues with their CF that she has not yet had to deal with—hemoptysis and a friend with end-stage CF who needs a lung transplant. For young kids or teens who do not have CF, this book is a very informative resource. As a CF adult incredibly familiar with the CF regimen, however, I honestly found it challenging to review the concentrated medical detail in this book which ultimately

“Sara captures the reality of a modern-day family coping with CF.”



distracts from the storyline and plot.

The book covers a span of a few weeks until Kat has her State Championship gymnastics meet. A lot happens in just that short amount of time, yet the gymnastics meet is the climax of the story—the reward for all the effort she has exerted to survive. It is a feel-good ending. Like any CF story, this book will help school-aged kids, tweens, and teens with CF feel less alone if they know there is a character like them in the story.

This book is available on SaraKominsky.com or Amazon.com. ▲

Isa Stenzel Byrnes is 49 years old and has CF. Her column, Spirit Medicine, is featured in every issue of USACFA. She lives in Redwood City, California. She is 17 years post-lung transplant.

Fruit trees: pomegranate trees, peach trees, plum trees, persimmon trees, lemon trees, lime trees, and orange trees;

Countless plants and herbs: basil, rosemary, sage, thyme, oregano, chives, hardy hibiscus, hyssop, bloody dock, lavender, mullein, fennel, horehound, pineapple sage, peppermint, spearmint, pineapple mint, garlic, ginger, eucalyptus, menthol, echinacea, bee balm, lemon balm, and beauty berry;

Even more fruits and vegetables: poke salet, prickly cacti, passion flower, blueberries, blackberries, *muscadine grapes*, strawberries, tomatoes, cucumbers, squash, string beans, lettuce, broccoli, brussels sprouts, corn, bell peppers, collards, turnip greens, sweet potatoes, okra, cabbage, jalapeno peppers, onions, leeks, cantaloupe, honeydew melon, and watermelon;

Numerous other flowers: sedum, elephant ear, coreopsis, wormwood, vertigo grass, ligularia, angelonia, begonia, portulaca, butterfly bush, coleus, salvia, artemisia, gaura, zebra grass, sunflower, marigold, nasturtium, gunnera, vinca, phlox, roses, Japanese maples, daisies, yarrow, astilbe, creeping speedwell, ajuga, and celosia, among many others.

I further assured the success of my multiple gardens by making my own

uniquely created compost and utilizing rainwater (collected via rain barrels attached to gutters) in lieu of regular fountain water, all while maintaining my current status as a Master Gardener and Master Naturalist. I was pleasantly surprised to be awarded the 2016 Pulaski County Master Gardener of the Year, in addition to being a finalist for the 2017 Arkansas Master Gardener of the Year Award.

Interestingly enough, 2017 was not only a year for award recognition, it was also, after 54 years, the year for finally getting the correct diagnosis—cystic fibrosis. With this new diagnosis, I could finally receive the much-needed treatment I so urgently needed. The greater news was that I could continue to cultivate and utilize my deep-rooted passion for gardening, nature, agriculture, and horticulture coupled with my natural acumen and inclination for medicinal herbs to supplement my newly prescribed CF treatments:

- Anxiety: hops have long been used for stress and insomnia.
- Colds/flu: garlic aids in fighting an array of viruses.
- Headache: feverfew helps with fevers, headaches, and migraines.
- Mucus: elecampane is used for lung disease, including asthma, bronchitis, and whooping cough.

- Nausea: peppermint, such as peppermint tea, not only calms nausea but the nerves as well.
- Pain: turmeric helps to relieve pain by helping to reduce inflammation.
- Stomach aches: ginger is warming and calming to the digestive tract and assists with stomach upset, indigestion, and even nausea. It also has antimicrobial properties that help combat many common stomach bugs.

Love: the rose is not only the symbol of cystic fibrosis, but also the symbol of love. My mother's name is Rose; everything I initially learned about love stemmed from her petals. The rose flowering plant has a very calming smell. It makes you not only feel the love for your journey, but for the beauty of plants, herbs, and gardening. That's my story and I'm sticking to it! ▲

Terry Wright is 58 years old and has CF. He is a director for USACFA. He is a Certified Master Gardener, Master Naturalist, and Expert Agriculturist and Horticulturist. Terry lives in North Little Rock, AR, with his wife Michele R. Wright, Ph.D. Together, they are the founders of the National Organization of African Americans with Cystic Fibrosis (NOAACF). He can be contacted via his website (<https://noaacf.org>) or via email at noaacf@gmail.com.

acupuncture treatment.

Overall, my digestion was noticeably better post-treatment, in coordination with the Chinese herbs. I am thinking my joints would improve with acupuncture, but it will most likely take time and quite a few sessions. One thing that stands out is when Dr. Shaw said that the idea is for me not to have to come back. He said that his treatments are not meant as a lifetime prescription; instead, the purpose is to get my body back into balance and working

as efficiently as possible. Ironically, eastern medicine now resonates with me more today because of my improved health due to the recent progress that western medicine has made in CF treatments (modulators). These western medications are adding quality and longevity to our lives, in turn making our bodies more receptive to alternative therapies. ▲

Sonya Ostensen is 45 years old and has CF. She lives in Melbourne, Florida, with her

husband and daughter. She received her Bachelor's in Science in Environmental Sustainable Resource Management from Ohio State University. She loves to travel with her family and experience new cultures, and she has a passion for wildlife rehabilitation. Her favorite activities include gardening, baking, walking the beach, and climbing trees with her beautiful daughter. Sonya is a CF Roundtable director. Her contact information is on page 2. You may also message her through Facebook at [Facebook.com/Sonya.Ostensen](https://www.facebook.com/Sonya.Ostensen).



Open To New Treatment Options

By Andrea Eisenman

My life would have ended in my early 30s were it not for western medicine—lifesaving new drugs like Pulmozyme, TOBI, and, most importantly, a truly life-altering double lung transplant. But I also knew complementary care, which I was offered just a few days following my transplant and was already utilizing prior to my operation, was something that made me feel better in the process.

I have written extensively before on my experience with acupuncture: how it helped my diabetes, my sinuses, and how it gave me a calmer mind. I have also used it for effective pain management. However, it is something that has to be done to me by a practitioner; it is not something that I can do for myself. Although my acupuncturist did send me home with needles a few times and told me where to place them—reassuring me it is more the *intent* than the accuracy that mattered—I prefer to leave it to the professionals.

