

In The Aftermath, I Hope We Hug

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

Like many of you, I spent the last 12 months in the crosshairs of this pandemic as one of the vulnerable. In the past, whenever I've faced overwhelming emotional experiences or threats, I've done three things: read about the threat, listened to the experts, and watched how others responded. So, naturally, when I first heard COVID-19 may be coming our way, I read several books, including *The Great Pandemic* on the 1918 flu and *Crisis in the Red Zone* on the Ebola outbreak. While immersing myself in a veritable macabre library of pandemics and plagues, I also followed the news and watched the people close to me and society at large through the lens of my isolation.

None of this was foreign to me because, when I was young, and facing the very real prospect of my own demise, I responded similarly. Upon my diagnosis, my parents, aside from making sure I had access to the best CF care at the time (manual chest PTs,

mist tent, and non-time-release enzymes that digested my digestive tract as well as my food), also created an isolation bubble for me that they hoped would protect me from germs, bacteria, and smog. To limit direct contact with my siblings and them, I spent most of my time in my clean



MARK TREMBLAY

room alone, which, because of the renovations my father had made, enabled me to watch my family through a glass slider facing the kitchen and another glass slider facing the backyard where they spent most of their time. I responded to the situation by finding ways of interacting with them by entertaining them through the glass and entertaining myself by reading anything I could find—my oldest brother's science fiction books, my dad's Westerns, and every volume of the family's encyclopedia collection.

Not surprisingly, my response to this period of isolation was similar to my childhood, in which I read voraciously and watched people. In all my reading, which invariably led me to focus mostly on the psychological and philosophical aspects of the crisis, I revisited a study on maternal deprivation that caught my attention during a lecture in an Introductory Psychology Class at LeMoyne College. The researcher who coined the phrase,

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EDITOR'S NOTES

CF Awareness Month is this coming May, readers. In this issue we're focusing on sexuality and sexual health with CF. **Laura Mentch** writes about the various circles of sexuality, as designed by a former University of Kansas professor for one of his classes. In **Dr. Xan Nowakowski's** "Pearls of Wisdom" column this issue, they discuss inclusivity in a clinical setting—the importance of it and what it looks like. We're also featuring a compelling recounting of growing up with CF during the decades of sex, drugs, and rock and roll. **Dominic Quagliozzi** shares artwork, which, in his words, illustrates what it means to feel the feeling of being sexy again. **Cindy Baldwin** details her early years struggling with fertility and the eventual correlation between hormone production and the stress of living with cystic fibrosis. You can read more about her journey to becoming a parent in her "Family Matters" column. **G.M. Brown** and **Melissa Shiffman** share information about the new CFSRH resource guide, put together through CFReSHC thanks, in part, to an Impact Grant from the Cystic Fibrosis Foundation. This guide, years in the making, is written by patients for providers and aims to improve standards of care and improve knowledge for both patients and providers.

This spring, we also wish **Kathy Russell** a happy retirement from *CF Roundtable* and we say farewell to her column, "Speeding Past 50," which happens to be one of our longest-running columns. Kathy has been an intrinsic part of USACFA. She was a founder of our organization and has held every executive board position throughout the years: president, vice president, secretary, and treasurer.

Beth Sufian writes about how the new American Rescue Plan Act can benefit individuals with cystic fibrosis in her column this issue. **Lara Govendo** writes about the importance of dancing to your own drummer, rather than being confined to society's view of what normal looks like. In her "Spirit Medicine" column this issue, **Isabel Stenzel Byrnes** details how our sexuality changes as we age and the importance of focusing on what's on the inside, rather than the outside. **David Tarnow** chronicles his improvement, both physically and mentally, with the help of Trikafta in his "Savoring Serendipity" column this issue.

Laura Tillman expertly collates all the latest CF research and developments from the internet in this issue. For our "In The Spotlight" interview this issue, **Amy Gutierrez** talks with Mickey Davis about life after transplant and his appearance on a podcast. In the "Voices From The Roundtable" section you can read about **Colleen Adamson's** experience getting both of her #FauciOuchie vaccinations as well as her side effects from each shot. **Patricia Brown**, another adult with late-diagnosed cystic fibrosis, sheds light on her lifelong mission to get answers for her untreated medical issues. We're also featuring an in-depth review of *Breath From Salt* written by one of our prior scholarship winners, **Dr. Rob De La Noval**.

I hope you enjoy reading this spring 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

Medicare Coverage For Cystic Fibrosis: Testing, Management, And Treatments

Each part of Medicare offers different coverage that can help you get the treatments and care you need for cystic fibrosis. Items and services covered under each part include:

- Medicare Part A. Part A is hospital insurance. It covers any inpatient care you need. This includes stays in the hospital and rehabilitation facilities, as well as limited home healthcare services.
- Medicare Part B. Part B is medical insurance. It covers outpatient care such as the treatments you receive from your doctor. Part B



LAURA TILLMAN

also covers: ambulance rides, urgent care visits, diagnostic tests, medical equipment used at home

- Medicare Part C. Part C is also

called Medicare Advantage. It covers everything that parts A and B do and often includes coverage for additional services and prescription drug coverage. Medicare Advantage plans use networks to provide coverage, so you'll often need to stay in network to get care when you use a Medicare Advantage plan.

- Medicare Part D. Part D is prescription drug coverage. Medicare parts A and B, together known as original Medicare, don't offer any prescription drug coverage unless you receive the medication during a hospital stay or doctor's office visit. Stand-alone Medicare Part D plans can be added to original Medicare so that the prescriptions you take at home are covered. All Part D plans have a list, called a formulary, that tells you which prescription drugs are covered and how much they will cost.

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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.

Spring (May) 2021: Sexuality and Sexual Health in CF. (Current issue)

Summer (August) 2021: Alternative Therapies and CF. What alternative therapies do you use in addition to your prescribed treatment plan (acupuncture, massage, herbs, supplements, Shiatsu, Reiki, etc.)? What resources do you use? How has the addition of alternative therapies helped your CF? Was your CF clinic receptive to adding in these alternative therapies?

Autumn (November) 2021: Caregiving and CF. How does caring for others affect your physical, mental, and social well-being? 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.



ASK THE ATTORNEY

American Rescue Plan Act Helps With Insurance Premiums

By Beth Sufian, J.D.

On March 12, 2021, President Biden signed the American Rescue Plan Act (ARPA) enacted by Congress. The \$1,400 individual stimulus payments included in ARPA will help many individuals with CF who are in need of assistance. Additionally, the healthcare provisions of ARPA will also help some with CF by providing COBRA premium assistance and Affordable Care Act premium assistance.

Nothing in this article is meant to be legal advice and is only information. The ARPA is a brand-new law and there will be additional guidance issued by the federal government in the coming weeks. The information contained in this article is accurate as of March 28, 2021, but information may change after additional federal guidance is issued. Nothing in this article guarantees a payment of COBRA premiums by any entity. Nothing in this article guarantees the amount of premium a person will pay if purchasing an insurance policy of the Affordable Care Act Healthcare Exchange.

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

I. COBRA Premium Assistance

ARPA established a new COBRA premium assistance benefit for employees and dependents who, because of a COVID-19-related job loss or reduction in hours, became ineligible for employer-sponsored group health benefits.

Under the existing COBRA statute, individuals who are no longer eli-

gible for employer-sponsored group health benefits are permitted to extend their benefits upon certain qualifying events if they make a timely COBRA election and pay monthly premiums. The employer collects the premiums from the individual and may charge up to 102% of the base premium. For many, a COBRA extension of benefits may be the best available option if the person has lost their job. For many who had an employer who had been paying part or all of their health insurance premium, the need to COBRA the insurance coverage after job loss typically requires the person to pay the full premium. **The ARPA changes that for many people.**

A. 100% Subsidy Of COBRA Premiums For Up To Six Months.

ARPA provides for a new federal subsidy of 100% of COBRA premiums for up to six months. The subsidy is available beginning April 1, 2021 and ends September 30, 2021. The subsidy

is available to individuals who lost their employer-sponsored group health benefits due to a COVID-19-related involuntary job loss or reduction of working hours. The ARPA COBRA Premium Assistance benefit is not available for voluntary termination of employment or a voluntary reduction in hours.

Under ARPA, the federal government pays the COBRA premium assistance to employers. The COBRA premium assistance pays both the employee and the employer's portion of the insurance premium if the employer and the employee share the cost of the premium. The subsidy is limited to cost-of-premium assistance. Individuals will still be responsible to pay deductibles, copays, and out-of-pocket amounts according to the terms and conditions of the plan.

Because the COBRA premium assistance is paid directly to the employer, the covered individual does not need to apply to the federal government for the assistance. ARPA requires the employer to provide detailed notices to individuals regarding eligibility, amount, and timing of assistance. Generally, an individual's point of contact for COBRA premium assistance is the employer's COBRA administrator or the point of contact specified in the employer's notice of COBRA premium help sent to the individual.

B. Refund Of Premiums If COBRA Premium Assistance Received.

However, individuals with COBRA extension coverage should make certain that they are receiving the new federal COBRA premium assistance before they stop paying COBRA premiums. Non-payment of premiums is a legitimate reason for the insurer to stop coverage. Once the COBRA extension coverage is properly discon-



BETH SUFIAN

tinued, it generally cannot be restarted.

If a person pays a premium for a COBRA coverage period for which the person is eligible for COBRA premium assistance, ARPA

requires the employer to refund the premium payment and apply the COBRA premium assistance to that coverage period.

C. New 60 Day Special Election Period.

ARPA creates a special election period for any individual who did not elect federal COBRA continuation coverage, but who otherwise would have been eligible for the COBRA subsidy. This special election period also applies to individuals who elected federal COBRA continuation coverage but discontinued the coverage before April 1, 2021.

These individuals are allowed an opportunity to elect COBRA coverage within 60 days of receiving the required employer notice. The resulting COBRA continuation coverage begins with the first period of COBRA continuation coverage beginning on or after April 1, 2021.

D. ARPA Does Not Govern State “Mini-COBRA” Laws.

The new ARPA rules apply only to the federal COBRA statute and do not govern state versions of COBRA extension of coverage—often called “mini-COBRA” laws. The federal law applies to employers with 20 or more employees, so smaller employers are not covered by the federal COBRA statute.

E. New Rules Coming.

The Department of Labor and Internal Revenue Service will be issuing regulations and guidance regarding the application and administration of the COBRA subsidy provisions of the Act, so there will be additional information in the future regarding the application of the benefits set out in the ARPA.

“For many, a COBRA extension of benefits may be the best available option if the person has lost their job.”

II. ARPA Expands Affordable Care Act (ACA) Subsidies

The ARPA also makes health insurance coverage purchased from the insurance exchange marketplace more affordable.

A. ACA Premium Tax Credits.

The ACA reformed the individual health insurance market in part by creating insurance exchange marketplaces to purchase individual coverage. The ACA also established subsidies for health insurance purchased through insurance exchange marketplaces. These subsidies are often referred to as premium tax credits.

Premium tax credits subsidize the cost of insurance and reduce the amount of premiums paid by individuals. Under the ACA, individuals earning between 100% and 400% of the Federal Poverty Level (FPL) are eligible for a premium tax credit. The amount of the premium tax credit depends on family income, but premium tax credits for ACA health insurance policies are available to many families. The ACA determines the amount of premium that is affordable based on a percentage of the individual's income. If the insurance premium exceeds the specified percentage of income, the individual receives a subsidy to pay for that part deemed unaffordable.

B. ARPA Expands ACA Premium Tax Credits.

ARPA expands the availability of ACA premium tax credits. During 2021 and 2022, the ARPA increases the amount of the ACA premium tax credits—making the premiums paid by an individual zero in many cases—and expands availability of marketplace premium tax credits to eligible individuals whose income is above 400%

of the FPL.

Under ARPA, individuals and families earning up to 200% of the FPL should usually have to pay 0% of their income for health insurance premiums. That means that 100% of premi-

ums for health insurance purchased through a state or federal insurance exchange marketplace will be subsidized during 2021 and 2022.

Individuals with an income between 100% and 150% of FPL are eligible for a subsidy equal to the full amount of their premiums. While the amount of the subsidy decreases as income increases, the ARPA makes health insurance more affordable for every person in every income level when they purchase health insurance from a state or federal insurance exchange marketplace.

C. New Credits Are Retroactive.

The ARPA premium tax credit changes will be retroactive to January 1, 2021. So, people who purchased health insurance on an exchange this year will receive a refund.

D. New Special Enrollment Period.

On January 28, 2021, the Biden Administration established a new COVID-19 emergency, special ACA enrollment period which began on February 15 and will continue to May 15, 2021. During this special enrollment period, individuals may enroll in health coverage that will become effective on the first day of the month after a consumer enrolls through www.HealthCare.gov. (See *CF Roundtable* Blog Post dated March 31, 2021.) ▲

Beth Sufian, J.D., 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.



SPIRIT MEDICINE

What's On The Outside And Inside

By Isabel Stenzel Byrnes, L.C.S.W., M.P.H.

I recently heard a touching quote that is the inspiration for my Spirit Medicine column this issue: *"The purpose of life is to know the difference between what's on the outside and fleeting and what's on the inside and eternal."* (Author Unknown)

During this COVID-19 period, what we look like seems to be a whole lot less important than before. The pandemic is forcing us to prioritize health, safety, comfort, connecting with loved ones, helping those in need, and social justice. I work remotely, so I am fine being a bit fuzzy on Zoom and having people just focus on my face and shoulders. I put on a decent top, but don't have to be concerned with wearing makeup or buying new clothes. Life is so much easier when we do not have to care about our looks!

As a young person with CF, I often was very self-conscious about my external appearance. My barrel chest, emaciated frame, clubbed fingers, the bulge of my port, and other issues contributed to poor self-image. I cared more about being comfortable than what I looked like. When I was in my 20s, my mother used to say, "Make an effort to look nice! You are in the most beautiful time in your life!" But I didn't feel well. I didn't feel beautiful.

Thankfully, many people with CF are healthier these days and don't show many signs of illness. Still, though, I've heard of my friends on Trikafta feeling self-conscious about weight gain. Everyone is self-conscious about something. We all live in a culture that values both youth and image.

It is easy to spend a great deal of energy on external appearances. To survive, we want to be attractive to our mates, in our workplaces, and to the world at large. Attractive people gain favor regardless of whether we want to admit that.

