Testimony of
Ms. Melanie Lawrence, Cystic Fibrosis Foundation Volunteer, Health Care Advocate

U.S. Senate Health, Education, Labor and Pensions Committee
Subcommittee on Primary Health and Retirement Security
Hearing: "Superbugs: The Impact of Antimicrobial Resistance on Modern Medicine"
July 11, 2023

Good morning. Thank you, Subcommittee Chairman Markey, Ranking Member Marshall, and distinguished members of the Senate Primary Health & Retirement Security Subcommittee, for inviting me to testify before you today. My name is Melanie Lawrence, I am 43 years-old, and I am living with cystic fibrosis (CF). I am grateful to be part of this subcommittee's discussion on a subject that I am unfortunately all too familiar with, antimicrobial resistance. While I am here to speak to you about my experiences with infection, drug-resistant bugs are not a problem exclusive to people living with CF – they are a problem for everyone. People with CF provide a glimpse into a future that everyone will experience if we don't address this growing threat. As I share more about my experience, I ask that you consider the public health risks that all Americans face if we do not jumpstart innovation and develop new, more effective antimicrobials as soon as possible.

I was diagnosed with CF at age 5. At the time, my parents were told that my life expectancy was 16 years old. When I turned 16, the median life expectancy had grown to 31 years old—and now, at age 43, it is 56 years old.

As you are aware, cystic fibrosis is a life-threatening genetic disease that causes persistent lung infections and makes it very difficult to breathe, often leading to respiratory failure. More than 40,000 people in the United States live with CF and there is no known cure. People with CF face a heightened, life-long risk of infections, and often rely on antibiotics as part of their daily care. Still, all too many – like me – battle antibiotic resistant infections for which there are no effective treatment options available.

However, cystic fibrosis is only a *part* of who I am and it does not define me. I am a single mother to the most amazing 12-year-old son. I am a daughter, a sister, a friend, a proud aunt, and a passionate contributor to the greater good. I believe that it is my life's purpose to connect with others and remind the healthcare industry that patients are human beings with full, complex lives outside of the exam room who deserve to be treated as such. I find my work serving on volunteer committees with the Cystic Fibrosis Foundation, the Cystic Fibrosis Learning Network, and patient advisory boards extremely rewarding. I am grateful for the opportunities to give back and improve how health care is delivered and how providers think about patients – as people first. I love being out in nature and catching the sunrise, I am a hot yoga enthusiast and enjoy challenging myself wherever possible.

Sadly, I have lost many friends to CF-related infections over the years, some dying before their 21st birthday. Many other CF friends continue to struggle with the management of their symptoms. I believe the stable health I do have is a combination of luck, new therapies, and hard work. Each and every day I spend hours taking medications, doing physical therapy, exercise, meditation, and breathwork–all while raising a very active 12-year-old and trying to create as many meaningful memories with him as I can while I am physically able to do so.

Since I was a teenager, I have participated in as many clinical trials and research studies as I can. Despite significant medical advances and new therapies that have helped stabilize my health, lung infections due to multi drug-resistant Pseudomonas aeruginosa and Methicillin-resistant Staphylococcus aureus (MRSA) bacteria are the chronic complications of CF that impact my life the most.

Chronic respiratory infections continue to be a hallmark of living with CF because of the persistent mucus in the lungs of people with the disease. More than 60% of people with CF culture positive for at least one chronic pathogen in their lungs starting from a very young age and that figure climbs to over 80% among adults living with CF. Like me, nearly 20% of CF adults have chronic infections caused by pseudomonas and 25% of people with CF will culture MRSA each year.

As a result, I have relied on antibiotics my whole life. Throughout my childhood and early teenage years, antibiotics were highly effective. Each time I caught a cold or contracted an infection, I could trust that a two-week course of antibiotics would have me feeling better and back to living life as usual. By age 13, the bacteria in my lungs were already outsmarting oral antibiotics and I needed intravenous (IV) antibiotics once a year in addition to oral antibiotics to keep my infections under control. The IV antibiotics were administered via a peripherally inserted central catheter (PICC) line – an IV that was threaded into a vein up my arm. For the next five years, IV antibiotics were administered in the hospital one to two times each year and required me to stay in the hospital for two weeks, often missing school and many holidays with my family. My hospital refers to this time as “cleanouts” when CF patients would have a two-to-five-week course of IV antibiotics and respiratory therapy to help prevent exacerbations and lengthier hospital stays as a result of infection.

By age 18, a two-week course of IV antibiotics was no longer enough to combat the bacteria growing in my lungs. I needed larger doses of IV antibiotics for up to five weeks at a time. This took place partially inpatient at the hospital and partially during regular hospital visits. Looking for a better solution, I participated in a clinical trial for IV Tobramycin that ended up being so damaging to my kidneys (nephrotoxic) that I was prematurely removed from the study. That trial also resulted in constant tinnitus (high-pitched ringing in my ears) that I still have, and will continue to have every minute, of every day, for the rest of my life.

In my twenties, antibiotic resistance became a bigger issue as did the subsequent side effects the more potent antibiotics caused. As the bacteria became resistant to antibiotics, I began to lose many of the “tools” in the toolkit to combat drug resistant bugs and treating my lung infections. It was also the decade where my lung infections first began leading to hemoptysis, or the coughing up of blood from my lungs. Sometimes the bleeding can be so severe and life-threatening that I need a medical procedure called an arterial embolization to block the bleeding arteries. The bleeding in my lungs can then become a breeding ground for bacteria, resulting in a vicious cycle of infections. Due to these complications, I need antibiotics more frequently and for longer periods of time than typically prescribed.