This acupuncturist also introduced me to massage therapy—Swedish, Shiatsu, and reflexology. As a result of the spinal fusion I had when I was 16, the nerves in my back and parts of my buttocks are very sensitive due to the rearrangement of muscles and nerves during the surgery. Because some areas were scarred and nerve-sensitive, having a back massage was not so pleasurable. Initially, getting therapeutic massages were too intense but, eventually, I acclimated to the intensity and felt that moving the stiff muscles and scar tissues did provide relief. I had better flexibility and less pain afterwards; I just had to be open to it.

During the pandemic, I steered clear of getting a massage or acupuncture for fear of being in a small enclosed room with another person, even with

us both wearing masks. My transplant doctors and the news scared me so much, as I knew how vulnerable I was, and still am, of dying from COVID-19, so I adhered to the guidelines and limited my exposure to everyone, even if it meant missing out on some healing from a practitioner.

While at the acupuncturist's office, I was treated first with Reiki before my acupuncture treatments. It relaxed me



ANDREA EISENMAN

and took my mind off my worries, which were always swirling around me. I was a bit obsessive about my own health, my mother's health, my good friends with CF, etc. My Reiki master mentioned that I could learn to treat myself, so I looked up classes and workshops and enrolled. I am not into angels and woo-woo stuff helping me, so I happened to find a down-to-earth practitioner and learned the first and

second degree (level) of the three total degrees of Reiki within six months of each other. I was told that, to truly benefit from Reiki, I must practice every day, so I tried to make it a priority. It worked nicely with my need to rest each day in the early afternoon. It worked so well that I drifted off to sleep for about 60-90 minutes after or during my practice most days. It was like hitting a restart button. I woke up feeling refreshed and ready to tackle things I was putting off. Reiki even reduced my migraines, so that I was not always taking medication for them. I loved it so much and felt it empowered me to help myself, so I became a Reiki master in 2016.

I was also able to practice Reiki on friends and family. Many loved it, especially my mom who had had an intestinal blockage. After she had a stoma placed and then had her intestines reconnected, she must have had a lot of scarring. This helped her when she was in frequent abdominal pain. To this day, it still helps with my back pain. The effects of therapy don't last forever but they do tamp down the pain so I can function more effectively. Sometimes, when I have my hands on a placement near my eyes, I can hear the clicking of my sinuses opening and at times I feel them draining.

During the pandemic, knowing Reiki and practicing it every day has been a huge boon to my wellbeing. It has alleviated stress and even anxiety during the height of the COVID-19 pandemic.

Currently, I am battling extreme back pain due to my spinal fusion. My lower spine is drifting away from the fusion just above my sacrum. My doctors noted the appearance of arthritis and degeneration after a recent X-ray.

These are causing nerve pain, which affects my everyday life and much of what I enjoy doing: walking, playing tennis, riding a bike, and swimming. I like to stay active for my lung clearance. Working out also puts my mind at ease. I guess the post-workout endorphins are a thing!

I have been seeing a wonderful physical therapist to help with my back pain. I have seen several different therapists over the course of the last 12 years as my fusion/spine started separating. So far, this new place is the best—they treat my individual needs, they don't go by a book, and they really tailor my exercise homework specifically to me. That said, this PT is young and always curious. He has been taking classes on weekends on vascular and visceral techniques. It is starting to help me without hurting me. Initially, my muscles in my quadriceps were tight and pulling the front of my body down so he had to use acupuncture needles and electric stimulation to overcome that. Honestly, this was not pleasant but helped me stand up straighter instead of walking with my head down and butt out (like I was an octogenarian). Loosening these muscles also released my knees, which were also a problem. I had a meniscus tear that had to be surgically fixed two years ago by laparoscopic repair. Yes, I think all of the years of prednisone use has worn down my joints, muscles, and tendons. But this PT is helping me get back to the things I love and move without so much pain.

I am now learning the benefits of visceral work. So, while I may not be able to do this to myself any time soon, I am open to receiving this treatment from the PT, along with strength-building exercises to do at home (just another thing to add to my already full dance card during the day). Solving my physical problems reduces my stress and

anxiety, too. I do start to get depressed by all of my limitations.

Don't get me wrong, I also use a foam roller and lacrosse balls to get into my sore muscles at home. I learned to do this at the current physical therapy place. I roll out my quads and IT bands every day and do a "couch" stretch. Plus, I execute other passive movements when I do not have enough time to do a strength-training circuit. Stretching is very helpful, especially since I do many of my daily treatments while seated.

The orthopedic surgeon I saw regarding my back noted that I am not

and ready to schedule my ablation with the hopes of eradicating my back pain.

To help ease the nerve pain from the first trial, my PT worked his magic using a visceral treatment he just learned. I have no idea how he does that, but I walked out of there virtually pain free. Somehow, it also cleared up my gut. I do not need to know how or why, I just appreciated that I was no longer in such intense pain.

While the nerve ablation changes nothing structurally, it can reduce pain for about six to 18 months. During that reprieve, I will have to work hard on building up muscles to

“During the pandemic, knowing Reiki and practicing it every day has been a huge boon to my wellbeing.”

a good candidate for another spine surgery, so other options need to be exhausted first. For the last few months, I have been seeing a pain management doctor. He suggested looking into nerve ablation therapy because the steroid injections into my spine didn't work as intended. For ablations, he has to do two trials called a Medial Branch Block, where he injects lidocaine into certain branches in my spine. The first trial reduced my discomfort by 80-90%. However, for the first few days after the injection, the nerve pathways in my lower back were on fire. It was horrible. I was sure this procedure didn't work for me. When his nurse called the following day, she said they only want to know about the first day—how much pain relief I had and how long it lasted. As it turns out, the procedure did work! My second trial was less painful, but I still had some soreness the next day. It seems I am done with the trials

keep supporting my back and tighten my core. The nerves do regenerate, but, for the last year I have not had a major reduction in pain that lasted more than a few days or so. I'm hoping the ablation changes that. The rest of my body is a bit of a mess, so I hope to continue with my PT to resolve each area of disaster one at a time using visceral work.

On my quest to feel good and look for new possibilities to ease my pain and gain strength, I try to remain hopeful, stay active, and stay open to trying new things. It has gotten me this far. ▲

Andrea is 56 and has CF. She lives in New York, NY, with her husband Steve and dogs, Willie and Roscoe. Andrea is the Executive Editor for USACFA. She enjoys cooking new recipes, playing pickle ball, biking, tennis when possible, and staying active as her health allows. Her contact information is on page 2.