CF can also impact the external things that give us self-worth. Our appearance is one of those, but there's also our achievements (what we've accomplished), our social circle (whom we know), what we do (our careers), and our net worth (our financial portfolios). Sometimes we cannot pursue

and maintain the external things that help us feel good about ourselves.

Yet, all on the outside is fleeting.

All my life, I've only had one wish: to grow old. I didn't want to die of CF, and I just wanted another birthday. And another, and another. And now that I'm 49, the season of youth is behind me and aging is ahead. And it's interesting to observe the change in my body and getting to experience what everyone else who is privileged to grow older goes through.

The topic of this issue is sexuality. In our culture, sexuality is much more than just the dance of attracting a mate for reproductive purposes and sexuality is one important part of our identity throughout the lifespan. But sexuality changes as we age. In a long marriage, like the one I am privileged to have, sexuality and passion are less important now than commitment, friendship, and serving as witnesses to each other's lives.

I recently went to see a dear friend, a long-term beloved volunteer in the CF community, who has been married to his wife for over 55 years. He is aging and his health is suffering. Our bodies are so temporary; we change and look different over time. Yet, in this elderly couple, their love was more palpable and visible than ever. What I saw inside was a deep dedication to keep each other going, a strong commitment to caregiving, and a steadiness in their enduring this season of their lives. It was beautiful.

I am privileged to work with the elderly. Elders have so much to teach

"It's interesting to observe the change in my body and getting to experience what everyone else who is privileged to grow older goes through."



ISABEL STENZEL BYRNES

us. These elders must cope with an enormous amount of loss: loss of role and identity and loss of loved ones. Some face the loss of their homes and many of their possessions as they downsize to smaller apartments. They lose their wealth as they pay for caregivers and assisted living facilities. All of these external things are fleeting and temporary. We cannot grasp too much at them, because change is inevitable.

I also believe many elders possess a different kind of beauty, one that transcends the beauty of youth. With grey hair and wrinkles, their eyes twinkle and skin glows, and their smiles capture gratitude, acceptance, and wisdom like no other. These elders remind me that true beauty is the spark inside the body, not on the outside.

If so much of life is fleeting, what part of the inside is eternal? As we grow older, what does last forever? It is up to each of us to develop our own under-

standing of what stays the same and what changes. I believe we are all like a stone thrown into the pond...the ripples continue outward beyond our sight and our noticing. The energy inside us is cast out to others and lasts forever. The stone inside us is our spirit, our spark, and fire. It is our creativity and willpower. It is our motivation and wonder. It is our generosity and service. It is our love. It is the essential Truth. What is eternal is a life force beyond our own; it is God inside us. Even if you are on disability, even if you are isolated, even if you are on public assistance, you are showing the world something incredibly valuable. Your purpose is to show your inner spirit, which allows people around you to distinguish the difference between what's on the outside and inside. The external aspects of our lives cannot take away these internal treasures. Your unique spirit serves as an example to all

about what really matters.

Finally, I believe our souls are eternal. But every person has their own spirituality to define what happens to our souls after we die. One bereaved CF parent feels her daughter's spirit is eternal. She "feels" her and "sees" her in different ways. She shared, "I'm not saying it's real, but it's real to me."

As we age, as we get sick and get better, as our external life circumstances change, these internal resources stay the same. Sometimes they even expand. In hard times, these inner aspects are rattled and shaken and forced to germinate into something brighter. But they never go away.

Each of us is on a path to decide where to put our focus: on the outside or on the inside. ▲

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

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- **Medigap.** Medigap plans, also called Medicare supplement plans, cover some of the out-of-pocket costs of original Medicare. They don't offer additional coverage, but they can allow you to receive medical care without worrying about out-of-pocket costs like deductibles or copayments.

Some of the services Medicare covers are listed below:

Testing and diagnosis. Some cystic fibrosis patients don't know they have the condition until adulthood. You'll have coverage for the testing you need under Medicare Part B or a Medicare Advantage plan. Doctor's and specialist's visits. Medicare Part B or a Medicare Advantage plan will cover your doctor's office visits and your visits to a specialist. You don't need a referral to see a specialist if you're using Medicare Part

B, but you will need a referral with many Medicare Advantage plans. **Physical therapy.** You can get physical therapy coverage through Part B or a Medicare Advantage plan. Medicare doesn't limit the amount of physical therapy you can receive as long as the therapy is deemed medically necessary by your doctor. **Respiratory care.** Respiratory care, including the services of a respiratory therapist, is generally covered under Part B or a Medicare Advantage plan. However, if you receive respiratory care in a hospital, skilled nursing facility, or as part of home healthcare service, it will be covered under Part A. Medicare Part B and Medicare Advantage cover outpatient pulmonary rehabilitation. However, you may need preauthorization before you can use this service. Medicare will also provide coverage if you need a lung

transplant. Your doctor's visits and preparation will be covered under Part B, while your actual transplant and hospital stay will be covered under Part A. Medicare will cover prescription drugs that have been FDA approved. Coverage will fall under a Part D plan or Medicare Advantage plan that includes prescription drug coverage.

Commonly covered medications include: medications to open your airways. Medications in this category include albuterol, ipratropium, and theophylline. Medications to help you cough up sputum. Medications in this group include guaifenesin, hypertonic saline, and N-acetylcysteine. Medications to help you absorb nutrients. Medications in this group include pancrelipase and pancreatin. Medications to decrease lung inflammation.

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PEARLS OF WISDOM

Let's Talk About Sexuality:

Inclusive Clinical Education for 21st-Century CF Clinicians

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

Welcome back to “Pearls of Wisdom”—and thank you for such a warm welcome for the column in the last issue of *CF Roundtable*! This time I’m circling back around to one of the first topics I ever wrote about in cystic fibrosis publications: inclusion for patients of different sexualities. So, for this focus topic on sexuality and CF, I thought it would be perfect to shine a light on how inclusive clinical education can prepare care providers to show up strong for our diverse patient population as we continue to age.

Questions about aging are certainly central in education for today’s clinical professions students, regardless of whether they want to specialize in CF care. And as our own community lives longer and grows older, clinicians face new challenges and opportunities in helping people with CF stay healthy. With patients regularly surviving into middle age, intimate relationships have become much more of a focus in the CF life course. Likewise, as more people with CF have survived well into adulthood, our adult community has become ever more diverse. This includes emerging attention to the complexity of sexuality among our population, and our increasingly central effort to actualize our sexual selves.

If that sounds like a mouthful to read, think about trying to fit all of that richness into a 15-minute clinical encounter! Clearly the challenge is to help clinicians work smarter rather than harder in supporting us as fully actualized adult patients, many of whom have thriving sexual relationships—or know with confidence that we do not wish to have any sexual relationships.

So how do we educate clinicians inclusively about sexuality and its importance for working with CF patients? Honestly, that can vary. But a common theme in all the different approaches out there for helping clinicians learn to care for people of different sexualities is to talk about sexuality—actively, and often!

As a practicing aging researcher, I often include the concept of the “4Ms” in my work. These are four concepts (Medication, Mentation, Mobility, Matters Most) for quality care for older adults. (“Mentation” may be an unfamiliar term for some. This refers to mental health—emotions, cognition, etc.) I have found them as resonant for CF care in general as for the specific types of care our older peers with and without CF may receive. I have also reflected on their specific value for sexual and reproductive healthcare among people with CF. So, I thought I would provide a short overview here of what Matters Most to me about incorporating sexuality-related concepts and clinical skills into CF care.

Of course, this also includes attention to the other three “Ms”—Medication, Mentation, and Mobility. We patients know well that CF affects most everything in our lives, and certainly in our health. But I always come back to that fourth “M” as the cornerstone of making space for sexuality in healthcare, especially for people like us who live with rare and isolating chronic conditions. For me, good healthcare has always been, first and foremost, about making space for the uniqueness and individuality of each patient. To do this effectively, clinicians need to know a little bit about how to talk and a lot about how to listen.

What Matters Most about sexuality in CF care can vary greatly. This owes in part to the expansiveness of sexuality itself. This term can best be described as a large umbrella that covers many different elements: attractions, practices, expectations, etc. Our sexuality includes everything from the sex and gender patterns of our attractions to our preferences for different types of sexual activity to our goals in sexual relationships. Indeed, it even includes whether we are interested in sex at all! So, we can think of sexuality in terms of attraction patterns—bisexual, asexual, homosexual, heterosexual, etc.—and also in many other ways.

Each of these aspects of sexuality can pose different implications for quality CF care. I will give a few examples here to encourage expansive thinking about how sexuality might become relevant for specific individual patients.

Examples related to the mechanics of sexual activity are important to consider. For instance, using sex toys if one has CF requires extra careful attention to sanitizing and lubrication. Many of us also prefer for our partners who



XAN NOWAKOWSKI

have penises to wear condoms for any type of penetration, even if we are also using extensive lubrication as recommended. Likewise, barrier methods can be helpful for preventing transmission of oral bacteria, especially if a partner has had any kind of recent infection like strep throat or thrush. And across any partners we have at a given time, practicing good infection control remains a universal must—both for our own partners and for any other partners they themselves have.

There are also broader issues to consider related to how we feel welcome when discussing our sexual partners and practices. This gets us more into the territory of what “Matters Most.” I can always give a clinician more technical details or explanations about my sexual activities or my relationships with my partners. But I cannot make that clinician acknowledge my humanity and make space for me to be myself. That must come from within each clinician—the willingness to ask open questions and listen thoughtfully to the answers. Ignorance is not a barrier to effective clinical care, but obstinacy certainly is.

I wrote a chapter in a recent book of mine about safe sex with CF, and all the things this means as I continue to grow older. I definitely have found that what “Matters Most” in CF care also continues to change with time and context. Both the emergence of new treatment options and the long-term side effects from existing ones shape how my sexuality affects my CF management.

For example, I have been on quinolone antibiotics enough times to experience permanent damage to the connective tissue in my joints. The drugs that saved my lungs and kidneys from tissue death have also necessitated avoiding sudden movements or anything that puts substantial torque on my joints, which were already quite compromised from lifelong CF-related arthritis. Anything that puts impact on the joints is out of the question. I have heard my

friends with double lung transplants say similar things about the changes the surgery itself introduced, as well as the side effects from the many medications needed to prevent rejection.

So, when thinking about how changing CF care and patient sexuality intersect, it matters to think about what the person has already experienced and what may be possible for them now. Sometimes this involves a lot of changes. In this age of highly effective CFTR modulators, many adults with CF are finding their lung function holding steady or even increasing substantially after long periods of decline. Many are also finding their sexual and reproductive functioning changing—the phenomenon of “Trikafta babies” among many people with uteri who take the triple combo is very real. And although unplanned pregnancy may not be a possibility for many gay and lesbian couples, changes in reproductive functioning may introduce new options for having children—such as artificial insemination.

Even those of us in the so-called “10%” of CF patients ineligible for modulators are often still benefiting from other advancements in care like inhaled mucolytics, aerosolized steroids, novel airway clearance devices, nutritional supplements, improved pancreatic enzyme formulations, etc. Although I am in the 10% myself, my lung function at 37 is substantially better than it was at 27 thanks largely to inhaled steroids. This definitely impacts my ability to participate in and enjoy different types of sexual activity, and also affects the broader context of my intimate relationships. A world in which one dares to envision the future is a very different world indeed—one with many unknowns.

Science on sexual and reproductive health also continues to evolve, both generally across different care populations and specifically within the CF community. For a more detailed over-

view of how the latest clinical science and best practices in sexual and reproductive healthcare intersect with sexuality in CF management, I encourage everyone to stay tuned for the upcoming chapter in the CFReSHC resource guide devoted to sex, gender, and sexuality issues! This new resource will help providers master the basics of what “Matters Most” in talking about sexuality with adult CF patients as part of their sexual and reproductive care. That material will date itself quickly but provides a good starting point for learning and action.

In these times of rapid change, some things remain constant. Although our status as rare disease patients can make many things in our lives very different, we often share certain basic needs with our peers outside the CF community. In healthcare as in other areas, we share the universal human needs of inclusion, affirmation, and compassion. Likewise, we benefit from the healthy curiosity of people who seek to help us. So, what continues to “Matters Most” in receiving care that affirms our unique sexualities is the simple ability to share openly about ourselves and who we are in a safe environment. This freedom, in turn, gives us the more nuanced ability to collaborate with providers in identifying our care needs related to those experiences. ▲

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FAMILY MATTERS

Into The Unknown: Female Fertility With CF

By Cindy Baldwin

The first time my CF doctor mentioned anything about reproduction, I was 14 or 15. Judging me old enough to have the CF clinic version of “the talk,” he gave a 30-second lecture on safe sex that included the statement that “while most men with CF are sterile, women with CF don’t typically experience fertility problems at higher rates than women without CF.” As an aside, I also want to pause here and say that while I use “women” and “female” throughout this article because it’s largely based on my personal experience and the language which doctors have used to discuss this with me, not all people with CF who have uteri and experience menstruation are women and many of these same frustrations may be shared by trans or nonbinary CF patients.

That early message followed me through my teen and young adult years, doctor after doctor assuring me that women with CF didn’t experience significant fertility problems as a result of CF. By the time I was 18, I knew there was something a little off about that advice—although I had started menstruating at a pretty typical age, I’d never had my menstrual cycle settle into anything like a regular rhythm. In a “good year,” I’d have about four periods a year. Anytime I got even a little sick, it wasn’t unusual at all for me to stop menstruating for nine months or more. Anytime I brought this up with my CF team they were baffled, particularly because my weight was fairly normal for my age.

By the time I was ready to try for a baby, in my mid-20s, I knew that my irregular periods were likely to be a sign of fertility troubles, despite the continued reassurance from my CF team that CF didn’t cause fertility problems in women. What’s more, I had connected with the newly formed Cystic Fibrosis Mothers group on Facebook, and knew from discussions there that many women with CF had problems conceiving. Some women with CF had normal cycles but thick cervical mucus that prevented them from getting pregnant while others, like me, had inexplicably

long or unpredictable menstrual cycles with no medical explanation.

When it became clear that I was unlikely to get pregnant without intervention, my primary care doctor ordered a slate of tests to try to diagnose the reason for my irregular cycles. I was negative for known illnesses that can affect fertility, like polycystic ovarian syndrome or endometriosis. I had extremely thick cervical mucus consistent with what was reported by other CF women, but that seemed like a relatively small hurdle when I couldn’t even predict when my next period

might arrive. I read book after book on female fertility and began charting my cycles—checking my temperature and other fertility signs every day and writing it all down on a graph I kept tucked into a drawer in my nightstand.