By age 30, I began having chronic upper extremity blood clots and could no longer receive IV antibiotics via a PICC line. The blood clots also made me a poor candidate for a port, a device that can be inserted as an alternative delivery method for antibiotics over a long course of treatment for people with CF. My only option for IV antibiotic treatment was to get a temporary IV threaded through my jugular vein During this time, the bacteria in my lungs became so resistant that one antibiotic alone did not stand a chance. I needed to take a combination of two to three antibiotics at a time just to keep my infections at bay. However, even multiple antibiotics couldn’t eradicate the bacteria in my lungs, they just bought me time and allowed me to get my head above water.

Now in my forties, the bacteria in my lungs are resistant to nearly all antibiotics except for Tobramycin, which I cannot take because it is so toxic to my already-damaged kidneys and hearing. There is no eradicating the bacteria in my lungs and the recurrent infections have led to permanent scarring in my lungs along with pockets of collapse. My focus is now on managing my symptoms and maintaining the best quality of life possible. Every single antibiotic I try results in insufferable side effects that require me to take additional drugs to counteract them, or I am forced to discontinue the course early because they make me feel so miserable. The side effects vary and impact my body as well as my mental health. They cause rashes, kidney damage, depression and everything in between. Today's antibiotics are not nearly the friendly savior I used to depend upon, and I regularly have to ask myself which is worse: the infection or the side effects?

These challenges have led to a more stressful life experience for not only me, but for my son, my family, and my friends as well. In the past, infections were stressful, but we knew that there was an "easy fix" with a quick course of antibiotics. Now, it feels like much more of a gamble with my life. For me, something as simple as the common cold can take months to rebound from and often turns into pneumonia. I no longer have the security of relying on antibiotics to help me heal, so I live with chronic fear and anxiety about when the bacteria residing in my lungs will act up or when another infection will take me away from the moments I cherish for a few months or the even the simple daily tasks that we often take for granted. Ultimately, on a deeper level, I am always navigating a humbling loss of control, loss of autonomy, and a deep subconscious fear of death - and mostly, of leaving my son without his primary caregiver–the person who knows him the best and loves him without abandon. His mom.

I live in a constant state of introspection–both mind and body. Up to this point, much of my life has depended on me being attuned with my body and hyper-aware of what my body is trying to tell me. This year, I've learned that this has caused me more anxiety than I wanted to admit. I realized I had an inability to be still or to sit with my body in silence. My body is both my biggest ally, keeping me alive and fighting off infection, whilst also being my biggest threat, trying to kill me from the inside.

Yet, I am not a victim by any means, and I am committed to doing everything in my power to stay as healthy as I can for as long as I can. Living with CF has been a gift, not a curse. It has opened my eyes to the fragility of time and the importance of connection, and that is a gift we should all be so lucky to receive while we're healthy and able to appreciate it, rather than when we're dying and it's too late.

I am a big believer in the mind/body connection so I work hard at staving off the threat of lung exacerbations as much as I can. I combine both Western and Eastern medicine, work with a therapist to keep my anxiety low, practice mindfulness, meditate, do breathing exercises, and lead a healthy lifestyle. I wash my hands constantly, take vitamins, get rest, and constantly assess the risk vs. benefit of social interactions. My friends know to disinvite me to events if someone is sick and are mindful of my germ exposure. It has become second nature for my son to sanitize his hands every day when he gets out of school. He doesn't complain when we have to leave a party early because mom is tired, and he understands when he has to skip a birthday party or social gathering because the germ risk is too high. It pains me that he's had to grow up in a more heightened state of awareness, but I like to think he's more empathetic because of it.

For me, my family and all people living with CF, it can be a challenge to navigate social risks because a part of feeling alive is joining in social events. We want to travel, we want to go to the movies, we want

to go to concerts, and we want to attend family gatherings in the winter even though the flu is circulating. We want to feel alive and actively participate in life just like you do. Life is for living after all.

This is my story, my experience of what it's been like to live with antibiotic-resistant bacteria. While my life may look quite differently from yours, it is not an uncommon experience in the CF community. And while right now it may seem like it is unique to people living with CF, these bacteria are abundant and it is inevitable that more people will encounter antimicrobial resistant bacteria. It is not a question of if you can catch them, but when.

I am grateful for organizations like the Cystic Fibrosis Foundation that recognize the significant threat antimicrobial resistance poses to the CF community, and in 2018 created the Infection Research Initiative as part of a sweeping effort to advance infection research. To date, the Foundation has committed over $140 million to the initiative because they know that for people with CF – and all of us – to lead full lives our providers need more tools in their toolbelts. They need more antibiotics. Better antibiotics. Full stop.

We have all relied on antibiotics at some point in our lives and how lucky are we that they've been available and effective for many of us? But the bacteria are outsmarting us and without new and novel alternatives, they will win this war. Private sector investments alone won't solve the problem. We need the federal government to lead and support innovative policy solutions with an all of the above approach to help people like me live long enough to see our children thrive. Personally, I want to see my son graduate college or even become a grandparent – something I've never even allowed myself to imagine because it feels so out of reach without new antibiotics.

I thank the subcommittee for giving me the opportunity to share my story and I ask that you work to help find solutions for patients with a heightened risk for infection like me, and for all Americans, as you consider legislation this Congress.