CF: THE MIND GAME

Using Every Arrow In Our Quiver

By Mark Tremblay, M.A., M.P.A.

It seems alternative therapies or ancillary treatments inevitably come up whenever CF folks gather, which makes immanent sense considering that most CF adults are either consciously or subconsciously fighting for every breath. Although I'm tempted to take this opportunity to detail my alternative therapies of choice, I'll instead exercise some restraint and talk about why I think it's important to pursue alternative therapies and use all the arrows in our quiver.

Let me begin by saying most mornings I drink a glass of orange juice with green superfood to make up for the fact that I don't get enough fruits and vegetables in my diet. Admittedly, the drink is disgusting and tastes even worse than it sounds, but it prevents me from having to cram bulky fruits and vegetables into my gut while I'm trying to hit my ambitious daily protein and caloric targets.

Additionally, when I'm feeling run down, I eat oranges every two hours around the clock. I began doing this after I read about Linus Pauling's groundbreaking research on how vitamin C can help fight infection. However, it should be noted that while Pauling's research did show that high doses of vitamin C may enhance immune function in the general population, those benefits do not necessarily translate to CF patients. One key reason is that certain immunological responses, such as the release of large phagocytic cells into the lungs in response to infection, increase irritation, swelling, and congestion, thereby exacerbating pulmonary restriction.

Nevertheless, I believe the very act

of researching, testing, and ultimately incorporating alternative therapies can benefit us mentally even more than the direct physical benefits we may derive from the interventions themselves. To illustrate this, indulge me while I delve deeper into why I eat oranges when I'm run down. Before I begin, I should point out that it is fairly well known in dietary medicine that vitamin supplements in general are a poor substitute for food-based micronutrient sources because a high percentage of the nutrients in pills and capsules are never metabolized.

When I originally started taking megadoses of vitamin C, it was based on my somewhat naïve fondness and admiration for Linus Pauling, an iconic Nobel-prizewinning scientist and one of the world's most well-known humanitarians; he is less known for his vitamin C research, which has been largely discredited. Nevertheless, the world was seemingly as equally enamored as I because his advocacy of vitamin C tripled the world's vitamin C consumption almost overnight and launched the modern-day vitamin supplement

industry. However, it has since been revealed that his vitamin C advocacy was largely based on his relatively unscientific observation that children at a snow camp in the Swiss Alps who received one mg of vitamin C daily had shorter-lasting colds.

That begs the question: if I've known this all along, why have I continued to eat oranges every two hours at the onset of a cold? The answer lies in why I started and how my reasons have evolved over time. I was 19 years old and studying organic chemistry when I first became fascinated with Linus Pauling and his vitamin C research. At the time, although I understood chemistry better than most, I could not even begin to fathom the complexities of the immune system in a CF patient. Consequently, I surmised that if I could enhance my immune function, I could shorten the length of my colds and therefore reduce the number of days I was highly susceptible to exacerbation. At the time, my lungs were somewhat healthy and, more often than not, I could weather colds and even mild exacerbations with just extra rest, vitamin C, and oral antibiotics.

But I've recently realized there are other mental and emotional reasons for my continuing this practice even though I no longer believe in the direct health benefits. Since my earliest and sometimes traumatic encounters with this disease, I subconsciously developed a bad habit of obsessively "checking" my throat—swallowing repeatedly and consistently throughout the day to see if my throat is, in fact, sore or if I'm just overly worried about the possibility of being sick. The high acidity in the oranges irritates my throat, thus tricking my brain into interpreting even negative throat checking results as ambiguous findings. This effectively



MARK TREMBLAY

mitigates my tendency to catastrophize or project negatively into the future the worst possible outcomes, which causes me heightened anxiety, sleep disturbance, emotional instability, and more worry. Regardless of whether I end up suffering through a full-blown exacerbation, eating oranges decreases the frequency of my pointless throat checking, lessens my anxiety, enables me to heal and rest more easily, which, in turn, diminishes the probability that I'll suffer a full exacerbation.

As I've gotten older, colonized more pernicious and resistant bugs, and my CFRD has become less stable, my ability to weather a cold without ending up in full exacerbation mode has lessened, despite the addition of Trikafta. However, when I'm feeling run down and my wife or I pick up a bag of oranges, it's a key step in preparing me for the battle ahead. I'm telling my body to still have hope that we can get through this without an exacerbation. Therefore, the mere act of buying and eating oranges instills hope in me that this battle-worn, tired, old body still has another fight left in it and maybe, just maybe, this time I'll be able to beat the enemy without firing a shot or losing ground.

Not only do I believe incorporating alternative therapies is beneficial, but I also believe that researching, testing, and selecting alternative therapies is beneficial, both psychologically and emotionally. When we spend time doing these activities, we are affirming that better health is within our grasp and we are equipping and empowering ourselves to play a fundamental role in producing that outcome.

To explain this, let me tell you about a trip to Belize that I never took. I played for a rather competitive rugby club in college, and it was every team's goal to make it to the playoffs, which meant you got an all-expense-paid vacation to some exotic location to participate in an intercollegiate rugby club

“I believe that researching, testing, and selecting alternative therapies is beneficial, both psychologically and emotionally.”

tournament. Since I grew up in a middle-income household, in the poorest county of upstate New York, and hadn't been anywhere more alluring than Binghamton, New York, in more than a decade, the goal of going became all consuming. To that end, I trained heavy in the weight room, spent more time on the treadmill, pushed myself harder in practice, and even watched tapes of the great European teams in an effort to improve my technique. In my junior year of college, we had a particularly strong rugby team that featured outstanding seniors. Despite losing two of the best players in the league during most of the spring season while they were in recovery, we ended up having a banner year and ended the season with just two losses.

As soon as we clinched a playoff spot, I began dreaming of Belize. I became a non-stop Belize commercial to the great annoyance of my teammates. However, as the day drew near, San Pedro, the location where we were slated to go, caught the attention of national media outlets for political unrest and violence. So, as luck would have it, two days before we were about to board the plane, the trip was canceled. However, later that day when the rugby moderator came across me moping in the library, he sympathized with me and reminded me that, even though the trip was canceled, it wasn't all for naught: I had improved my strength and stamina, I became a darn good rugby player, I helped two of my buddies get sober, and I took dozens of mental vacations to Belize, which were probably better than the actual trip would have been. He went on to say

that he spends almost every summer doing missionary work in Belize and that it's not as great as it seems. In short, I benefited from the placebo effect of a Belize trip that never was, which is the same thing our minds do when we're proactively pursuing alternative therapeutic approaches.