The one fertility test that *did* help give us more information was a straight-

forward blood test to check my hormone levels. My PCP explained that, at age 23, my hormone levels were more consistent with what he’d expect to see in a middle-aged woman experiencing perimenopause. There was no real, documentable explanation for this but, eventually, the accepted theory among all the doctors I saw came to be something like this: for whatever reason (a reason science hadn’t yet explained), *something* about the stress of living with cystic fibrosis was causing my body to shut down normal hormone production. I was experiencing the same kind of thing seen by elite athletes whose training is so strenuous that their periods stop, my doctor said. Despite the fact that this was something usually

“Within three months of starting Kalydeco, I had not only gotten pregnant—but I’d almost certainly gotten pregnant twice in three months”



CINDY BALDWIN

only associated with CF women who are severely underweight, it was the only theory that began to make sense of what was happening to me.

Ultimately, the thing that confirmed this theory was also the way I eventually got pregnant: in 2012, the FDA granted approval of Kalydeco, the first CFTR modulator, to treat patients with the G551D mutation, which I had. Within three months of starting Kalydeco, I had not only gotten pregnant—but I'd almost certainly gotten pregnant *twice* in three months (the first was a very early miscarriage). I became one of the first three or four women in the world to experience the now-familiar Vertex baby boom—the unexpected fact that for many women with CF who have previously experienced infertility, going on a CFTR modulator often leads to pregnancy.

My CF team agreed that the way Kalydeco had led to me suddenly getting pregnant was proof that all the things I'd been experiencing—long, irregular cycles and perimenopausal hormones—had something to do with the stress that living with CF placed on my body. When Kalydeco helped alleviate some of that stress, it was able to do

what all the things I'd previously tried and couldn't—normalize my hormones and lead to a successful, healthy pregnancy.

It's been almost a decade since then, and, in the interim, a lot more research has been done in female fertility with CF. In 2013, Emma Harris, founder of Cystic Fibrosis Mothers, shared a survey of 219 women with CF indicating that 33% of respondents were unable to conceive without fertility treatment and a further 4% were unable to conceive before beginning Kalydeco, after which they conceived naturally (compared to the 10% of women in the population at large who experience infertility, those are pretty high numbers!).

In the last few years, an increasing number of patients and doctors have recognized the need for further study on CF and female fertility. Groups like the Cystic Fibrosis Reproductive and Sexual Health Collaborative (CFReSHC) have pioneered regular research, discussion, and patient outreach about how female sexual health and fertility can be affected by CF. The Cystic Fibrosis Foundation recently created a task force focused on sexual

and reproductive health. Still, like many aspects of women's health in general, the impact of CF on female fertility and sexual health is a historically under-studied area and deserves a lot more consideration.

These days, I'm a happy mother to a precocious and delightful eight-year-old daughter. Since starting Kalydeco (and later switching to Trikafta), I've experienced, for the first time in my life, somewhat regular menstrual cycles. Although my cycles are still longer than normal, they no longer fit the profile of perimenopause. I have to admit, experiencing regular periods for the first time in my 30s has been a wild ride! How on earth do people do this every month? I feel very optimistic about the future of research into CF female fertility and greatly hope that, in the future, women with CF who would like to carry a child will have more support and resources than were available to me. ▲

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 with HarperCollins, including The Stars of Whistling Ridge, which releases in June 2021.

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Medications in this group include beclomethasone, flunisolide, fluticasone, ibuprofen, methylprednisolone, and prednisone.

Medicare will also cover medications you need temporarily—such as, antibiotics or antiviral medications you need to treat an infection. Keep in mind that not all Medicare Part D or Medicare Advantage plans cover every prescription you might take for cystic fibrosis. Plans cover only prescriptions that are part of their formulary. Medicare will also cover the at-home medical equipment you need. This is

known as durable medical equipment and is covered under Medicare Part B. Some common covered equipment includes: at-home oxygen therapy, including, oxygen tanks, tubing, and other supplies, nebulizer machines, vests for chest physical therapy, positive expiratory pressure devices. To ensure full coverage, you must get your equipment from a supplier that participates in Medicare and accepts assignment. Most of the services you need will be covered by Medicare. Exceptions include: Experimental treatments. Medicare won't cover any treatments or

procedures that haven't been approved by the FDA to treat cystic fibrosis. Long-term skilled nursing care. Medicare will cover only 100 days of skilled nursing care. Those 100 days are covered only if you meet set conditions, including a recent hospital stay of at least 3 days. Plus, you'll owe daily coinsurance fees starting on day 21. Long-term home healthcare. Medicare covers only home healthcare that's medically necessary for a condition expected to improve. For example, Medicare would cover home healthcare if you're homebound and

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John Bowlby (and later Harlow, who performed ethically questionable studies on rhesus monkeys), asserted that children have an innate desire to attach to one primary attachment figure (e.g., a mother, father, or caregiver). If a child is deprived of physical proximity to a primary attachment figure, he or she will initially become depressed, aggressive, less empathetic, and later be at a greater risk of both delinquency and attachment and conduct disorder. Subsequent researchers broadened the attachment theory to other key relationships in a person's life. Due to my disease and my parents' completely understandable response to it, I experienced significant maternal attachment and human attachment deprivation as a child.

Fortunately, when I was nine years old, we moved from California to a small, rural town in upstate New York where my health greatly improved and my isolation all but ended. While I can't say for certain whether the period of isolation during my early years negatively impacted me, I can say that, by the time I read about Bowlby's attachment theory during my freshman year at college, I was living in a halfway house serving out a five-year probation sentence after having spent nearly half of my short life as an angry, violent alcoholic and drug addict.

Throughout this past year, I've wondered to what extent attachment theory and human proximity deprivation may explain why, as the duration and frequency of my social contacts, human interactions, and physical proximity decreased, I became increasingly fearful, less trusting, quicker to anger, and less empathetic to my family, friends, and the community at large. Similarly, I'm curious whether the degree of angst, anger, fear, alienation, and divisiveness that we all observed, particularly through the summer and fall of last year, which led to hundreds of deaths, tens of thousands of injuries, and billions of dollars in property damage, was exacerbated by human proximity deprivation.

Undoubtedly, scores of books will be written to try to answer these and other vexing emotional and psychological questions regarding how various public health responses impacted people. However, I contend that the sooner we move past these esoteric and theoretical questions and arrive at the central question of what we will do personally, as unique individuals in all our identity roles, including that of a CF patient, the better.

“Throughout this past year, I've wondered to what extent attachment theory and human proximity deprivation may explain why I became increasingly fearful, less trusting, quicker to anger, and less empathetic to my family, friends, and the community at large.”

As I too wrestle with this central question, I am reminded of a conversation that I had with my dad nearly four decades ago regarding his experience in the 'Korean War' which, although never declared a war by Congress, was historically recognized as the only armed conflict the U.S. Marines ever lost. I caught him late one night in his office and peppered him with several questions about how cold it was, whether he was shot at or had to shoot anyone and, lastly, whether the Marines lost. Finally, after trying to wave me off unsuccessfully for several minutes, he relented, took his glasses off so I could better see the scar on his forehead where they operated on him after he was mortally wounded, exhaustedly exhaled his response, and said, "Son, when I was 18 in bootcamp, they told us all the reasons we needed to win and those reasons gave us the courage to land at

Inchon beach. Months later, when we were withdrawing from the Yellow River after taking 90 percent casualties on the reservoir and had to fight our way out, surrounded by the enemy, I was forced to realize wars aren't won—they are only survived. Years later, I came to the conclusion that the most important question wasn't whether we won or lost the war, but how I personally survived, how I'd heal, and how I'd live the rest of my days to honor what was lost."

In the wake of the war, despite remarkable insight and self-awareness, my dad became a very stern, stoic, hard, and joyless man. Although I'm assuming he told my mom he loved her, he reserved that only for her, because he certainly never shared that affection with us, his children, and he never shared a hug with anyone other than her, that I can recall. Sadly, I told him I loved him and hugged him just once, and that was hours before he lost his battle with cancer, which a class action lawsuit claimed was caused by the chemicals he was exposed to in Korea.

After my dad passed and I had several years of sobriety under my belt, I noticed that my anger subsided and I began to find peace. Eventually, I stopped watching people and started truly seeing them. I stopped simply talking to people and instead started sharing my life with them. I stopped holding

back my tears and started shedding them. Most importantly, I stopped merely shaking hands and started offering hugs. In the rooms of AA, at TJ's Diner hanging out with my sober friends, talking with my sponsor, and in the embrace of those who loved me, I began healing from the trauma and isolation of my earlier years with the help of the CF community and my recovery family, but this crisis has shown me that I have so much more work to do.

This past year has been anything but easy for most of us. My whole family contracted COVID-19 and I had a particularly rough go of it that left permanent damage. I knew CF patients who died from it, one who committed suicide, and nearly half the people I knew in recovery either relapsed, overdosed, and/or committed suicide. The experience retriggered childhood trauma, revealed unresolved interpersonal conflicts, fomented long-

held resentments, and magnified perceived differences. To be completely transparent, I thought, felt, and acted in ways of which I am anything but proud, but I survived due to my faith, family, friends, and countless prayers. So, now, I have to find my path to emotional healing and answer the most pressing question, namely: who will I be in the wake of this to honor what was lost? When this is all over, I hope to cry as much for the CF community and the people in recovery as I do for the countless individuals without CF and nonrecovering addicts and alcoholics who have lost loved ones, apartments, homes, and businesses. When the time is right and herd immunity is achieved, when our immersion into human deprivation ends, I hope that, when I offer a hug again, which I know I will, it will be returned without fear or reservation and with the same warmth and affection with which I extended it. In the aftermath, I hope the

world grieves for what was lost, heals from its many wounds, more deeply loves one another, and hugs more than ever with greater warmth and affection than before this pandemic. ▲

Mark Tremblay, M.A., M.P.A., is 51 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.

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need a nurse to treat you for an infection. Medicare doesn't cover extended home healthcare. Any other type of long-term care. Medicare never covers stays at assisted living, custodial care, personal care homes, or nursing homes. Medicare considers all these services to be nonmedical and doesn't cover them. <https://tinyurl.com/yaue9arg>

CF Patients, Carriers Of European Ancestry At Higher Pneumonia Risk

Cystic fibrosis (CF) patients and carriers of European ancestry are at a higher risk of developing pneumonia. CF patients were also found to be at an increased risk of more severe pneumonia. The findings may help in identifying patients more susceptible to pneumonia caused by a number of triggers, including COVID-19 infection, and in starting early approaches that might prevent more severe disease. Researchers conducted a genome-wide

association study. Genome-wide association studies look for genetic variants that might serve as predictive markers of the presence of a trait or disease. Study results showed that the genetic region most strongly associated with both pneumonia susceptibility and severity among those of European ancestry was located in the CF-associated CTFR gene. CF carriers were also more susceptible to pneumonia, but to a lesser extent than people with the full-blown disease. This is consistent with results from a previous study showing that these carriers are at higher risk of several CF-related conditions, when compared with people without CFTR mutations.

<https://tinyurl.com/ydhpxot8>

Minorities In US Ineligible For Key CF Therapies Due To Unknown Mutations

Individuals with cystic fibrosis (CF)

from racial and ethnic minority groups in the U.S. are twice as likely to be ineligible for disease-modifying therapies than white patients, because their mutations are not known to be suited to approved treatments. The resulting lack of treatment access exacerbates these groups' already severe disease course and earlier mortality. CFTR modulators are compounds that help to restore healthy CFTR function by targeting specific mutations. The specificity of these mutations means that each modulator only works for patients with those specified mutations. Approximately 90% of patients with CF have CFTR mutations that are currently FDA-approved for CFTR modulators. Patients of a minority group were over twice as likely to have CFTR mutations that were not classified compared to non-Hispanic white patients. Patients without two known CFTR mutations

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Late Diagnosis Cystic Fibrosis

By Patricia Brown, R.N., M.S.

You know the drill: pulmonologist; infectious disease specialist; emergency room visits; gastrointestinal specialists; Christmas Eve in the hallway of the local, overfilled ER. These are the realities of cystic fibrosis. But what if there was no diagnosis of cystic fibrosis? What if all these specialists scratched their heads and suggested you try something else. What if you heard all of this as a nurse? This is my story of being diagnosed at age 67. I'm now 69 and connected with the wonderful multi-disciplinary team at my local CF clinic.

Today, most people in the United States are diagnosed in infancy via a chloride sweat test. I was born in California in 1951 when sweat tests were not done. My childhood was spent being ill and coughing constantly. In the 1950s and 60s, one didn't go for doctor visits in my town in Illinois. The doctor was called and the patient toughed it out at home. The doctor maybe prescribed you some codeine

cough syrup, but probably not. The illnesses continued. Throughout grade school I missed so many days of school, my parents occasionally heard that I may not be moved to the next year. My first "related" hospitalization

occurred while I was in nursing school—Coxsackie B virus with severe pleural pain.

For decades, more doctor visits ensued. There was no mention of CF. I had sinus surgery and the ENT said, "I'm shocked at how awful your sinuses are." I'd had sinus infections non-stop for decades. I'd try a new antibiotic and my sputum would convert to clear for two weeks, then the cycle started again.

In my mid-30s, I was unable to get pregnant. By this time, I had my Master's Degree in Nursing. I was sick of being sick. I had a pulmonologist I respected and admired. I asked, "Do you think I might have some odd version of CF?" He laughed and said no. My lovely pulmonologist died, unexpectedly, and I went to someone new.

My lifelong bouts of diarrhea were getting much worse. I saw a gastrointestinal specialist. He said I had pancreatic insufficiency and prescribed a pancreatic enzyme. I suggested we get to the bottom of the pancreatic insufficiency. He ordered a CT scan of the abdomen and, when I received the



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cannot qualify for CFTR modulators. Eligibility for CFTR modulators also affected lung function, as measured by forced expiratory volume in one second (FEV1). Patients across groups who were ineligible for these CFTR modulators had the lowest FEV1 measures, meaning worse lung function. The researchers went on to note that besides being less eligible for CFTR modulator therapy, minorities tend to be under-represented in pharmaceutical trials. This issue will grow as the CF community's demographics continue to change.

