

12th
Edition

Patient Voices



Mental and Emotional
Health of Patients
and Families

A publication of the American Thoracic Society
Public Advisory Roundtable

 **ATS**
American Thoracic Society



ATS

Public Advisory Roundtable

ATS Patient Voices is published by the American Thoracic Society Public Advisory Roundtable (ATS PAR). Since 2001, ATS PAR has been a core component of the Society and a mutually beneficial partnership wherein organizations that represent persons affected by respiratory diseases, illnesses requiring critical care, and sleep-related disorders collaborate with the ATS to advance their shared educational, research, patient care, and advocacy goals.

The ATS strives to improve health worldwide by advancing research, clinical care, and public health in respiratory disease, critical illness, and sleep disorders. The roots of the ATS reach back to 1905, when a small group of physicians and researchers began sharing information about tuberculosis. Since then, it has grown into an international society with more than 15,000 members.

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Preface



Donna Appell, RN

Chair, ATS Public Advisory Roundtable

The ATS is very honored to present the next installation of the ATS Patient Voices booklet to its readers, and I am very honored to present the ATS Public Advisory Roundtable (PAR) to you. Over two decades ago, Dr. William Martin, then ATS president, envisioned an assembly of patient representatives that could provide insight and lived experience to enhance the robust community of professionals dedicated to lung, critical care, and sleep medicine. His vision came to fruition with the creation of the public arm of the ATS, the Public Advisory Roundtable (PAR). PAR is comprised of leaders and patient representatives of non-profit organizations serving those concerned with lung health. We are an

integral part of the ATS and while every patient community is made up of many individuals, we strive to be the inspiration behind the work of the ATS. Certainly, we are the need. We are very grateful to ATS for realizing the importance of the patient's voice in its efforts. We have been invited to join in its work, sit at the table and help inform the outcomes. The ATS has been at the forefront of patient integration within medical specialty societies and for us as PAR members it has been quite an honor.

Patient Voices is a written example of our input as a collection of lived experiences from those chosen by PAR to exemplify real-world challenges and successes. The stories in this edition, Patient Voices 12, discuss the Mental and Emotional Health of patients and caregivers while they struggle with the difficult and challenging journey of their chronic illness. As you will discover, their stories are moving and inspirational and we are very proud of them.

Our work with the ATS has brought about many achievements. We have and continue to contribute in many ways including research, programming, and advocacy. But our most successful contribution is on the shoulders of the people we represent, the patients that have come forward to share their lives with us. They have added depth and yes, *breath*, to us all and for us all. We are grateful to each one of them for allowing their vulnerability to teach us more than we could learn on our own. We are delighted to share the best part of us in this edition, presenting Patient Voices 12.

Foreword



M. Patricia Rivera, MD, ATSF
ATS President



Karen Collishaw
MPP, CAE
CEO, ATS

Respiratory illnesses affect millions of lives worldwide, imposing physical burdens that are well-documented and widely studied. What may often be overlooked is the equally significant mental and emotional toll these conditions exact on patients and their loved ones. This year's 12th edition of Patient Voices delves into the emotional journey faced by those living with respiratory disease, giving readers insight into their unique perspectives as patients.

Since 2001, the ATS Public Advisory Roundtable (PAR) has helped to highlight the patient experience and to weave them into the fabric of the American Thoracic Society. Along with PAR partners, comprised of various patient advocacy groups, PAR highlights the experiences of those most personally affected by the disease: the patients.

Each account in this year's Patient Voices is a testament to patients' courage and strength in their battle against lung diseases. Their narratives reveal the challenges of misdiagnosis, stigma, and the indomitable spirit it takes to endure and persevere with respiratory illness. Their voices remind us that the medical community must listen carefully and compassionately to the thoughts and feelings of each patient, as doing so can make a difference in their diagnosis, treatment, and healing journey.

This work's insights also emphasize the need for collaboration among medical professionals, patients, and advocacy groups to ensure comprehensive and effective patient care. By joining forces, we can foster a greater understanding of the psychological dimensions of lung disease and, in turn, develop more holistic approaches to treatment.

As we read each patient's story, we thank them for bravely sharing their experience. Their candor empowers us to raise awareness about the far-reaching effects of lung disease, reinforcing the importance of empathy and compassion in healthcare practices.

May this edition inspire us to redouble our efforts to enhance the lives of those affected by respiratory illnesses and to prioritize the mental and emotional well-being of patients and their families. ●



Catherine Clark

Respiratory Syncytial Virus,
Bronchiolitis, Asthma

In the fall of 2022, my son Carl developed what I thought was just an ordinary cough. He was a bit under three years old at the time and colds and flus are common at that age, so I wasn't too concerned at first. I'm a nurse by profession and his cough seemed standard to me; there was no fever, and he was eating, playing, and sleeping well. When Monday came, I sent him off to school with no issue, but I got a call from his teacher asking me to come get him, so I took him to the doctor as a precaution. He received oral prednisone and I thought everything was fine.