In the end, I'm confident spending time researching, testing, and selecting alternative therapies to incorporate into our care routine is emotionally, psychologically, and mentally beneficial because these activities are born out of hope for a better future, reinforce our belief that better health is within our grasp, and empower us to believe that we can be instrumental in manifesting that better future. Also, in the context of a disease which constantly reinforces powerlessness, proactively pursuing alternative therapies can help us feel more powerful so that we may better enjoy the fruits of a more fulsome optimism. ▲

Mark Tremblay is 52 years old and has CF. He lives in Albany, NY, with his wife, MaryGrace. He has a Master of Arts in Psychology from Marywood University and a Master of Public Administration from Syracuse University. Mark has worked in the New York Governor's Division of Budget for six years and presently works full time at the Department of Health. He is the President of "CF Vests for Life," which collects donated therapy vests, nebulizers, and oxygen saturators for distribution to CF patients around the world. Additionally, he is the leader of the Attain Health group, "CF Warriors for Recovery and Freedom." Mark is also a director of USACFA. His contact information is on page 2.



LIVE OUT LOUD

Unpopular Opinion: I'm Not Getting Vaccinated

By Lara Govendo, M.S.Ed.

It feels like the mark of the beast if you're *still* wearing a mask. The thing is, I've been wearing a mask for years now, but I don't really feel like explaining that to the glares from strangers. I hate feeling like I need to explain myself because of my choice to protect myself—it seems so counterintuitive.

I also know that I'm the exception to the rule. I decided against getting the vaccine for several reasons. The most important one being that my behavior wouldn't change even if I did get it. I will be masking, sanitizing, and distancing for quite some time—even more vigilantly than I already have been.

In a world where we are always trying to fit in, it becomes exhausting to tailor my needs to my health. Explaining to everyone why I make the choices I make is incredibly demeaning. It almost feels like I have to give the details in order to meet society's benchmark of approval as to whether my reasons are valid. Otherwise, I am grouped into the category of "not doing my part" to help humanity.

Of course, these matters are always magnified in our minds. Is it really a big deal? Maybe. Do people forget what I've said? Probably. But it feels big in my mind because I'm already self-conscious about my decisions, which isn't fair, either.

I had a co-worker freak out because I'm not vaccinated. He thought it was safe for us to be in a room together unmasked because we were both vaccinated. Once I disclosed that I wasn't vaccinated, it was this yelp of: *what? No, you're joking.* Then me diving into the explanation of why I'm not, waiting for the *oh, yeah, makes sense* nod of approval.

The vaccine feels like one more thing

that is dividing us. For transplant recipients, the vaccine has 15-20% efficacy. Not unlike the yearly flu shot, it may provide some protection, but is never 100%, of course; that's just science. Nothing is ever fully figured out with complete accuracy; we can't expect that. But we also can't put all our faith in those who are human because errors happen.

With all the adverse side effects surfacing from the vaccine, I'm not willing to risk my already fragile health in the hope that it will give me a tiny amount of protection. That is not worth it to me when I've fought so hard for the current health I have. I was on the fence for getting the shot initially, but the reports of potential complications have completely changed my mind—the vaccine isn't for me. I have current heart complications. I've had blood clots a few times, and I'm not

willing to increase my risk of getting them again. I take a lot of risks in my life, but they tend to be calculated ones. This one isn't worth it to me when it won't bring any peace of mind. It will only bring more worry while I wait to see if the aftermath of the vaccinations affect me.

The rare side effects and small percentage of things that can go wrong tend to happen to me. I would be remiss if I didn't listen to my intuition and instead just went along with what everyone else is doing. I've always been in tune with my body and known when something is wrong or if something isn't going to work. Ignoring what I intuitively know, just to appease everyone else, feels sickening. I think it's important to acknowledge that, too.

I'm also hesitant as the vaccine hasn't entirely prevented the spread of COVID-19. A nurse friend, who is vaccinated and works with all vaccinated individuals, spoke of an outbreak of COVID-19 at their place of employment. The person responsible was asymptomatic and ended up spreading it to others unbeknownst to them. The threat of COVID-19 hasn't really changed with the vaccine. And, especially with our CF immune systems, we can't take the risk of believing it has.

Call me crazy, but as people living with a chronic illness our whole lives, we have always had to do what is different. We are used to living more isolated. We know how to go into self-care mode, tunnel-visioning what we have to do to be or stay as healthy as we can. This world of sickness is our jam. I think it's time we used our skills to educate others to bridge the gap of understanding. For far too long we have felt left out from the normal world because we don't, according to



LARA GOVENDO

society, fit the mold of a typical life. But we do have something to offer, and lending our voice to those who don't speak up for themselves is activating our advocacy skills in a different, profound way.

I want to open the conversation to those who haven't gotten vaccinated, are scared of the ramifications, and are ashamed to say anything. I also want to make it clear that getting the vaccine is an individual decision, one that should be addressed with the medical professionals in your life. Feeling pressured to conform and to put something in our bodies because it's a moral decision doesn't feel good. And it's important to listen to our own health journey track records.

Our health isn't linear and neither are our paths. We have to be cognizant of the long view of our health while keeping the short view in check. The decision to get vaccinated isn't clear cut. Our situations are more complicated. That's just our normal reality.

I honestly wish that I could get the vaccine without worrying about adverse affects. COVID-19 feels like it's lurking at every corner, and feeling less vulnerable to the threat would be fantastic. I also know that where my body is at right now, I can't afford to take this risk. I'm grateful for the scientists who have worked diligently to provide some level of protection for the general public. I just hope it's enough for the rest of us

who live in the gray area, always. ▲

Lara Govendo is 34 years old and has CF. She lives in Vermont as a wild adventure enthusiast who holds a Master's Degree in Mental Health Counseling. She currently works as a mental health counselor for middle schoolers. She also writes about living life beyond chronic illness and develops educational programs to restore hope to those in need. Thanks to her double lung transplant in 2017, you can now find Lara traveling on the regular, exploring the glorious outdoors, and belly laughing with her loves. You can find her online at www.laragovendo.com (and on Facebook and Instagram) at "Lungs4Lovey." You can email her at lgovendo@usacfa.org.

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IN THE SPOTLIGHT

With Suzanne Joyce

By Andrea Eisenman and Jeanie Hanley, M.D.