<https://tinyurl.com/yar7o628>

Bronchoscopy Plus BAL Safe Way Of Checking Lung Health Of Patients

Using bronchoscopy to examine the airways and the surrounding tissues of people with cystic fibrosis, coupled with the collecting of lung fluid through bronchoalveolar lavage (BAL), is safe and a reasonable alternative when sputum samples are not possible, a study reports. In bronchoscopy, a thin tube (bronchoscope) through is inserted through the nose or mouth, then down

the throat and into the lungs. It is used in CF research to identify immune cells and microorganisms in alveoli (air sacs of the lungs) to study airway inflammation. BAL consists of injecting a sterile saline solution through the bronchoscope into alveoli, and then collecting the fluid, along with cells, for analysis. It has been shown to be useful in helping predict pulmonary exacerbations in children with CF, and in microbiologic sampling of patients whose sputum is scarce due to the use of newer CF modulator therapies. Chronic lung

“There was ongoing embarrassment due to coughing through every meeting, movie, party, interview, and life moment.”

results (weeks later because I had to get on the phone to beg for the results), I opened the letter indicating that I had severe pancreatic atrophy consistent with CF.

Finally, after decades of trying to get doctors to hear my complaints of thick, dark green sputum no matter what the treatment, here was the diagnosis. My new pulmonologist was surprised by my suggestion and ordered a chloride sweat test. Local hospital labs laughed when I called them. They reminded me that this is an infant test and inquired if I might be mistaken. I persisted in calling labs until, finally, one agreed. The technician admitted she didn't know how to do a test on a 67-year-old patient and didn't know what the expected adult normal values were. Finally, the test came back confirming CF.

My pulmonologist saw me fre-

quently to establish the correct treatments. I spent my time online looking for resources. I found the Cystic Fibrosis Foundation and, via their website, my local CF clinic. How my life changed! I was placed on Symdeko and immediately felt better.

As soon as Trikafta was approved, I was placed on it that very week. I felt normal for the first time in my life—no coughing, no wheezing, and no clearing my throat. Walking was no longer a trial.

I doubt I need to give advice to any CF patients as they are familiar with this story, but for those not yet diagnosed, you need to search to get to the bottom of each symptom. For physicians seeing patients with persistent cough, sinus problems, diarrhea, and infertility, I suggest you listen to the constellation of symptoms rather than to individual symptoms. My wise

CF pulmonologist reminded me that this is a rare disease and that your average physician is not looking for rare diseases.

I've avoided describing the attendant "feelings" here, but I acknowledge how difficult it is to wade through office gatekeepers, test schedulers, and records clerks. As a nurse, I know the lingo and am familiar with the barriers to information, yet I found it frustrating and demotivating. There was ongoing embarrassment due to coughing through every meeting, movie, party, interview, and life moment. I recall a sense of shame over the huge sputum production unfamiliar to a non-CF individual.

My compassion for others with chronic diseases has heightened and my concern for my fellow CF peeps grows daily. Be your own bell ringer. It took me six decades of bell ringing. Don't give up. ▲

Pat Brown, R.N., M.S., is 69 years old and has CF. She lives in Trabuco Canyon, California. She loves dogs and birds. She is a beginner piano student. She is the author of a work of historical fiction, The Bruges Tapestry by P.A. Staes. You can find out more at www.thebrugesapestry.com.

inflammation remains a problem in CF. To identify novel therapeutic targets to combat CF lung inflammation, the use of primary immune cells is critical. Therefore, research bronchoscopy with BAL is a highly useful tool to facilitate the development of improved therapies to target inflammation. The study noted that throat swaps that might be used when a sputum sample cannot be collected lack sensitivity in detecting *Pseudomonas aeruginosa* and other potentially harmful bacteria. Sore throat and cough were the most common side

effect among CF patients. Fever and headaches were also reported. Most patients with a fever and headaches also had poorer lung function, with predicted FEV1 values lower than 65%.

<https://tinyurl.com/y8gm89j2>

Sinus Surgery Can Be Helpful For Those With Poorer Lung Function

Endoscopic sinus surgery led to better lung function in people with moderate or severe cystic fibrosis, and some with mild disease, with benefits sustained one year after surgery, a medical

records review found. These findings support the role of sinus surgery in improving lung health, especially for patients with the greatest need. Sinus disease affects about one-fifth of those under the age of 18 and over half of adult patients. Studies indicate nearly all people with CF have clinical findings consistent with chronic rhinosinusitis (CRS), or inflammation of the nasal cavity and sinuses. Nasal polyps can also develop. Endoscopic sinus surgery (ESS) is a procedure for treating sinus disease.

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FOCUS TOPIC

SEXUALITY AND SEXUAL HEALTH IN CF

Sex-ploration!

By Anonymous

Growing up with CF, I felt ashamed of my body—I was embarrassed both by my near-constant cough, which could be heard well before I was seen, and the foul-smelling stools that plagued me throughout childhood. I dared not “drop a deuce” in the school’s bathroom as all the mean, cool girls congregated there between class periods. After second grade, I learned to hold it until I got home, if possible, because the ridiculing and name calling were too painful. I hated my horrid disease and what it was doing to me and my body. I wanted to lash out.

Even though I was late to puberty and starting menses, I was sexually active at an early age. My late arrival to pubescence was probably due to having zero fat on my small-framed body, and I was a late bloomer as far as developing breasts and starting my period. I was self-conscious about this and often compared myself to those without cystic fibrosis. Even before puberty, I was interested in sex and couldn’t wait until I was old enough to have it! In the 60s, people with CF seldom lived past their teenage years. This led me, at the time, to believe that I was headed for an early death. I wanted to live fast—if I died young, at least I would have had fun. This meant sex, drugs, and teen rebellion! I experimented with recreational drugs as they were a release and a way for me to defy CF. I was often furious about my disease, and smoking marijuana or dropping acid, although I knew it was harmful, was an escape for me. I rebelled hard.

To say I had low self-esteem was an understatement. I hated being so different from my peers. I looked for any way to just not feel so different.

Growing up, I didn’t know anyone with CF and even if I had, we weren’t allowed to meet at clinic. My pediatrician held firmly that it was not healthy for those with CF to meet for it risked fatal cross-infection. Our parents were allowed to commiserate with one another, which proved therapeutic for them, but patients had no way of connecting with one another to feel less isolated. This was the 70s! I do not think my doctor understood the suffering in silence that some of us experi-

“I think these relationships and the sex I had was something that made me feel confident and begin to appreciate my body as my partner did.”

enced. I would have given anything to know someone else whom I could talk to about CF and feel less alone. I had plenty of friends, but none of them was living with a terminal, chronic condition. Eventually I started receiving some interest from the opposite sex, and that started to change my feelings about myself and how I presented myself to the world.

I started to “date” or, rather, get to know boys and immediately become intimate with them. I seemed to be with someone for many years, not being secure enough to break up with them even though I knew the relationship had run its course. I was probably too insecure to think I would find someone again who could accept all of what CF brings—the coughing, the medications, and the occasional IV antibiotics (which at that time were minimal for me). But that was how I felt.

I think these relationships and the

sex I had was something that made me feel confident and begin to appreciate my body as my partner did. Even though CF made me feel like I had a defect, I could feel normal as I was able to have sex and feel pleasure from that. And, more importantly, I felt loved and desired. I had many relationships that lasted years. I was in a relationship more often than not. I had been engaged twice before I realized that I would rather be alone than be with this person forever after, or until death did

us part. As I matured, I realized many of my relationships were with men who didn’t fully appreciate me. Now I see this as a reflection of how I felt about myself back then. I guess I felt I didn’t deserve to be appreciated and just was lucky to be with someone.

For birth control, I used various methods. At first, I used a diaphragm but hated the spermicidal jelly that had to be used with it—it became a mess. I hated using spermicidal creams and foams so much that I consulted my CF doctor about getting my tubes tied. I acknowledged to him that I was probably never going to be healthy enough to have a child, and he agreed, so he referred me to a surgeon who did this procedure. The surgeon convinced me that it might be best to wait on this decision and so I did. He felt I might regret having my tubes tied and that I could do it later in life. Eventually, I started taking birth control pills. I

stayed on them until my 30s. Around that time, my PFTs hovered between the 20s and 30s. I started battling hemoptysis when I engaged in sexual intercourse, which ultimately curtailed my sex life and dating. I began to focus on listing for a bilateral lung transplant and lost interest in being physical with anyone during that process.

Once transplanted, for some reason, I bled for three weeks of every month rather than the usual one week. As a result, I became extremely anemic and almost passed out a few times on the street. I was put back on birth control to control my bleeding and remained on it into my 50s. Even when I wanted to stop using it, I was told by my endocrinologist that the estrogen in the pill would help me keep my bone density in the healthy range. From having CF and being on prednisone post-transplant, I was at a higher risk of developing osteoporosis. Thankfully, my bone density was decent until I had to stop taking birth control at 53 due to a blood clot forming around a PICC line.

The transplant turned my life around for the better. I not only felt physically well, but I felt better about myself. I was no longer constantly coughing and calling attention to myself in what I felt were negative ways. I seemed more outwardly normal. When I met new people and told them I had a lung transplant, they didn't believe me.

So, after all these years, I felt normal and accepted. Yes, I had some new scars under my breasts and the surgery rendered them numb for about six months post-transplant. Aside from that weird sensation, I felt empowered and good about myself. I started to feel less needy and insecure about being so different from others. I still had a mountain of medications to take daily, but I no longer needed to spend hours doing treatments. I was freer. I knew that when I started dating or even making new friends, I was not going to settle for those I had settled for prior to transplant. I felt worthy for once. I started dating, and the bar was set higher for prospective mates. I started to enjoy having sex again without worrying my lungs would start to bleed.

In my 40s, I started to notice I had all of the symptoms of being premenstrual—bloating, moodiness, headaches. Despite all that, I was bleeding less or not at all compared, to when I was younger, likely due to the birth control pills. My sexual desire or urges that were more prominent in my youth were receding. I had vaginal dryness for the first time in my life. My memory was nonexistent. I assumed I was entering perimenopause. Once I stopped taking birth control, I went into menopause immediately, including hot flashes every few hours. At first, I was checking my glucose levels constantly as it is

a similar feeling to low blood sugar—the heat from within and intense sweating. Thankfully, the frequency of hot flashes only lasted about six or seven months and tapered every month thereafter. The vaginal dryness, however, remained, making sex painful. To ease the dryness, I started using Estrace, an estrogen cream that you insert into the vagina a few times a week. Again, not loving the mess of creams and such, my compliance was not great and, therefore, the results were not, either. But I do try to use it or, as they say, I may lose it.

I think now I have lost it! Post-menopause, I no longer have a sex drive. While overall, I feel more confident about who I am and have self-esteem, sex is not a priority. I am sure it has to do with my lack of female hormones post-menopause but it could also have something to do with the current COVID-19 pandemic—I do not want to be physical with anyone! It is quite shocking to me to lose my libido after enjoying sex most of my life. But as with most things CF brings along with all of its glory, adapting is key. I will have to make more of an effort and so will my partner.

Who knew I would live so long. Looking back, would I have done things differently? I would probably not have smoked pot. But sex? I would do it again in a heartbeat. ▲

Cystic Fibrosis Mothers

Cystic Fibrosis Mothers is a website dedicated to providing information on parenthood to women with cystic fibrosis around the world. Our aim is to provide a central online resource for the global cystic fibrosis community. It includes personal stories, research articles, advice and links to further sources of information built up over time.

We also provide a private support group on Facebook with more than 500 members worldwide. To visit our website go to: www.cfmothers.com.

If you would like to join our Facebook support group, please go to: <https://cfmothers.com/cfmothers-forums/>.



The Cystic Fibrosis Reproductive And Sexual Health Collaborative

Releases Sexual And Reproductive Health Resource Guide: A Resource Guide Written By Patients For Providers And Other Women With CF

By G.M. Brown and Melissa Shiffman, M.A., L.M.S.W.

With life expectancy now exceeding 40 years of age for patients with CF, those assigned female at birth are concerned with the lack of attention given to their unique sexual and reproductive health (SRH) concerns. The Cystic Fibrosis Reproductive and Sexual Health Collaborative (CFReSHC), established in 2016, is a collaborative of patients, providers, and researchers working together as equal partners to improve sexual and reproductive resources, healthcare, and scientific knowledge about CF-SRH issues. Over the past four years, CFReSHC engaged women with CF on a variety of focus topics, from hormones to contraception to fertility to menopause, with the goal of addressing SRH issues across the lifespan.

To help improve both provider and patient knowledge as well as standards of care, CFReSHC recently published an online CF-SRH resource guide. The target audiences for this guide are the CF community, women's and CF health providers, related specialists, and researchers. The 11-chapter guide written by women with CF for providers and patients covers: Incontinence, Body Image, (In)Fertility, Pregnancy, Family Building, Sexual Function, Hormones, Vaginal Health, Menopause, Contraception, and Parenthood. A chapter on Sex/Gender/Sexuality will be added to the

guide by June. Each chapter has a downloadable PDF version for those who would like a hard copy of the chapter(s).

Funded by a Cystic Fibrosis Foundation Impact Award, the Resource Guide provides clinicians with questions to initiate conversations with patients about specific SRH top-

various providers.

"The knowledge and personal experiences of patients informed this work at every step—developing a valuable resource for providers. The ultimate goal is improved health outcomes through patient engagement, and co-production between patients and their healthcare providers," asserted Dr. Pat Walker, Co-Director of the Cystic Fibrosis Center at Mount Sinai/Beth Israel in New York City and Project Advisor.

While the CF-SRH Resource Guide does not offer medical advice (consultation with your provider is crucial), each chapter offers an overview of

“The guide provides vital information to the CF community, helps enhance mutual dialogue in the clinic, and ultimately promotes women's sexual and reproductive health and wellbeing.”

ics, information, and guidance on integrating CF-SRH into the clinic setting, as well as additional content that increases awareness about CF-SRH topics. To prepare the guide, over 40 participants with CF, called Patient Partners, read peer-reviewed articles and online resources, organized each chapter, gathered patient narratives, and wrote the content. They virtually presented their findings to their peers, those with CF aged 18+ assigned female at birth, during Patient Task Force (PTF) meetings for feedback. Then meeting attendees brainstormed peer-to-peer advice and topic-specific questions they felt important to create a dialogue between patients and their

how the topic impacts adults with CF assigned female at birth. Many women with CF shared their personal stories to better illustrate the experiences women with CF undergo and to show other women that they are not alone. Chapters provide checklists and valuable resources for both providers and patients on such areas as pregnancy, fertility, genetics, and family building. Chapter writers reviewed over 250 sources on topics where, in many instances, much of the research is either dated or sparse. The guide also includes helpful links for both providers and patients.