He developed a low-grade fever on Tuesday, which wasn't too concerning. But on Wednesday, I woke up in a panicked flurry when I realized he hadn't stirred me awake as he normally does. I ran to his room and found him lethargic, with labored breathing. When I picked him up, he was

burning hot with a fever of 102.7°F – the highest he’d ever had. We went to his pediatrician who assessed his lungs and found it mostly clear. His pulse oximeter reading was 93 percent, which didn’t match the level of respiratory distress he clearly was in. We rushed to the ER and after an x-ray and testing, the medical team determined that he had respiratory syncytial virus (RSV) and bronchiolitis with asthma exacerbation.

They put an oxygen mask on him at which point he perked up, but it didn’t last. Over the next few hours, as we were waiting for an IV drip, his health started to rapidly decline and he was moved to the intensive care unit, where he was put on a ventilator, an oscillator, and intubated – all to stabilize him. As his liver and kidneys began to fail, I prepared myself for the worst. I’d never seen any patient so septic in my entire life. I felt awful, certain that my baby was going to die. There wasn’t a single medical professional in that room that day, including myself, that expected Carl to survive. Later he was diagnosed with ARDS, sepsis, disseminated intravascular crisis, cardiogenic shock, kidney injury, ischemic bowel, ischemic injury bilateral legs, and kidney injury.

It was singularly the most stressful and terrifying event that I’ve ever been through, not knowing what was happening nor what the outcome would be. But as a nurse, I am trained to stay calm under duress. I focused almost exclusively on Carl’s immediate needs and compartmentalized the experience’s impact on my emotions to deal with another day. In the moment, I was solely concerned with his welfare.

“It was singularly the most stressful and terrifying event that I’ve ever been through, not knowing what was happening nor what the outcome would be.”

Somehow, Carl pulled through thanks to the life-saving medical treatment he received in the ICU. But it wasn’t so easy. In the ICU he had to have a transmittal tarsal amputation on his left foot and surgery on his right ankle because of the treatments he was given, and those orthopedic wounds proved to be very challenging to heal. A year later, he’s running, playing, and growing; back to his normal self. But the same cannot be said for my husband and me. The experience has left us with emotional trauma, anxiety, and depression.

Before Carl was discharged from the ICU, I found a therapy center and started going for treatment recognizing that I could not deal with the stress of almost losing my child by myself. I realized I couldn’t automatically switch off my fight-or-flight instinct after Carl healed. Everything felt like a big deal, like life or death. When my son started potty-training a few months after the ICU stay, I couldn’t stop crying from the pressures of managing that process. It was at that point that I reached out to my primary care physician for antidepressants, which have been incredibly helpful.

With selective serotonin reuptake inhibitors, I feel like I've been able to be a more effective mom and just feel better all around, while still working with my therapist to process what happened. I've had to build a support system for myself since my husband's family and my own are several hours away in other cities.

When you have a sick child, it often feels like you're running on fumes because there is no help. But help can be found if you look for it. Some of the best help that I've gotten over these last few months has been from my friends. I encourage anyone who is caring for a sick child without the benefit of family nearby to make sure they are getting the emotional support they need by reaching out to friends and medical professionals and seeking therapy. ●

Respiratory Syncytial Virus (RSV)

- RSV is a common respiratory virus that causes cold-like symptoms in children and adults.
- Severe RSV can be unpredictable and is the leading cause of hospitalization in infants
- Adults 65 and over and adults with chronic conditions or weakened immune systems are at high risk for developing severe RSV.
- People do not form long-lasting immunity to RSV and can become infected repeatedly over their lifetime.

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Joanna Conroy

Cystic Fibrosis



I have always tried to live a semi-normal life, despite having cystic fibrosis (CF). I was diagnosed with it as a child. In 1976 when I was born, my parents had not even heard of the condition yet, but it soon became as much a part of their lives as it did mine, especially when my younger sister Noelle was born a year later. She was diagnosed with CF first, as she had health issues that necessitated frequent hospital visits. After she was diagnosed, it became clear that the asthma and food allergies my parents thought I had were symptoms of CF.

I felt very isolated from my peers growing up. It was difficult to fit in when most kids had never heard of CF. I distinctly remember always trying to explain my coughing to others and feeling embarrassed by it. The saving grace was that my sister was going through it, as well – so we had each

other. We also have two other siblings (who do not have CF), so Noelle and I never felt truly alone, at least when we were home. We would share a room when we were at the hospital together for what my family would call “tune ups.” At certain times, it was even fun because we would get to meet other kids who shared the same condition, and it became a bonding experience for us all.