Suzanne Joyce was first interviewed for our “In The Spotlight” column back in 2017. Quite a few things have changed in her life since we ran that interview, and I thought our readers would love to catch up with her and hear about her transplant journey. Those who are in a similar situation may find her experience heartening. She shares the challenges of living in two different places, which is never an easy feat. Suzanne keeps herself busy with offering two iRest yoga nidra sessions weekly on Zoom, walking her dog Jade, and breathing fully again. Meet our latest star, once again! Spotlight, please.

How old are you and where do you now live?

I’m 58 years old, and I split my time between living in Clearwater, Florida, and Haverstraw, New York.

In our last interview you had just broached the subject of lung transplantation with your physicians.

What has since changed?

I began using oxygen 24/7 and, in 2018, I was hospitalized three times over an eight-month period. My doctor in Tampa stressed to me that I was in the transplant “window,” so I decided to be listed for transplant in January 2019 and had my transplant one month later.

How was your transplant experience?

For the first three months, I felt so disoriented and foggy. I was in the hospital for 23 days, with 11 of those being spent in the ICU. It was the most traumatic thing that I’ve endured in my life. I had three episodes of a pneumothorax (a collapsed lung), which were terrifying events, but they did resolve. Additionally, I was diagnosed with both gastroparesis and a bezoar, a solid mass of indigestible material that most often accumulates in



SUZANNE JOYCE

the digestive tract, sometimes causing a blockage. The bezoar took a long time to dissipate and the gastroparesis still plagues me to some degree, albeit less. I lost 20 pounds while in the hospital and my weight was down to 88 pounds when I was discharged. I never felt more dependent on others, more vulnerable, or more insecure than during this period of time. That being said, I don’t for one minute regret having gone through transplant.

What are the benefits and drawbacks to lung transplant, in your experience?

The benefits are truly life changing. I no longer constantly hack up mucus or blood, I no longer have daily nebulizer and Vest treatments, and I’m no longer chronically exhausted, just to name a few advantages. The drawbacks for me, currently, are increased anxiety and other side effects from the transplant medications, as well as concerns about facing a new kind of uncertainty about my life span and, more impor-

tantly, what am I going to do with this new life?! That’s a good problem to have.

Were the downsides resolved? If yes, how?

Over time, the bezoars eventually disappeared on their own. Medications did not help with that. With gastroparesis, which is caused by nerve damage, including damage to the vagus nerve, I had to switch to a low-fiber diet, could not eat large meals in one sitting, and I felt sick after eating. I tried all kinds of things to stimulate my vagus nerve—humming, stomach massage, chewing gum, deep relaxation, cold water, walking, and more. My symptoms improved, but I can’t say what really helped. I still do stomach massage to help my GI system to keep moving. For anxiety, I take Wellbutrin and Lexapro, which I have taken for years. I exercise intensely and often, and I practice yoga nidra and pranayama (breath work) to deeply relax.

How do you feel now, post-transplant?

I feel fantastic physically! I am thrilled to draw in a full breath of air and, if I want to very slowly exhale it all the way out, without difficulty and without coughing, I can. I feel strong, healthy, and vibrant. I’m very grateful for my donor, my medical teams, and all my caregivers, both near and far.

I did not have clear expectations about what to expect as it seems that, with CF, each transplant experience is different. I guess I thought I’d just take each issue as it comes. I would have liked more information on what to expect during the early part of recovery. And no one told me about the pockets of cellulite!

How did you decide to get your transplant where you did? What was the deciding factor (or factors)?

I had been in Naples, Florida, where there was no CF center, during most winters, and my strategy was more of “if I get sick, I’ll fly back to NY” plan. As my disease progressed, I realized this wasn’t such a good strategy. I considered visiting CF centers in Florida and started with Tampa General Hospital (TGH). I liked the fact that they were also a transplant center, should I decide to take that path. My CF clinic at Beth Israel/Mt. Sinai did not have a transplant center, so I knew I would have to leave Dr. Walker, my pulmonologist, for a transplant no matter where I went. I was impressed with Tampa General and decided I would continue my care there. However, if I were to be hospitalized or transplanted at Tampa General, it would involve a three-hour drive from Naples and that was too far away for me and my caregivers at the time. So, I relocated to Clearwater, Florida, about an hour from TGH.

I contacted Peer Connect (run by the CFF) for a mentor who had her transplant later in life because receiving a transplant at 26 must be different in some ways than receiving one at 56. Lisa Stackhouse was (and still is) my mentor—she educated me a lot as far as the various stages of her transplant. We have become close friends ever since then.

What do you think is important to share about transplant for those considering one?

It’s important to be informed and prepare yourself for the mental and emotional part of your recovery. Just like you will need the strength of your abs and legs to get you off the couch, you will need a go-to self-regulation tool such as calming breath work, guided meditation, biofeedback, somatic therapy, yoga nidra, etc. It’s a good idea to experiment with different practices and learn one or more that work for you. Have your caregivers join

in or at least know about what works for you so they can remind you to use it when you need it.

Were you hesitant to get a lung transplant at your age?

I had just turned 56 when I was transplanted. Pre-transplant I questioned if I should consider it at all because I felt I had lived a life full of interesting experiences and accomplishments, and maybe it was time to just let my body follow its natural path. I’ve been prepared to die since I was 12 years old, when life expectancy with CF was 16 years. I also felt so tired of life centering around keeping myself alive that part of me just wanted to slip away. When I got to TGH, I realized how many people (mostly those without CF) were transplanted who were older than me. That took care of any concerns I had heard about age being a problem. Then I was left with deciding existentially whether to go forward with transplant. In the end, I decided I had it in me for one more fight.

What was your experience with Trikafta?

I tried Trikafta for two months last fall. Immediately my sinus issues were completely cleared up and my insulin usage decreased after a few weeks. I experienced a mix of new GI issues so there was no net gain there. I had to stop taking it because my existing anxiety increased overall and skyrocketed with any situational triggers. I also had to change some of my meds in order to take Trikafta, which also contributed to increased anxiety. For me, the cons outweighed the pros.

Are you still able to teach yoga remotely? What else are you teaching remotely?

I haven’t taught yoga since 2018. Being on oxygen just doesn’t work for a teacher. I do offer iRest yoga nidra weekly over Zoom to the CF community. I’ve wanted to offer this guided

Continued on page 30



What is the Boomer Esiason Foundation?