"This guide is the first of its kind:

Continued on page 23

THROUGH THE LOOKING GLASS



PHOTO BY ROB ROHDE

Featuring (L to R) Missy Peterson, Patrick Baird, Isabel Stenzel Byrnes, Michelle Compton, Anabel Stenzel, Tom Martin and Lisa Steiding

Lucky 7

The fifteen of us gather
 Yet only seven are seen
 Seven double lung transplant recipients
 One, twice.
 Graced with another chapter after cystic fibrosis
 The lucky seven have survived.
 It's a gamble, this chance to live
 The seven of us have beaten the odds
 Because someone else didn't
 Standing behind us are the shadows
 Of eight saints who gave us breath
 And with this breath
 We are free, really free!
 Free to be friends, lovers, artists,
 athletes... adults
 We are free to laugh, love, to take chances
 We are free to face each other
 There is no shame, only intimacy

With this breath
 We see everything
 The hope, the gratitude, the amazement
 The fear, the sorrow, the yearning
 Our joy above all
 And with this breath
 We won courage
 To come to the edge and roll the dice
 And to know we need more courage
 For the next hand
 The seven of us make a promise to each other
 And to the eight saints
 I'll stay in the game if you stay in the game.
 Please.

-I. Stenzel Byrnes, 2009

FROM OUR FAMILY PHOTO ALBUM...



**BETH SUFIAN WITH HER NEW
DOG, MIN.**



COLLEEN ADAMSON



**BOOK PANEL AT THE LOS ANGELES CHAPTER OF THE HISTORICAL
NOVEL SOCIETY WITH FELLOW MEMBERS (LEFT TO RIGHT):
A.E. WASSERMAN, PATRICIA BROWN (WRITING AS P.A. STAES),
JERI WESTERSON AND SEAMUS BEIRNE.**



G.M. BROWN VISITING YELLOW SPRINGS, OHIO.



MICKEY DAVIS IN THE MIDDLE WITH TWO OF HIS NURSES, TODD AND ELISSA, FROM SEATTLE CHILDREN'S HOSPITAL, ONE-MONTH POST-TRANSPLANT.



ROB DE LA NOVAL LEADS A DANCER AT LATIN DANCE IN SOUTH BEND, INDIANA.



STEVE AND MELISSA SHIFFMAN WITH THEIR NEW DOG, MARLOW.

Feel Sexy, 2015

By Dominic Quagliozzi
Watercolor on paper
14" x 17"



DOMINIC QUAGLIOZZI

I made this drawing as part of a series of work in the weeks after receiving a double lung transplant. It was about the moment when all my fragility turned to vibrance—that sensation when you wake up one day feeling sexy for the first time in a long time. After my transplant, I felt like my body and mind were completely wrecked. I had spent years waiting for the call, while being tangled up in oxygen tubing, with a g-tube poking through my abs, and no stamina for sex—all very familiar for a person with CF. As I emerged out of depression, self-doubt, and vulnerability, I wanted to make this watercolor both a pronouncement and a statement of fact: I could feel the feeling of being sexy again. ▲

Dominic Quagliozzi is 38 years old and is a visual artist living and working in Los Angeles, CA. He creates art that is guided by his lived experience with cystic fibrosis and being a recipient of a double lung transplant. Working across multiple media, he presents themes of patient experience, vulnerability, physicality of the body, and the intersection of chronic illness and sexuality. He has exhibited across the United States and internationally and has used art to advocate for, and connect with, others waiting for organ transplants.

by engaging women with CF to write chapters and prioritize questions for clinic, the guide provides vital information to the CF community, helps enhance mutual dialogue in the clinic, and ultimately promotes women's sexual and reproductive health and wellbeing," remarks Project Director, Sandy Sufian, Ph.D., M.P.H., Associate Professor at the University of Illinois at Chicago.

Each month, CFReSHC holds two-hour virtual meetings on focus topics selected by PTF members. During the first hour, a speaker, frequently a health-care provider and/or researcher, shares her research and/or current research being conducted on a selected focus topic. Meeting attendees are given the opportunity to ask the presenter questions about their research and any future research projects. In the second hour, small breakout groups share their personal stories. This supportive environment allows attendees the opportunity to learn from one other while identifying patient-driven research needs. Finally, meeting attendees develop and prioritize research questions on a focus topic. CFReSHC surveyed members of the PTF to identify focus topics. Topics such as, Low Libido, Breast Health, Nutritional Needs, and Mental Health ranked high in previous surveys, and CFReSHC plans to address these issues in future meetings.

Since its inception, CFReSHC has welcomed an impressive roster of researchers and clinicians to present their work at our meetings, including Dr. Pat Walker, Co-Director of the Adult CF

Clinic at Mount Sinai Beth Israel; Dr. Jennifer Taylor-Cousar, Co-Director Adult CF Clinic National Jewish Health; Leigh Anne Bray, Ph.D., R.N., C.N.L., University of Alabama-Birmingham; Dr. Jeanne Sheffield, Director of the Division of Maternal-Fetal Medicine, Johns Hopkins; Dr. Emily Godfrey, University of Washington; Elinor Schwind, Genetic Counselor Mount Sinai Beth Israel; Dr. Traci Kazmerski, Pediatric Pulmonologist at UPMC Children's Hospital of Pittsburgh; Dr. Raksha Jain, Medical Director of the Adult Cystic Fibrosis Program, UT Southwest; Sigrid Ladores Ph.D., R.N., P.N.P., C.N.E., University of Alabama-Birmingham; and Dr. Sheila Mody, UC San Diego. CFReSHC has a repository of over 60 potential research questions that are ready for translation into viable research studies that use Patient-Centered Outcomes Research ("PCOR") methodology to maximize patient engagement.

CFReSHC uses the principles of PCOR to engage the adult CF community directly in the research process, by including patients as stakeholders in generating research. Typically, researchers drive the research agenda and patient input is traditionally garnered through focus groups, surveys, or study participation; i.e., like in a clinical trial. The results of this type of research are often disseminated in academic journals, but not necessarily directly to the patient community. By using the principles of PCOR, patient voices were included in all aspects of generating the resource guide. Patient Partners worked directly

with researchers and providers throughout the process—identifying the need for a resource guide, writing grant applications, and implementing the project. They also disseminated the valuable data directly to the community in language accessible to patients. Using PCOR provides meaningful patient-generated CF-SRH outcomes because it is based on patient priorities and promotes improved knowledge and health-care outcomes.

CFReSHC extends an open invitation to patients, providers, and researchers to collaborate on this exciting work. Please visit www.CFReSHC.org to learn more about our research questions, meeting schedule, and upcoming research projects. ▲

G.M. Brown is 50 years old and has CF. She lives in Cincinnati, Ohio.

Melissa Shiffman is 47 years old and has CF. She lives in New York City, New York, with her husband and two children. She is a social worker and began advocating with the CF Foundation in 2011. She served as National Advocacy Co-Chair for three years. She continues to advocate in Washington, D.C., and New York on behalf of the Foundation for policies that will help extend and better the lives of people with CF and their families. She is a member of the Cystic Fibrosis Reproduction and Sexual Health Collaborative, which produced the Cystic Fibrosis Sexual and Reproductive Guide—a guide written by patients for providers and patients on topics such as body image, contraception, hormones, family building, and more.



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Beyond The Birds And The Bees: *The Circles Of Sexuality*

By Laura Mentch

What does the word sexuality mean for you? Different cultures, ethnicities, and groups of people carry different beliefs and practices about many things, including sexuality. Our individual attitudes, values, and feelings about sexuality develop from our own experience. The influences of our family, culture, community, and education contribute to our sense of sexuality. What people or experiences have helped guide your values about sexuality?

The *Circles of Sexuality* model was introduced in staff training at our family planning clinic by Dr. Dennis M. Dailey, a former professor of social work at the University of Kansas. Dr. Dailey designed this concept for his *Human Sexuality in Everyday Life* course to support students in creating healthy relationships. He offers a view of sexuality as five intersecting circles: Sensuality, Intimacy, Sexual Identity, Sexual Health and Reproduction, and Sexualization. The “circles” are applied in many human service fields and have supported my work in sexuality education and training. I hope you will find this interesting and helpful in your own understanding of being a sexual



LAURA MENTCH

person.

“The Circles” help us expand our understanding of sexuality and the interrelationship of these parts of our sexual being.

Sensuality.

Our feelings about and experiences of our bodies and other people’s bodies.

The elements in this circle include skin hunger, body image, sexual response cycle, and fantasy. Skin hunger is the need to give and receive touch.

Intimacy.

The ability and need to experience emotional closeness to another person and have it returned.

Our intimate relationships are characterized by caring, sharing, loving/liking, emotional risk taking, vulnerability, self-disclosure, and trust. If asked about your intimate relationships, would you include a sibling or your best friend from many years with whom you freely share your emotions and feelings?

Sexual Identity.

A sense of who one is sexually, including a person’s gender identity and sexual orientation.

How we perceive ourselves as sexual beings include our biological sex, gender identity, gender expression, and sexual orientation.

Sexual Health and Reproduction.

All behaviors and attitudes that have to do with reproduction and keeping the sexual parts of the body healthy.

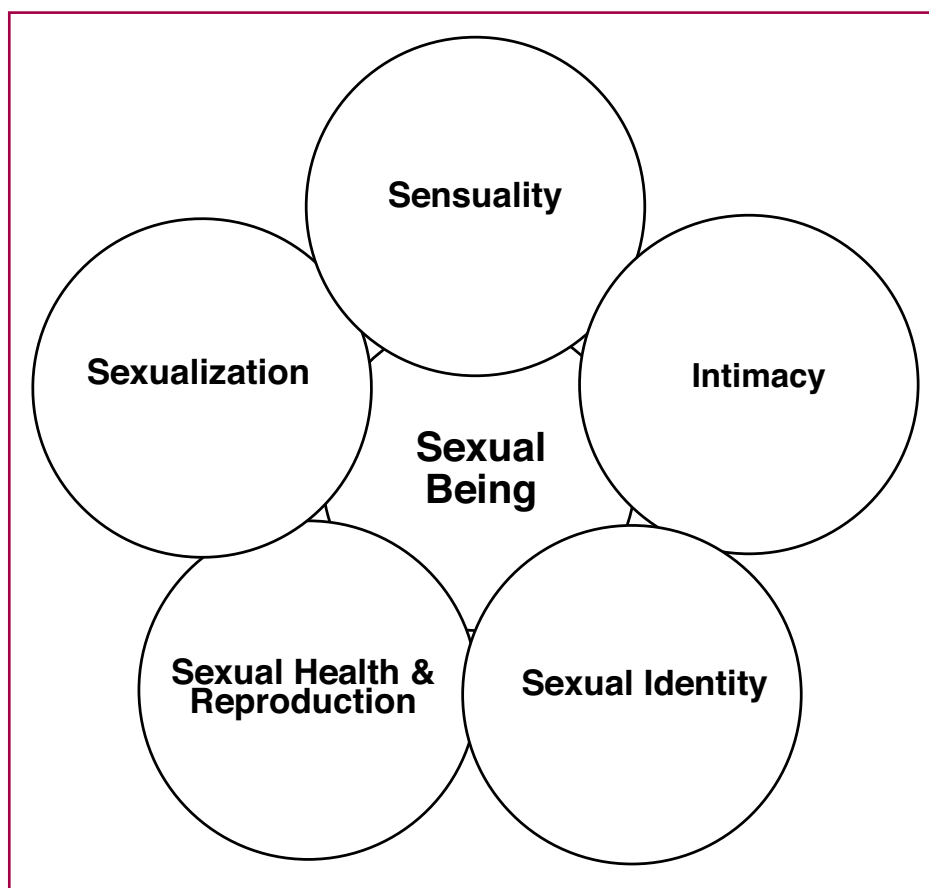
The concepts in this circle are those of typical sexuality education: anatomy and physiology, health and hygiene, pregnancy, birth control, and

TILLMAN continued from page 15

The main goals of ESS are to remove polyps and irrigate out excess mucus, and to reduce inflammation and the number of bacteria. It is also done as a preventative measure for lung transplant candidates, as the sinuses are a likely source of infectious bacteria. Prior studies examining the impact of ESS on lung function tests report conflicting

results. The majority compared pre- and post-operative lung test outcomes without accounting for factors that may influence the results, such as different disease severity levels or a person’s use of disease-modifying therapies. Improvements in percent predicted forced expiratory volume in one second was the primary goal. Mild lung disease

was defined as a %FEV1 higher than 70%, 40% to 70% as moderate disease, and less than 40% as severe lung disease. Lung function was assessed 90 days before surgery, and for one year after ESS. Results of the adjusted model showed the effect of ESS varied by the severity of lung disease. The %FEV1 significantly increased by 8.1% among



of intimacy? Could body image also relate to sexual identity or sexualization? The summer 2020 *CF Roundtable* focus on diversity included an article by Mica sharing the challenges of receiving appropriate and respectful healthcare as a transgender person. Healthcare providers' appreciation or neglect of our sexual identity can affect our patient experience. *CF Roundtable* has featured articles on incontinence, a sexual health concern. Many adults with CF have shared their experiences of pregnancy, surrogacy, or adoption. Others write about the joy in having close relationships with children in their extended or chosen families. These are issues of reproductive and sexual health and intimacy.

Each of us has a different experience living with CF. We are also unique sexual beings. How has the intersection of your CF and your sexuality influenced you? ▲

Laura Mentch, is 68 and has CF. She lives in Bozeman, MT, with her partner, Michael. She is the volunteer historian for USACFA. Her contact information is on page 2.

Discussion of the Circles of Sexuality adapted from the The Unitarian Universalist Association and the United Church of Christ in addition to Advocates for Youth and Dr. Dennis M. Dailey, Ph.D., Professor Emeritus, The University of Kansas.

sexually transmitted infections.

Sexualization.

The use of sexuality to manipulate or control others.

Sexualization ranges from media messages/images, flirting/seduction, withholding sex, sexual harassment, incest, sexual assault, and rape. These experiences are common and often have a profound effect on our lives.

How might this model relate to the experience of living with cystic fibrosis? Recent *CF Roundtable* articles have included some of the concepts within the circles. The spring 2020 *CF Roundtable* newsletter focus on weight issues offered articles on the common concern of body image within the CF community. How can the way we feel about our bodies affect our experience

patients with severe lung disease, and by 3.0% in those with moderate lung disease. A 7.3% increase in lung function was also seen in a subset of mild lung disease patients. Among patients with better lung function after ESS, the mean improvement was sustained one year after surgery. The ESS effect did not vary by CFTR mutation, age, whether

it was the first or second surgery, or whether the surgery was performed alone or with bronchoalveolar lavage. These results support the role of ESS in improving pulmonary status in the CF population.