In 1993, NFL Quarterback, Boomer Esiason, learned that his son, Gunnar, was diagnosed with the incurable genetic disease cystic fibrosis (CF). Never ones to back down from a fight, he and his wife, Cheryl, founded BEF and decided then and there to fight for a cure and for the cystic fibrosis community.

Cystic Fibrosis is an inherited chronic disease that affects the lungs, digestive system, and reproductive system of about 30,000 Americans by causing a thick build-up of mucus that leads to blockage, inflammation, and infection.

What does BEF do?

In addition to assisting the CF community with the following programs, we also support CF clinics and research centers:

- Educational Scholarships
- Lung Transplant Grant Program
- CF Patient Disaster Relief Fund
- Covid-19: CF Patient Assistance Program
- Team Boomer
- You Cannot Fail
- You Cannot Fail Hospital Bags & Survival Kits
- Gunnar Esiason’s Blog
- Gunnar Esiason’s The State of Health Podcast
- Jerry Cahill’s Cystic Fibrosis Podcast
- Did You Know Video Series
- CF Education Days & CF Speaking Engagements

www.esiason.org

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JOYCE continued from page 29

meditation to the CF community for a long time. iRest has been such an effective way to help me in anxious times and in my daily life. Using Zoom, etc., so much last year, it seemed like an accessible platform for guided meditation and a good time to offer iRest to support others in experiencing some deep relaxation. If you are interested in joining my iRest classes, which are on Fridays at 3 p.m. EDT, or just want more information, please email me and I'll get you in the loop: exesq1@gmail.com

How are you staying in shape physically and mentally?

I exercise often and I like variation. I enjoy Pilates reformer, Peloton (bike, HIIT, and strength classes), BEAM classes, yoga, and stand up paddle boarding. To maintain my mental health, I do take meds and meet with my NYC therapist every two weeks over the phone, as well as exercise, practice pranayama, and iRest.

What does getting the COVID vaccine mean for you?

I got my second vaccine March 12, 2021. It does not seem at this time that I'll be able to travel or see others more because my immunosuppressant drugs prevent me from mounting as much of an antibody response as others who are not immunosuppressed.

What are you doing for fun or to relax?

I like to read, talk, and laugh on the phone or via Zoom. I love to walk on the beach or take my dog at the dog park, and of course lots of streaming.

Are you still in touch with your doctors in NY?

I am and I miss them all very much. I hope to see them if I go back to New York in late summer. I'd like to activate my plan, which was six months in Florida and six months in New York once I'm comfortable with the COVID-19 situation. I'll certainly need to see a transplant center in NYC but I don't know which one yet.

What do you miss about New York?

What is better in Florida?

What I miss most about New York is the city and its sense of place. I miss walking on the streets of NYC and along the water,



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trying new restaurants, discovering a small shop I never noticed before, museums, meeting a friend for coffee in some interesting café, the parks, and so, so, much more. The weather in Florida is superb. Even if it's not beach weather, the sky is usually a beautiful blue and

there is so much greenery everywhere. That helps my mood.

Jeanie Hanley is 59 and has CF. She is a Director and the past President of USACFA. Andrea Eisenman is 56 and has CF. She is a Director of USACFA

and is both the Webmaster and Executive Editor of CF Roundtable. Their contact information is on page 2. ▲

If you would like to be interviewed for "In The Spotlight," please contact either Andrea or Jeanie.



MILESTONES

Please share the milestones in your life with our readers. Your successes and achievements may serve as a source of motivation for others in need of an infusion of “positive mental attitude” in the pursuit of their goals. Send us a note specifying your “milestone.” Include your name, age, address and phone number. Mail to: **CF Roundtable, 9450 SW Gemini Drive, PMB43881, Beaverton, OR 97008-7105. Or email to: cfroundtable@usacfa.org**

ANNIVERSARIES

Birthday

Ella Balasa

Richmond, Virginia
29 on May 1, 2021

Mark Tremblay

Albany, NY
52 on June 6, 2021

Mike Darrar

Post Falls, Idaho
55 on August 25, 2021

Wedding

Mike and Kathryn Darrar

Post Falls, Idaho
31 years on August 17, 2021

Transplant

Jenny Adams

Gig Harbor, Washington
Bilateral lung transplant
5 years on April 22, 2021

Mike Darrar

Post Falls, Idaho
Bilateral lung transplant
10 years on May 3, 2021

TILLMAN continued from page 7

the bacteria swapped roles: *S. aureus* lacking the ability to make purine was placed with purine-producing *P. aeruginosa*. Again, the purine-deficient bacteria used the purine provided by the other bacterial species to grow. Thus, purine exchange between these bacteria could occur in either direction. This mutually beneficial cohabitation could be a reason some CF lung infections are so difficult to treat. Such interactions can have severe impacts during infection as polymicrobial synergy has been shown to increase antibiotic resistance and disease severity in certain cases.

<https://tinyurl.com/yfusecop>

Molecular Analysis Identifies Key Differences In Lungs Of Cystic Fibrosis Patients

A team of researchers has developed a first-of-its-kind molecular catalog of cells in healthy lungs and the lungs of people with cystic fibrosis. The catalog reveals new subtypes of cells and illustrates how the disease changes the cellular makeup of the airways. The findings could help scientists in their search for specific cell types that represent prime targets for genetic and cell therapies

for cystic fibrosis. This research provides critical insight into how the disease alters the cellular makeup of the airways, which will enable scientists to better target the next generation of transformative therapies for all people with cystic fibrosis. Because these cells can self-renew and produce a continuous supply of specialized cells that maintain, repair and regenerate the airways, therapies aimed at correcting CFTR mutations in stem cells hold the best hope for a one-time, universal treatment for the disease. Using a novel computer-based bioinformatics approach to compare the gene expressions patterns of the various cells, the team was able to create a catalog of the cell types and subtypes present in healthy airways and those affected by cystic fibrosis, including some previously unknown subtypes that illuminate how the disease alters the cellular landscape of the airways. The airways of people with cystic fibrosis showed differences in the types and proportions of basal cells, a cell category that includes stem cells responsible for repairing and regenerating upper airway tissue, compared with airways of people without this disease. Specifically, the

researchers discovered that among the basal cell populations, there was a relative overabundance of cells that appear to be transitioning from basal stem cells into specialized ciliated cells, which use their finger-like projections to clear mucus out of the lungs. The increase in transitioning cells provides further evidence suggesting that expression of the mutated CFTR gene disrupts normal function of the airways, leading to changes in the way that basal stem cells produce specialized cells.

<https://tinyurl.com/p6mk9n8c>

AND

<https://tinyurl.com/wyzyhx2p>

AND

<https://tinyurl.com/vw2wzz27>

AND

<https://tinyurl.com/yeo8vc5u>

AND

<https://tinyurl.com/39k9p563>

AND

<https://tinyurl.com/2rn7zp5u>

Spirometry Measurements Obtained At Home vs Clinic Evaluated

Although the cause is unclear, spirometry measurements obtained at home had poor agreement with results

obtained in the clinic. Researchers obtained home and clinic spirometry data from the CAPTAIN study (ClinicalTrials.gov Identifier: NCT02924688), a phase 3A, double-blind parallel group study in adults with uncontrolled asthma despite pharmacologic therapy. Patients had spirometry measurements taken at least once in the clinic using a MasterScope device, and recorded measurements at home each day using a peak flow meter (AM3 device). Among the patients who had both clinic and home spirometry measurements available, the agreement between clinic and home trough forced expiratory volume in 1 second (FEV1) measurements was poor. According to the researchers, possible explanations for the lack of agreement included the different devices and methodologies as well as a lack of supervision and coaching for home measurements. The comparison of home and clinic spirometry in the CAPTAIN study suggests that home spirometry performed with the AM3 device cannot be used as an alternative to clinic spirometry, and that caution should be exercised when using home spirometry data in research or clinical care.

<https://tinyurl.com/yu7ytemw>

hMSCs Show Potential In Treating Chronic Lung Infections

Human mesenchymal stem cells (hMSCs) effectively treated infections caused by non-tuberculous mycobacteria (NTM) in cell-based tests and a mouse model of cystic fibrosis. Although this strategy may help treat those infections in people with CF and other lung conditions, the findings show the treatment's effectiveness depends on the donor source of hMSCs. *Mycobacterium avium* and *Mycobacterium intracellulare* are two types of NTM. NTM infections can be very difficult to resolve. Treatment typically requires taking multiple antibiotics, often for years. Patients who suffer from chronic NTM infection not only deal with the conse-

quences of the disease but also the toxicity, as well as inefficiency and side effects of the antibiotics used to treat it. To find better treatments for NTM infection, researchers focused on hMSCs, which can become a variety of cell types. Studies have shown that hMSCs have anti-microbial, anti-inflammatory, and anti-scarring properties resulting in improved antibiotic effectiveness, thereby decreasing the dose required to eliminate bacteria. They are unique in their capacity to respond to infection by secreting multiple bioactive factors, contributing to the host environment. That gives hMSCs a clinical advantage over traditional pharmaceuticals. hMSCs significantly decreased the growth of MAC and trended toward a significant reduction in *M. intracellulare*. hMSC supernatants—the liquid that contains products secreted by these cells—also decreased growth in all conditions, but were significantly effective only in MAC.

Supernatants from 12 different hMSC donors were then cultured with MAC, *M. intracellulare*, and *M. avium* and tested over 24, 48, and 72 hours. Results showed the ability to decrease MAC growth varied based on hMSC preparation, with some supernatants killing most MAC, while others showed a lower capacity. This variable effectiveness among different donor hMSC supernatants was also shown in *M. intracellulare* and *M. avium* separately. Thus, it is essential to identify the appropriate hMSC donor and subsequent preparation for disease-specific applications. hMSCs then were cultured with MAC, *M. avium*, or *M. intracellulare* with or without the addition of the antibiotic gentamicin. Although the antibiotic-enhancing capacity of hMSCs was higher against MAC and *M. avium* more than against *M. intracellulare*, the results varied across different donor preparations. In some, the potency was not sustainable. Next, to test hMSCs in vivo, the most effective hMSC donor cells were used to treat normal, and CF

model mice infected 24 hours earlier with either *M. intracellulare* or *M. avium*. Treatment of mice modeling CF with hMSCs resulted in significantly decreased growth of both *M. intracellulare* and *M. avium* in the lungs compared with CF mice not treated with hMSCs at day seven. hMSC treatment also attenuated weight loss and improved a score of overall health in infected CF mice. Focusing on hMSC response to NTMs and efficiency of in vitro [in the lab] and in vivo anti-NTM activity provides direction for identifying the optimal hMSC signature for anti-NTM therapy.

<https://tinyurl.com/yzpawxnw>

Patients' Breath May Be Used To Detect *P. Aeruginosa* Infection

Lower levels of certain volatile molecules in the breath of children and adults with cystic fibrosis can distinguish with good accuracy between those with and without *Pseudomonas aeruginosa* lung infection. A reduction in the levels of a single molecule, called ethyl acetate, was a good predictor of *P. aeruginosa* infection in pediatric patients. In adults, a combination of five molecules was needed to achieve good predictability. These findings support future studies to further validate ethyl acetate as a potential non-invasive biomarker of *P. aeruginosa* infection in children with CF, as well as larger studies in adults to better assess the diagnostic potential of these molecules. Previous studies have shown that *P. aeruginosa* infection is associated with the production of several volatile molecules, which can be measured in the breath of CF patients, offering a potential non-invasive alternative for the detection of this serious infection. However, none of these molecules has been validated as a *P. aeruginosa* diagnostic biomarker through targeted analysis of breath of CF patients. Now, researchers evaluated the use of volatile molecules to identify CF patients with *P. aeruginosa* lung infection

Continued on page 34

and found that a reduction in ethyl acetate levels alone was found to be the strongest predictor of *P. aeruginosa* infection in pediatric patients. This link is consistent with previous studies and the team hypothesized that such reduction may be due to the breakdown of ethyl acetate by *P. aeruginosa*. No single volatile molecule was significantly associated with *P. aeruginosa* infection in adults, and only a combined reduction of five molecules — ethyl acetate, limonene, 2-pentanone 3-methyl, toluene, and 2-butanone — provided good predictability. This combination model was able to distinguish between CF adult patients with and without *P. aeruginosa* lung infection with 70% sensitivity and 100% specificity.