<https://tinyurl.com/yj7no9s6>

CF Antibiotic Gentamicin Does Not

Need To Cause Deafness, Study Finds

Scientists discovered the subtypes of gentamicin that are more likely to cause deafness and created a new formulation that is as effective at eliminating bacteria but much safer for patients. The team is planning to write to the U.S. Food and Drug Administration

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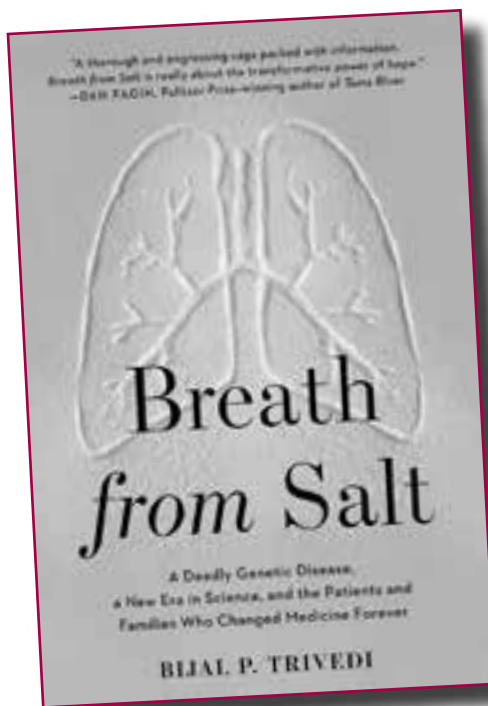
BOOK REVIEW

“No Man Is An Island”: A Review of *Breath from Salt*

By Bijal P. Trivedi
Reviewed by Rob De La
Noval, Ph.D.

There comes a time for each of us when we recognize a basic truth that will follow us for the course of our lives. I mean the fact that other people are *different*. Likely it hit you when you went over to a friend's house as a child and realized that their dinner routine was not quite like yours. Or maybe in geography class you recognized that for some privileged folks, the backdrop to their daily commute is the Roman Colosseum or the Smoky Mountains instead of the dull brick and mortar of your suburbs. Eventually, your capacity to entertain difference developed to the point that you could understand that in other cultures and in other times, people held values about the meaning of life, how society should be structured, and which goals were worth pursuing that were radically different from those of your own small world. And in that moment, perhaps, you grasped the relativity and contingency of your own existence, of your own beliefs, of your own values and way of life. You understood your *historicity*, the fact that you are a creature continuously emerging from the river of time; and, as the Greek writer Heraclitus told us so long ago, we never step in the same river twice.

If you have had an insight into your historicity—the sheer contingency of your existing in this way, at this time, in this place—then you have found a key for unlocking our future. For it is precisely because our history is made by human actors that we can go on to make the future history of others. “Acknowledge your historicity,” wrote the Canadian philosopher Bernard



Loneragan, and thereby seek not just to comprehend history but to *change* it. It was this refrain that rang in my mind as I read Bijal P. Trivedi's soon-to-be-classic of scientific journalism, *Breath from Salt*. In her remarkable tour through nearly a century's worth of scientific discovery, entrepreneurial ingenuity, and medical innovation, Trivedi lays out with scientific precision and human compassion the story of cystic fibrosis and of those who have lived with it, sought to understand it, and worked vigorously to heal it. I was not far into the book when I understood that this book is about *me*: about the history that renders my existence possible and that continues to impact the direction of my life. With each chapter, Trivedi makes visible those invisible threads that tie the quotidian rhythms of my life with the people who—unknown to me—shape my life like water shapes the seas. For behind all the details of my daily CF care there

is a story, a life, a passion, and often a pain that was transformed, by love, into a calling to alter the future in ways almost unbelievable at the time.

Take my digestive enzymes, for example. They pepper my day like table salt, spread generously on every meal; they are, I imagine, simply an assumed part of CF care around the world today. But these have a history, beginning with the groundbreaking discovery by Dr. Dorothy Andersen that cystic fibrosis was in fact *not* celiac disease, and that accordingly our pancreas could not produce the requisite enzymes for digestion. So—no Dorothy Andersen, no Creon and pizza night for me. Pulmozyme? Same story, different characters.

This time it was the pulmonologist Steven Shak who hit upon the idea that the enzyme DNase could be used to thin the mucus clogging my lungs. A few years later and his breakthrough has become, quite literally, my daily breath. What about Orkambi? Symdeko? Trikafta? Ditto, ditto, and ditto.

But what is particularly fascinating about the story Trivedi has so thoroughly and carefully told is the role that cystic fibrosis patients themselves have played in medical innovation for the disease. The story of Paul Quinton, emeritus professor of science at UC San Diego, captures the contribution of CF patients quite vividly. Having diagnosed himself with CF during his freshman year of college, Quinton became committed to finding the root cause of the disease. It would be clichéd to speak of the blood, sweat, and tears that Quinton poured into his research were it not for the literal aptness of the expression. Quinton, you see, wanted to understand what made

CF sweat unique, but sweat glands, unfortunately, are not regularly kept in stock at your local supermarket. And so, he procured his own research materials by a more direct route: taking plugs of his own skin. His body may still bear the scars, but my body profits daily from his detection that disruption in chloride transfer in CF cells produces our salty sweat and viscous mucus. Without that hard-won insight, drug development for CF could not have progressed along the path it has.

Quinton serves as a synecdoche for the indispensability of those with CF and their families in the quest for a cure for our disease. While the CF Foundation—from its origins in CF families taking up the charge to help their children, to its dizzyingly rapid development into a lobbying and fundraising behemoth—frames the book's narrative, one CF family takes center stage in Trivedi's account. That family is the O'Donnells: Joe and Kathy, parents to their son with CF, Joey (1974-1986), and his two sisters, Kate and Casey, born after their brother's death. This personal tale of parental tenderness and devotion, child bravery, and family resolution to impact the world for the sake of others like Joey, threads through the book's 500 pages, providing a much-needed respite from the thick scientific descriptions found on most every other page. Joe and Kathy O'Donnell hold a unique place in the narrative, and for good reason: they have raised more money together for CF than perhaps anyone else in the disease's history, and their work on several multimilliondollar fundraising campaigns led directly to the development of the CFTR protein correctors, potentiators, and modulators that have transformed CF care in the last decade. In a real way, then, I owe the health I enjoy today to the O'Donnells, and especially to Joey, who inspired such tremendous commitment and sacrifice

in his dear family.

One of the strengths of Trivedi's account of CF care in the last century is precisely her focus on the human side of the story. For however much we may speak today of "science" doing this or knowing that, "science" in fact does nothing at all; rather, it is scientists and drug developers who pursue their research, sometimes with all the purity of an unrestricted desire to understand

notes the complaints raised by key members of the CF community on this score, but nonetheless the mark-up for these potentiators remains astronomical—so much so that some CF patients outside the U.S. die from lack of access to these drugs, because, not infrequently, their governmental health insurance plans refuse to pay unreasonable prices. This is yet another arena where the CF community, like Paul Quinton,

“What is particularly fascinating about the story Trivedi has so thoroughly and carefully told is the role that cystic fibrosis patients themselves have played in medical innovation for the disease.”

their objects of study, but oftentimes with an equally strong desire for glory and, more regularly, for wealth. Trivedi does not shy from noting these motivations, but one senses a certain reservation on her part about dwelling too long in these grayer domains. The story she wishes to tell is one of almost unburdened positivity and growth, a tale of scientific and industrial heroes, and any discordant notes are therefore played only *pianissimo*. Perhaps the place where the hushed tones sound most conspicuous is the ethically murky terrain of venture philanthropy. Let me preface my following remarks with this admission of profound indebtedness: were it not for the results of venture philanthropy and the drugs it has produced, I may not have had the health to be writing these words today. But nonetheless the question remains: is it ethical that drug companies, depending so heavily on donor money to fund their product, should be able to charge such exorbitant prices for these drugs? The book's author

gave its own lifeblood to find answers and healing, and yet the fruit of that sacrifice has not become universally available. If other readers are of the same mind as I am, they will desire more from Trivedi on this controverted aspect of the latest chapter in CF care.

Not that this point detracts in any way from the author's monumental achievement. *Breath from Salt* feels as miraculous as the scientific progress it details or the organizational and lobbying genius of the CF Foundation. Trivedi's story ends with a dual triumph: the CF Foundation's far-sighted plan to put research first is vindicated in the appearance of those pharmaceutical marvels, those tiny pills to which over 90% of CF patients now (theoretically) have access. Sadly, however, the story grows more complex as we move beyond the events found between the book's covers. Since the early days of the COVID-19 pandemic, an increasing number of personal reports confirm what many have feared: the new

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Vaccinated!

By Colleen Adamson

Despite being a lung and kidney transplant recipient in addition to having cystic fibrosis, I received my first COVID-19 vaccine only because I am also an Inova Fairfax Hospital volunteer. I work at one of the thrift stores that provide funds for important programs, services, and equipment in support of Inova's non-profit medical, education, and community programs. I have not been able to work there since the pandemic started, but I hope to go back once it is safe to do so. It gets me out of the house and makes me feel good to support the hospital programs.

First Shot: January 20, 2021

Honestly, I was a little reluctant to sign up for the vaccine since I felt a little like I was cutting in line. People with CF and transplant recipients were not yet being vaccinated! However, given my situation, I felt that I should get the vaccine as soon as I could—so I signed up. As it turns out, starting the week that I got the shot, my county in Virginia opened up the vaccine grouping to include people like me with compromised immune systems. The only thing that *really* helped me was being able to sign up without any issues. I was not on the phone for hours and I did not deal with any website crashes, like other people were experiencing when trying to sign up for the vaccine.

I signed up for the first slot of the day, which was at 7:30 a.m. I did not wait long at all, maybe 10 minutes, which was good because it was cold outside! They had a separate line for the Fairfax Hospital team, and they took us first. Once inside, we got our temperatures taken and went upstairs to fill out the COVID-19 vaccination consent form. Next,

we went back downstairs to get in line for the vaccine. There were six lines and they moved extremely fast—I waited two minutes at most. There were roughly 30 stations to get the vaccine. I wore my “Today is a Good



COLLEEN ADAMSON

“The only symptoms I had after receiving the vaccine were fatigue and a sore arm for three days after the shot.”

Day” t-shirt (short sleeve; perfect clothing to wear for getting a vaccination). I showed it to the nurse who gave me the Pfizer shot, and she agreed with it wholeheartedly! I am lefthanded so I made sure to let the nurse know to administer the shot in my right arm. After I got the shot, I was sent to the waiting area to sit for

15 minutes. I brought reading material, but the whole time I was waiting I was setting up my next vaccine appointment on my iPhone and signing up for the V-Safe account that allows people to tell the Centers for Disease Control and Prevention (CDC) about any side effects they experience after getting the COVID-19 vaccine. For a week following the shot, I received daily texts from V-Safe asking about any symptoms I had and whether I was experiencing the onset of any new symptoms. V-Safe also reminded me when it was time for the second dose. The V-Safe tool is extremely easy to use and I highly recommend signing up for it. It is helpful for everyone, especially for the medical community, to know what symptoms people are having along with the severity of those symptoms. We are all learning as we go.

The only symptoms I had after receiving the vaccine were fatigue and a sore arm for three days after the shot. The fatigue started in the afternoon the day of the shot but abated after a two-hour nap. I had the same symptoms for the next two days. I never had

a fever or any other symptoms.

Second Shot: February 10, 2021

Several people who also had the vaccine warned me that the second shot might make me feel worse than the first shot did. I cleared my calendar for the rest of the week so I did not have to go anywhere in case I did not feel well.

I also made sure I had both ginger ale and ginger snaps in the house, as well as leftovers ready to heat up for dinner. I again signed up for the first slot of the day, which was at 7:30 a.m. I filled out the COVID-19 vaccination consent form ahead of time, as instructed in my registration email. This time I did not have to wait in line at all. I just walked right in, gave the consent form to the nurse, and got the shot. I wore the same shirt as last time and have since decided that it is now my lucky shirt! I again brought reading material as I knew I would be waiting for 15 minutes after the shot. Once I got home, I had similar symptoms to what I had after the first shot, namely fatigue and arm soreness at the injection site. I also had a touch of nausea at lunchtime, but it was not bad enough to preclude me from eating. That night I had trouble sleeping because my arm hurt quite a bit, more so than it had earlier in the day. The next morning, on February 11, I had a 99.4° temperature, in addition to a sore arm, so I took Tylenol and felt much better by lunchtime. I took a nap in the afternoon, and I have since felt fine. My arm still hurt a bit two days later but not enough to keep me from sleeping. I received daily texts again from V-Safe for a week asking about any symptoms I had after the second dose of the vaccine.

I watch the news and hear about people waiting hours to register and/or waiting in lines for hours to get each shot, so I am very thankful to be fully vaccinated! I will still follow the CDC guidelines and continue to wear a mask, stay six feet from other people, and of course wash my hands often—a typical CF day! ▲

Colleen Adamson is 52 years old and has CF. She lives in Alexandria, VA, with her husband, Scott, and their dog Penny. She can be reached at scott.adamson@cox.net.

SUSTAINING PARTNERS



Supported by a grant from AbbVie

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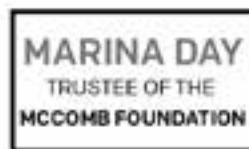


Cystic Fibrosis Foundation
www.CFF.org
Adding Tomorrows and Living Today



Scholarship for the Arts
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DIAMOND SUSTAINING PARTNER



ENDOWMENT-DIAMOND SUSTAINING PARTNER





IN THE SPOTLIGHT

With Mickey Davis

By Amy Gutierrez

Several years ago, I was casually scrolling on Instagram's "search" feature, and a picture of Mickey Davis in the hospital jumped out at me. Hospital pictures aren't uncommon on my search page, as IG's algorithm knows that I follow many people who frequent hospitals. Something about this picture spoke to me and prompted me to learn more about him. And so, in May of 2018, I reached out to Mickey on Instagram after seeing his incredibly quick transplant recovery. I knew intuitively that this was a strong, determined, and special human whom I couldn't wait to get to know better. We became such good friends in time that I wanted to surprise him for his one-year transplant anniversary. I collaborated with one of his favorite comedians, Theo Von, to surprise Mickey with a trip from his hometown in Seattle to my hometown in LA in May 2019 to be a guest on Theo's podcast. My hope is that everyone can get to know Mickey the way I do. He is an incredible friend, and an absolutely hilarious human being. Please welcome Mickey Davis, our newest star. Spotlight, please!