<https://tinyurl.com/yh2p94q9>

New Treatment For Lung Infections In Cystic Fibrosis Up To 100,000-Fold More Effective

A novel biometric nanostructured material used to treat lung infections in cases of severe cystic fibrosis increased its efficacy by up to 100,000-fold over the current treatment. Investigators from the University of South Australia described how they used an advanced, biologically-relevant co-culture model of human cystic fibrosis bronchial epithelial cells that were infected with *Pseudomonas aeruginosa* (*P. aeruginosa*). The treatment used to treat *P. aeruginosa* is the antibiotic Tobramycin, however its efficacy is severely limited due to permeability problems. The novel nanotech approach was designed to enhance efficacy in treatment for *P. aeruginosa* due to increased permeability. In testing with the bronchial epithelial cells, the nanotech eradicated *P. aeruginosa* after 2 doses which was a 100-fold improvement over the Tobramycin. When Tobramycin is paired with an antibiotic that permeates biofilms such as ciprofloxacin, the nanotech still performed. The nanotech enhanced penetration of Tobramycin across the biofilm barrier,

but not through healthy lung cells, which allows for increased concentration of the antibiotic at the site of infection. Therefore, this strategy would enable the administration of lower doses and a reduced toxicity. The study authors also detailed their comparison of liposomes and the nanotech technology. In this case, the nanotech was loaded with Ps1G, the glycoside hydrolase, and Tobramycin to test if the combination would protect Ps1G from proteolysis, trigger the enzyme's release in the presence of bacteria, and/or improve the total antimicrobial effect. The study found that the nanotech approach was deemed to be an effective strategy that better protected against proteolysis, produced a sustained release of Ps1G, and improved the antimicrobial effect by 10-100-fold. Additionally, the study authors observed an increased survival of in vitro and in vivo *Caenorhabditis elegans* infected with *P. aeruginosa*. When comparing digestible to non-digestible nanotech, the study authors determined that the digestible type triggered the enzyme's release in the presence of bacteria. However, there were negligible differences in the versions' ability to protect Ps1G from proteolysis and potentiate the antimicrobial activity when combined with Tobramycin.

<https://tinyurl.com/2576debx>

Computer-designed Enzyme May Help To Kill *P. aeruginosa* In Biofilms

An enzyme produced using computer design, in combination with the antibiotic tobramycin, efficiently kills *Pseudomonas aeruginosa*. It works to neutralize a metabolite called pyocyanin, required by *P. aeruginosa* to attach to surfaces and form biofilms. Pyocyanin is a molecule that promotes cell-to-cell interactions to enhance the bacteria's viability inside the biofilm and to better protect them from antibiotics. As they are in close contact with each other, these bacteria also can exchange genes that contribute to antibiotic resistance.

A research team had previously discovered an enzyme called PodA that could degrade pyocyanin and prevent the formation of biofilms. However, this enzyme could only be produced in small amounts and it lacked stability. The team set out to increase the stability and production of PodA, to test it under certain physiological conditions, and to find out if it could improve the efficacy of tobramycin. Results showed that bacteria treated with tobramycin and PodA10 had higher propidium iodide staining than did those with either PodA10 or tobramycin alone, suggesting a greater bacterial killing activity. Pyocyanin, the protective molecule, is produced by *P. aeruginosa* when there is a lack of oxygen, especially in the inner layers of biofilms. Its presence is toxic on the outer layers of biofilms where oxygen is present. The team found that adding PodA10 alone can remove pyocyanin from places where there is oxygen, resulting in higher bacterial metabolic activity.

<https://tinyurl.com/ywff9neh>

AND

<https://tinyurl.com/yfgfq7fm>

BX004, Phage Therapy for CF Bacterial Infections, Advancing in Trial

BiomX has developed a BOLT (Bacteriophage Lead to Treatment) platform that uses phages—viruses, or a virus cocktail, that can infect and kill bacterial cells—instead of antibiotics as bacteria-targeting therapies. BOLT was designed to rapidly develop phages (within six to eight weeks) targeting specific bacteria in a manner tailored to a given patient. The process begins with isolating a person's bacterial strain, followed by optimizing and producing the therapy for testing in clinical trials. According to BiomX, studies conducted in the lab showed that BX004 is active against antibiotic-resistant strains of *P. aeruginosa* and can penetrate biofilm. Phage are natural predators of bacteria,

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and specific to particular bacterial species or strains, targeting and killing them without disrupting other neighboring, potentially beneficial, bacteria. BiomX reported in a presentation that its Phase 2 proof-of-concept trial was testing BX004, as a nebulized therapy,

against a placebo in up to 40 CF patients with chronic *P. aeruginosa* infections. Treatment would be given for seven to 10 days, with the efficacy of this phage combination evaluated through changes in bacterial counts, and measures of lung function and

quality of life.

<https://tinyurl.com/ygcaf2lw> ▲

Laura is 72 and has CF. She is a former director and President of USACFA. She and her husband, Lew, live in Northville, MI.

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- We would like to act as a referral source for active adult support groups. Please send us your group name, leader's name and phone number, number and age range of your members and geographical area covered, and we will add you to our referral list.
- Please let us know of the major occurrences in your life (e.g., marriages, births, completion of educational degrees or training, career advancement, transplants, anniversaries, birthdays), and we will print your information in **Milestones**.
- Share your ideas for **Focus Topics**, feature articles or any suggestions for improvements you may have to help make *CF Roundtable* more relevant and interesting to you.
- You can reach **USACFA** and *CF Roundtable* at any time by email at cfroundtable@usacfa.org
- Send your questions of a general nature regarding legal issues that relate to CF to our legal advisor: **Beth Sufian, Esq.**, call: 1-800-622-0385 Email: CFLegal@sufianpassamano.com
- You may subscribe at www.cfroundtable.com



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IMPORTANT RESOURCES

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United Network for Organ Sharing (UNOS): Phone: 1-888-894-6361 <http://www.unos.org/>
Call for information on transplant centers, access for all patients needing organ transplants, and general transplant information.

Transplant Recipients International Organization, Inc. (TRIO): Phone: 1-800-TRIO-386 <http://www.trioweb.org/index.shtml>

An independent, nonprofit, international organization committed to improving the quality of life of transplant recipients and their families and the families of organ and tissue donors. For information, write to: TRIO, 7055 Heritage Hunt Dr, #307, Gainesville, VA 20155 or email them at: info@trioweb.org

American Organ Transplant Association (AOTA): Phone: 1-832-930-AOTA (2682) <http://www.aotaonline.org/>
Helps defray out-of-pocket travel expenses for transplant recipients. Helps to set up trust funds. For more information, write to: Administrative Service Center, American Organ Transplant Association, P. O. Box 418, Stilwell, KS 66085. Preferred method of contact is email: aotaonline@gmail.com

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