Where do you live?

I live in Federal Way, a suburb outside of Seattle, with my mom, Joyce. She is my primary support while I am recovering posttransplant.

How old are you?

I'm 33 years old and received my transplant right before my 31st birthday. I was diagnosed with CF when I was three years old. I remember my parents wondering about my health quite a bit when I was growing up. I remember being very young and my dad disciplining me because of my incontinence issues prior to my cystic fibrosis diagnosis. The timeline and



MICKEY DAVIS

sequence of events are a bit blurry, but I recall that suddenly, around the age of three, I no longer saw my regular community pediatrician. Instead, I saw a new doctor at Seattle Children's Hospital for my care. I'm unsure whether it was digestive issues (low weight) or lung issues that prompted my CF diagnosis.

How are you spending your time as someone who is at high risk for COVID-19?

I call it hibernating. I'm currently staying in and it sucks. But the silver lining right now is that I get this time to dig deep and devote time and resources to self-development. I'm making the best of this time, as those of us with CF do when we have health issues. Recently, I've found myself absorbed in building financial intelligence and taking action—with this transplant I now have a future and I know I better prepare for it!

When it's safe, what are you most looking forward to doing?

I'm hoping to complete the foundation I'm setting up during this hibernation period. I am eager to hang out with people I love and I can't wait for the ability to have time and wealth to fly to see friends. I can't wait for the freedom to spend a weekend, a week, or a month to connect with those who matter most to me. I want to be able to make current relationships stronger and develop new relationships as many of my past relationships haven't added to my growth, so hanging out with people with similar goals will be exciting.

How did you get to know the comedian, Theo Von? Are you still in touch with him?

Several years ago, Theo Von was a rising comedian but still small in the comedy scene. I enjoyed listening to Theo's podcast week after week and noticed that Theo always seemed both eager to connect with listeners and receptive to in-depth conversations. In February 2018, I called in to the show and explained that I had damaged lungs due to CF and asked Theo what advice he and the listeners had for me to gain confidence in pursuing relationships with women. Theo's strong suit is his puns; he nicknamed me Trick Lung Mickey. You can listen to the full podcast on YouTube:

<https://www.youtube.com/watch?v=6IBdpwCqUBU>.

In March 2018, Theo came to perform at a comedy club nearby in Tacoma and we met up after his performance. Theo and I had a great connection and hung out for a few hours at dinner. From then on, Theo has kept in touch with me via text and phone and, to this day, we are still in touch.

What was it like to celebrate your one-year transplant anniversary on Theo's podcast?

It was surreal to be able to hang out with Theo, thanks to Amy, and spend the whole weekend in LA. Celebrating with my two best friends and girlfriend, the three people closest to me in my life, all together was a great time. That weekend was one of the best weekends I've had in recent memory.

Doing the podcast felt like I was just hanging out with a buddy in the moment, and there were definitely times when I went into a stream of consciousness that helped me to process the emotion in real time. Doing the podcast with Theo was simply dreamlike. As a comedian he was massively popular during the time, so I received a huge amount of support from podcast listeners—I had countless direct messages, posts, and messages from listeners and people reaching out to connect. So many people were supporting me and cheering me on and the word that just kept lingering in my mind was “surreal.”

You can watch the entire podcast celebrating my one-year transplant anniversary on YouTube:

<https://www.youtube.com/watch?v=areLuJWF9c0>.

What have been the challenges of settling into your post-transplant life?

The biggest issue I've had is accepting that I need to start living. I have a future and it's time to prepare and that comes with so much anxiety. What do I do with the rest of my life? With CF, especially pre-transplant, you're functioning on the deficiency or lowest tiers of Maslov's hierarchy of surviving, a psychology theory in which there is a pyramid of five tiers of human needs and the lower tiers, such as food and clothing, must be met in order to achieve the higher tiers (esteem and self-actualization). Now that I'm post-transplant, I'm higher up on the hierarchy and it's no longer just about surviving. I now have an infinite number of

options, which is overwhelming.

What gifts has CF given you?

If you have the right mindset, the struggles and difficulties with CF create an environment for you to learn and see the silver lining. These adverse experiences from having CF have molded the mindset that I have today. CF has taught me discipline, accountability, and the importance of living in the moment.

What's your most hilarious CF story?

I was at a bar with friends when I was around 24 years old and I looked over and saw a woman in front of a line of rum shot glasses. I saw her take one of the glasses and she lowered it instead of drinking it. When she put the glass back on the bar, the glass was empty. It turned out she was putting shots of rum in a syringe to put in her g-tube! Of course, I felt an instant connection with her because of my familiarity with the use of a g-tube in CF. I walked over to her, lifted up my shirt with a smirk, and then walked away. We dated for a few months and we are still friends to this day.

What do you like to do for fun?

Fun for me can be boiled down to making connections in any form or fashion, whether that's meeting up with friends and having philosophical conversations or spending time just joking around. I love to dance and listen to hip hop. ▲

Amy Gutierrez is 39 years old and has CF. She is a director and Vice President for USACFA. She lives in Los Angeles, CA, with her husband Joel. She loves traveling internationally (when there isn't a pandemic), standup comedy, and college football. Her contact information is on page 2.

If you would like to be interviewed for "In The Spotlight," please contact either Andrea Eisenman or Jeanie Hanley. Their contact information is on page 2.



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
- Team Boomer
- Jerry Cahill's Cystic Fibrosis Podcasts & Wind Sprints
- Breathe In Podcast
- CF Patient Disaster Relief Program
- CF Step-by-Step Video Series
- Gunnar Esiason Blog
- Tru Heroes Nursing Program
- You Cannot Fail Hospital Bags
- CF Education Days & CF Speaking Engagements

www.esiason.org



SAVORING SERENDIPITY

Coming Back Up For Air

By David Tarnow

As we transition from Winter and into Spring here in North America, I'd like to take a moment to pause and reflect. I'd like to reflect on some of the changes in the seasons of my own life as it has shifted from the dark toward brighter days. Within the last 18 months, modern medicine has bestowed upon me and many others a wonderful gift in the form of a few blue and peach-colored pills. These pills, and their effect on my present health, and, by proxy, my hopes and dreams for the future have been nothing short of miraculous. Despite these positive developments, however, I have since come to understand and realize that healing the body and healing the mind are two very different, although interrelated, endeavors.

In the years prior to beginning Trikafta, and because my lung function and overall health had been in a free fall of precipitous decline, each pulmonary function test that I was tasked with felt like taking up the gauntlet. So much of what my subsequent days and weeks would come to look like depended on exhaling the contents of my weak and withered lungs into a plastic tube connected to a computer. Increasingly, the results of these tests and the outcomes of my clinic visits were disappointing and discouraging. As insult added to injury, I became complacent and yet fearful at the same time of the impending judgement to be levied upon me by my doctor. The long hospitalizations, infusions, and oxygen tubing, on which I depended, became overwhelming.

At my worst, being homebound and losing the freedom and ability to carry out any functional and seemingly ordinary act such as bathing, getting dressed, making the bed, preparing

food, or driving had a jarring effect on my sense of dignity and self-worth. As my body began to lose its vitality and its strength, so did my mind. As a once generally positive and loving person, I lament the fact that fear, instead, came



DAVID TARNOW

to dominate and motivate most all of my decisions. Rather than jumping the fear, the fear jumped me, in a manner of speaking, and robbed me of my confidence, my optimism, and my belief that things could and would get better.

As a result, I began to lose faith in the people and the institutions that were designed to protect me. In reality, this same fear was blinding me to the fact that I had also lost faith in myself. Without belief in myself or others, I felt isolated and resentful. This resentment would manifest in bouts of anger and self-pity—neither of which ever helped to change anything for the bet-

ter. I began to project my own pain outwardly onto everything and everyone. It was a miserly existence—a true existential crisis if there ever was one.

Having experienced these deepest depths of physical and emotional despair, hitting rock bottom has made coming back up for air, figuratively speaking, more of a challenge than I ever expected—a sort of mental whiplash, if you will. The memories of traumas past stick like crude oil or molasses to the surfaces of my conscious awareness and, like quicksand, they surround and engulf me as I attempt to navigate this new normal.

Thankfully, however, the achievements of modern medicine have, to a certain extent, through their positive effects on my physical wellbeing and abilities, become enablers of new-found hope. Through deep introspection and self-awareness, I am slowly relearning how to grant myself the permission to remember what it feels like to be hopeful, and it feels good. I will be the first to admit that all of these observations, thoughts, and changes are much more easily processed now, in times of peace and personal progress, than they were when I was waging a war for survival.

I hadn't quite made my mark on this planet as of then, and I still haven't as of this writing. The legacy that I would like to leave is not one of anger and fear, but of love, acceptance, and forgiveness. Who knows, maybe God took that into account when He decided to keep me around after many close encounters with death and dying.

As for the time being, I am going to concentrate on the small victories and the small wins that serve as continued affirmations to my recovering, cold heart that life is, in fact, getting better. I have been granted the privilege to flip

the script (plot-twist). This second chance has offered me the opportunity to change my belief from one of living as if I'm going to die to one of living as if I am going to live. And that, my friends, is something to celebrate.

I still struggle, as we all do, but I am going to choose to remain optimistic and try my best to unweight the

burden of unhealthy belief patterns which I have carried for so long. They no longer serve me in where I am and where I am going. My experiences, albeit traumatic, have been written into the book of time, but, thankfully, for now, there is more love to be shared, more breaths to be had, and more fear to be forgotten in coming to

terms with what is, now. ▲

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

BOOK REVIEW/DE LA NOVAL continued from page 27

CF wonder drugs appear to cause serious adverse effects in some patients, ranging from blood pressure increase to severe tremors to debilitating neurological and psychological symptoms. Having suffered some of these effects myself and consequently having had to come off these drugs, I could only read the exultant tone of *Breath from Salt's* conclusion with some sadness. What seemed at one point a definitive turning point in my own CF journey now looks decidedly unsure; once again, the goal posts seem to have shifted for many of us with CF. In time, these personal anecdotes will become rigorous studies, and we'll know more for sure of what lies ahead for us.

But beyond disappointment, there's more hope to draw from Trivedi's tome, for if one thing jumps from every page of her text, it is that the CF community will stop at nothing to find treatments that work. Whatever their faults, Vertex's miracle drugs are labors of love, dedication, and the brilliance of the human mind. If not they, then others who build on their once-in-a-century achievement, will move forward the wheel of progress until CF does indeed mean "cure found."

Upon closing this book, sitting in awe at how far we've come as a CF community, I felt a shiver run down my spine: how different my life would be,

were it not for the thousands who have cared enough about my tribe to sacrifice, to work to give me the best shot at a healthy life. The poet John Donne proclaimed centuries ago that "no man is an island"; so it is, especially for those of us with our unique genetic destiny. I expect that all who have the privilege of savoring Trivedi's inspired book will find Donne's words ringing truer with every page. ▲

Roberto J. De La Noval, Ph.D., is 32 years old and has CF. He lives in South Bend, Indiana, where he teaches theology at the University of Notre Dame. He can be contacted at robertdln@gmail.com.

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(FDA), recommending the agency to change its requirements on the way gentamicin is manufactured, as current instructions are making people go deaf. Statistics indicate that up to 20% of gentamicin-treated patients will have some degree of irreversible hearing loss. Nowadays, the gentamicin given in hospitals is a mixture of five different antibiotic subtypes containing up to 10% of impurities. Investigators used a series of techniques to separate the different compounds in gentamicin's composition and figure out which were responsible for the antibiotic's ototoxic properties (properties toxic to ear tissues). After establishing a protocol that enabled them to separate each compo-

nent of the mixture, they proceeded to test how each gentamicin subtype affected the inner-ear tissues of animals. Researchers discovered that gentamicin C2 (sisomicin) was the most toxic of the five antibiotic subtypes, while gentamicin C2b was the least ototoxic. Although both antibiotic subtypes had different levels of toxicity, their antimicrobial properties were identical and were found to be comparable to that of gentamicin's original mixture. Ototoxicity could be further reduced by eliminating other impurities from gentamicin's mixture. Since all gentamicin subtypes are approved for use by the FDA, it is likely that less toxic formulations would not have to be retested, allowing them to be

quickly brought into clinical practice. Both individual and reformulated mixtures of C-subtypes demonstrated decreased ototoxicity while maintaining antimicrobial activity, thereby serving as a proof-of-concept of drug reformulation to minimizing ototoxicity of gentamicin in patients. The team also noted that the ototoxic properties of each gentamicin subtype seemed to be associated with the way each of them interacted with specific channels within the inner ear. More specifically, they discovered that the antibiotic subtypes that bound most strongly to these channels tended to be the least toxic. Researchers are now planning to create a new ami-

Continued on page 36



LIVE OUT LOUD

The Danger Of “Normal”: Seeing The World Through Abnormal Eyes

By Lara Govendo, M.S.Ed.

I hate the word normal. It's like nails on a chalkboard for me.

I think it's always been a trigger word because I've never been able to be normal in any sense of the word. For years I tried to fit in the same box as that of my peers. I attempted to have the same cookie-cutter dreams they held. I was so desperate for community that I sought camaraderie in any form, even the normal one I thought was supposed to be my measuring stick.

What I didn't realize is that I was carrying so much shame. I was ashamed that my body wasn't capable of keeping up with everyone else's because it needed more time and attention. I was ashamed that the pressure of keeping up with the “do whatever makes you happy” narrative was making me deeply anxious and depressed. I was ashamed that I would never measure up to society's standards of success. The constant rat race of my worth being measured by how much I was doing rather than who I was as a person was exhausting. IS exhausting.

These days, anything normal makes me want to puke. When anyone utters the word “normal,” I cringe and say, what's that? Because the truth of the matter is that normal doesn't exist. And if we're striving to do what everyone else is doing and fitting into the box that society has put us in, we're doing it wrong. We weren't designed to be normal. We weren't designed to be the same. We were designed to be unique on purpose. We all have our own set of gifts and talents that we bring to the table. If we spend so much

time looking at what our neighbors bring, we'll forget what we have and how to use it.

Normal keeps us stuck. It tells us that we should fit in the same container of what everybody else does, is interested in, and the way they live their life. Otherwise, you're categorized as weird, insane, and other ridiculous adjectives.

“Being who I am on purpose has exponentially opened doors to bigger opportunities beyond my wildest dreams.”



LARA GOVENDO

Society has forced us to believe that there is a rubric for measuring one's level of normal. They have sold us the lie that in order to be accepted we must think, speak, and act the same. Most people talk about what makes someone normal. If we don't fit into the normal standard, others make us feel like something is inherently wrong with us.

My whole life I've tried to fit into a box for which I was never meant. All for the sake of “fitting in.”

What I've realized, especially in this year of isolation, is that I don't want to fit in anymore. I want nothing to do with

what normal is. I want to run far away from everything that includes the description of normal. I will never work a normal 9-5 job. My body wasn't made for that. I will never like what the normal person likes. I wasn't designed like that. I will never fit in a normal schedule. None of me wants any of that. I will never like being busy all the time. I need rest and I'm not ashamed of that. My life is different. It's beautiful and rare, authentic and vulnerable.

I was made for daring adventures, living abnormally, and taking chances. Thinking outside the box fills me with joy. Chasing after what constitutes a full life according to my own standard fills my soul with peace. To me, that's the life I want to live and the one I'm building every single day. And I am finally so proud of that. Believe me, that's not for everyone. And I get that. I wasted so much time trying to fit into a “normal” sized box when I wasn't ever designed for that in the first place.

Wholeheartedly embracing the life

I've been granted has been the best decision I've ever made. Being who I am on purpose has exponentially opened doors to bigger opportunities beyond my wildest dreams. And the biggest win is being celebrated for exactly who I am—and that will always be enough. In case you're wondering, being normal isn't something to strive for; settling into the *you* that you're meant to be is worth achieving.

In a world that is defined by normal, dare to be the one who stands out from the crowd. Make unpopular

choices for the greater good. And treat everyone you come across with curiosity, rather than shutting them out for the sake of being out of the ordinary.

When it comes down to it, our version of normal is very different than our neighbor's version. This can either open our eyes to new perspectives or shut our hearts down, impeding connection. We are always one decision away from living our most authentic life. But I want to challenge you by asking: if there wasn't a standard of normal, what would you be doing? Think about that... ▲

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 writes about living out loud 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." Her contact information is on page 2.

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DIAMOND ENDOWMENT PARTNER

Nancy Wech

TILLMAN continued from page 33

noglycoside that could further lower the risk of deafness.

<https://tinyurl.com/y7edasqz>

Posaconazole Vs Voriconazole For Primary Treatment Of Invasive Aspergillosis: A Phase 3, Randomised, Controlled, Non-Inferiority Trial

Researchers undertook this randomised, prospective, double-blind, double-dummy, controlled trial to evaluate non-inferiority of posaconazole to voriconazole for the primary treatment of invasive aspergillosis. Posaconazole (intravenous or oral posaconazole 300 mg twice on day 1, followed by 300 mg once a day for days 2–84) was compared with voriconazole (6 mg/kg intravenous or 300 mg oral twice on day 1 followed by 4 mg/kg intravenously or 200 mg orally twice a day for days 2–84) for 12 weeks or less. Findings demonstrated the non-

inferiority of posaconazole to voriconazole with respect to all-cause mortality up until day 42 in patients suffering from invasive aspergillosis. Good tolerability of posaconazole was reported, and fewer treatment-related adverse events were experienced by patients vs in the voriconazole group. Thus, posaconazole use as a first-line treatment for the condition is supported.

<https://tinyurl.com/yb75zy55>

Newer CF Bacteria Species Shows Antibiotic Resistance, Ability To Spread

The *Achromobacter* bacteria species that is an increasing source of chronic lung infections in people with cystic fibrosis (CF) shows evidence of patient-to-patient transmission and emerging antibiotic resistance. Recent studies are reporting the bacteria species *Achromobacter* is increasingly being detected in CF patients,

and associated with antibiotic resistance and more severe disease. Little is known about the transmission of this bacteria and its antibiotic resistance among patients. So a team of researchers conducted DNA analysis on *Achromobacter* bacteria isolated from 51 CF patients. Their goal was to further understand how these pathogens spread and how resistant they are to treatment. All patients received early antibiotic treatment for *Achromobacter* after first testing positive, with follow-up treatments based on antibiotic susceptibility testing to find the most effective therapy. In total, 182 genomes were analyzed from 101 clinical isolates of *Achromobacter* from the 51 patients. Before this study, all isolates included were identified specifically as the *Achromobacter xylosoxidans* using routine microbiology techniques. But following DNA analysis, the researchers found their

Peer Engagement Groups From Attain Health

ADULT GROUPS

Facilitator: Brian Devine, adult with CF

Meeting #1: Tuesday 6MT/8ET

Meeting #2 Wednesday 6MT/8ET

Weekly meetings for adults with CF to connect and support one another through the trials, tribulations and joys of life, as well as current events!

YOUTH, TEEN, AND MINECRAFT GROUPS

Facilitator: Quinn Porco, teen with CF

Youth Group: Tuesday 4:30MT/6:30ET

Teen Group: Tuesday 5:30MT/6:30ET

Minecraft Group (siblings welcome): Friday 6MT/8ET

Weekly group meeting during which Quinn encourages peers to live their best life; includes chat groups and gaming fun!

INHALE MELANINE, EXHALE POWER

Facilitator: Raeshaun Jones, adult with CF Wednesday 5MT/7ET

This group was created and geared toward individuals in the Black Community who are living with cystic fibrosis. In this group, we will discuss our personal expe-

riences within our communities as well as uplift and support one another on this trying journey in the fight against cystic fibrosis. "Living, one breath at a time"

CF FIGHTERS FOR RECOVERY & FREEDOM

Facilitator: Mark Tremblay, psychologist and adult living with CF Thursday 5MT/7ET

Mark Tremblay, age 51, with 32 years recovery from alcohol and drug addiction. Over the past 30 years, he has helped thousands of people with alcohol, drug, pornography, sex, relationship, and nicotine addictions. Mark has also managed addiction programs and ministries. He is opening this space to join you on your journey to find freedom.

MOMS WITH CF

Facilitator: Gillian Mocek, M.S.W., adult with CF and mother to sweet Simon Monday 6MT/8ET

She has incredible insights and wisdom for balancing CF and motherhood, and uses this platform group for other mothers who have CF to get

together, share, discuss victories and struggles with motherhood.

SOLID GROUND—BIBLICAL FAITH-BASED

Facilitator: Alma Martinez Svarthumle, adult with CF

Friday 1MT/3ET

Solid Ground—"A place to encourage one another, love on one another, and grow our faith in Christ together!"

Young Adult Group

Facilitator: Emma Chenier, college student living with CF

Monday 5MT/7ET

All about the transition into being a young adult—whether college or working—and being dedicated to your health.

LGBTQAI+

Facilitator: Dr. Xan Nowakowski, openly queer, agender, and polyamorous person living with cystic fibrosis Times vary. Meets monthly. Accepting people exactly as they are; encouraging them to embrace their inner fire.



For more information:

<http://attainhealth.org/peer-engagement-groups>

<https://www.jotform.com/attainhealth/support-group-intake-form>

collection was composed of five different *Achromobacter* species. These included 15 patients infected with *A. ruhlandii*, 12 with *A. insuavis*, 31 with *A. xylosoxidans*, and one with *A. aegryfacies*. Another patient was infected with a yet unknown *Achromobacter* species. To investigate patient-to-patient transmission, genome results were compared to identify specific bacteria with a related common ancestor (same clonal type), which was defined as bacteria that differ by less than 5,000 single-nucleotide variants (SNV) — single changes in the building blocks of DNA.

More closely related bacteria within a species, which suggests close transmission, will have less genetic variation than more distantly related bacteria within the same species. The analysis found 16 suspected patient-to-patient transmission cases that were investigated further. In 12 of these cases, multiple clonal relatives were isolated from at least one of two patient pairs, and in nine of these cases, isolates from different patients were more closely related than those from the same patient. Next, a phylogenetic tree (similar to a family tree) was constructed based on the

genetic relationship of the four suspected patient-to-patient transmitted clonal types — one clonal type of the *A. ruhlandii* species, one *A. insuavis*, and two from the *A. xylosoxidans* species. Of 14 suspected transmission cases with full phylogenetic information, 12 cases supported patient-to-patient transmission as bacteria from one patient was found to be descended from bacteria from another patient. To support this genetic evidence of transmission, researchers looked for overlap in patient visits to the clinic. Of the 16

Continued on page 38

patient pairs with suspected transmission events, all but one patient pair with microbial sampling were in the same hospital ward on the same day. The *A. ruhlandii* clone type AX01DK01 showed the most transmissions, being found in 27 isolates across 13 patients. To investigate antibiotic resistance, routine diagnostic measurements of antibiotic susceptibility profiles were assessed against 21 antibiotics for 92 isolates. For the 21 patients with single isolated samples, these bacteria were resistant or intermediately resistant to a median of 14 antibiotics. For 30 patients with multiple samples over time, those isolated early were resistant to a median of 14 antibiotics, while those collected later were resistant to 18 antibiotics. Statistical analysis found bacteria isolated later to be significantly less susceptible to antibiotics than early and single isolates. Nearly all isolates showed resistance or intermediate resistance to nine antibiotics; five showed some efficacy. No antibiotic was effective against all the bacteria tested.

<https://tinyurl.com/yaetn6dl>

Defects In Mitochondria May Sustain *Burkholderia Cenocepacia* Infections In CF

Specific immune cells called macrophages in cystic fibrosis are unable to kill the bacteria *Burkholderia cenocepacia* due to impairments in mitochondria, the cell's powerhouses. The finding suggests that boosting mitochondria function could help resolve chronic infection in CF. Macrophages, immune cells specialized in the detection and destruction of bacteria and other harmful agents, have been shown to contribute to CF. Macrophages had an impairment in their ability to undergo autophagy, a natural cleaning system used by cells to get rid of damaged components and pathogens. This made the cells unable to clear infection by the *Burkholderia cenocepacia* (*B. cenocepacia*). Mitochondria, cells' energy source, are particularly important for the proper function of macrophages. For an infection, healthy macrophages use their

mitochondria to produce mitochondrial reactive oxygen species (mROS) that trigger inflammation and destroy bacteria. Researchers observed that mitochondria from CF macrophages worked poorly compared to mitochondria in healthy macrophages. Two indicators of mitochondrial working capacity, called maximal respiration and spare respiratory capacity, were significantly impaired in CF macrophages. This meant that when called into action, their mitochondria would have more difficulty trying to respond to an increased demand for energy. The oxygen consumption rate, another measure of mitochondria's health, also was reduced in CF macrophages compared to healthy cells. Next, researchers looked at how *B. cenocepacia* affected the mitochondria of CF macrophages. Six hours after infection, the team observed that the mitochondria were smaller, less elongated and had lower interconnectivity scores, all signs suggesting that infection triggered the fragmentation of CF mitochondria. At a metabolic level researchers saw that, when infected, CF macrophages had a higher mitochondrial membrane potential compared to healthy macrophages. This meant that the metabolism in the CF macrophages changed and was more glycolysis-dependent, a more inefficient way for mitochondria to produce energy. Before infection, no significant differences in mitochondrial ROS production were found between healthy and CF macrophages. After infection, both macrophages increased their ROS levels. Yet, previous work had demonstrated that CF macrophages accumulated more bacteria due to a defective autophagy mechanism, which could mask defects in mitochondrial ROS production. Two hours after infection, CF macrophages slowed down mitochondrial ROS production and by eight hours there was a significant decrease in ROS compared to healthy macrophages. These findings suggested that mitochondria impairments affect the ability of CF macrophages to respond

to infections.

<https://tinyurl.com/yalnsvy2>

Phage Therapy Clears Resistant Infection In CF Lung Transplant Patient

For the first time, bacteriophage therapy treated a boy with chronic and antibiotic-resistant *Achromobacter* bacteria infection following a double lung transplant due to cystic fibrosis. Bacteriophages (or phages) are viruses that selectively infect and kill bacteria, while being otherwise harmless. The article describes the case of a young CF patient, successfully given phage therapy for a post-transplant, antibiotic-resistant *A. xylosoxidans* infection.

<https://tinyurl.com/ycct2hnl>

Research Reveals How Bacteria Defeat Drugs That Fight Cystic Fibrosis

Researchers have discovered a slimy strategy used by bacteria to defeat antibiotics and other drugs used to combat infections in people with cystic fibrosis. A common strain of bacteria, *Pseudomonas aeruginosa*, often thrives in the lungs of people with cystic fibrosis. Once a *P. aeruginosa* infection is established, it can be incredibly difficult to cure. The research showed that the stubborn germs living in the lungs of cystic fibrosis patients create a self-produced carbohydrate slime. And this slime makes the bacteria more resistant to the antibiotics prescribed as well as drugs that reduce the thickness of mucus. They found the first direct evidence that these carbohydrates are produced at the sites of infection and showed that one of the carbohydrates, called Pel, sticks to extracellular DNA, which is abundant in the thick mucus secretions prominent in cystic fibrosis lungs. This interaction makes a slimy protective layer around the bacteria, making them harder to kill and it reduces the pathogen's susceptibility to antibiotics and drugs aimed at reducing the thickness of airway mucus by

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digesting DNA. The work supports a hypothesis that it's the carbohydrates that group, or aggregate, the bacteria in cystic fibrosis lungs. Understanding the mechanisms that promote bacterial aggregation may facilitate new therapeutic approaches aimed at digesting

the carbohydrates holding bacterial cells together. The research also suggests that the carbohydrate Pel likely diminishes the efficacy of the most commonly used therapeutics for cystic fibrosis, which are inhaled antibiotics and a drug that breaks down the thick-

ness of the airway mucus, making it easier to cough up.

<https://tinyurl.com/ygkxob67> ▲

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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- Please notify us immediately of any address changes. Returned mail wastes money and delays mailings.
- 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

Medical Assistance Tool (MAT): <https://medicineassistancetool.org/> PhRMA's Medicine Assistance Tool (MAT) is a search engine designed to help patients, caregivers, and healthcare providers learn more about the resources available through the various biopharmaceutical industry programs. MAT is not its own patient assistance program, but rather a search engine for many of the patient assistance resources that the biopharmaceutical industry offers.

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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