Then we got older. We entered our teen years, which can be a challenging time for anyone, let alone when you have CF. Classmates would get annoyed with my coughing, kids would laugh or tease me, in their ignorance. It took a huge toll on me emotionally and impacted far more than just my health. It was hard on my family too, as my other brother and sister who do not have CF felt like my parents were granting my sister and me special treatment. It was difficult for my parents to be protective of us, without seeming to show favoritism.

Sadly, when Noelle was just 18 years old, she passed away from CF. She was waiting for a lung transplant that did not come in time. That was a very dark time for our family. We were all devastated, and I felt like I had lost the one person who truly understood what I was going through. Since her passing, I have tried to live my life as she would have, doing the things I love and not letting this disease prevent me from living my life to the fullest. It has not always been easy, though. In my thirties, I really struggled with balancing daily demands of work with being a mother and wife, and

a good CF patient. I recall once being asked to leave a spin cycling class because I was coughing too much. Those old feelings of shame and embarrassment from my youth came rushing back. I was so embarrassed and mad that I started to cry. My husband told me I should have explained my problem to the instructor, but there are times in my life where I just do not have the fight in me.

My family and friends have been an immense support for me through the years. I have a good group of friends with CF, and we stay in touch by phone and text messages. I also have a good friend who lives close by who also has CF, as does her sister. Just having that listening ear who understands the challenges you are facing can go a long way to providing the support you need to deal with health issues.

“We were all devastated, and I felt like I had lost the one person who truly understood what I was going through.”

Recently, things have gotten much better for me physically and, therefore, mentally. In November of 2019, I started a new medication that means I no longer need IV antibiotic therapy and my lung function has gone from 58 percent to 75 percent. This has given me a new lease on life as these days I barely cough. I still produce some phlegm, but not as much as before, which has enabled me to finally live a “normal life.” The impact that this has had on my emotional state cannot be overstated – for the first time in my life I look to the future with anticipation. Retirement was something I never would have dreamed of before. Now, it’s something that I am actively planning for and looking forward to enjoying. ●

Cystic Fibrosis (CF)

Cystic fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. While there is no cure, life expectancy has steadily improved in the United States. Some other facts about cystic fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
- CF individuals have abnormally thick mucus, which blocks the airways (obstruction) and leads to repeated infections and damaging inflammation in the lungs. Treatments are directed at trying to prevent.

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Phyliss DiLorenzo

Chronic Obstructive
Pulmonary Disease



In 2015, I had a severe bout of pneumonia and learned that I have emphysema. I visited the emergency room three times that first year for severe dyspnea. The following year, I was admitted to the hospital for four days with acute respiratory distress syndrome and three of those days I was on a ventilator. It was a week or so later that I had my first spirometry test and was diagnosed with Chronic Obstructive Pulmonary Disease.

What I've since learned since then is that COPD is a leading cause of morbidity and mortality worldwide. Age and smoking are common risk factors for COPD and other illnesses, often leading COPD patients to demonstrate multiple coexisting comorbidities. The common comorbidities of COPD are – as you know – lung cancer, heart disease, asthma, sleep apnea,

hypertension, pulmonary fibrosis, pulmonary arterial hypertension, diabetes, and osteoporosis, but also anxiety and depression.

The first year of my COPD diagnosis, 2015, had me battling many episodes of anxiety, as short-acting beta-agonists (SABAs) did little to address my continual hunger for air. Riddled with anxiety while struggling for air and depressed by the overwhelming fatigue that common everyday tasks now caused, my physical and mental health started to decline, and my employer eventually asked me if I wanted to go on disability.

I had worked in the position for 20 years. I was devastated. I didn't want to go on disability, and subsequently lost my job because of the absences, which made my depression and anxiety even worse. I felt like my life had been stolen from me ... I was like, what do I do now? Do I just sit at home and watch TV and try to deal with this air hunger? That didn't feel like an option for me.

I felt like my anxiety and depression were not addressed, at least at first, as the medical focus was placed almost entirely on my physical respiratory condition. I remember mentioning depression to my primary care physician and he asked me if I was lonely. I had worked in mental health for years, and I thought, of course not – I know what the difference is!

“Riddled with anxiety while struggling for air and depressed by the overwhelming fatigue that common everyday tasks now caused, my physical and mental health started to decline, and my employer eventually asked me if I wanted to go on disability.”

I now know that anxiety and depression frequently accompany certain chronic illnesses. Many COPD patients experience transitory mood symptoms during exacerbations, which improve spontaneously after recovery. Based on my own experience, I think identifying COPD patients with depression and/or anxiety remains a challenge for clinicians.

Eventually, with proper maintenance inhalers, long-acting muscarinic antagonists (LAMAs), and an inhaled corticosteroid, my anxiety subsided. I began to read materials from various sources, such as the American Thoracic Society, American Lung Association, National Heart Lung Blood Institute, and the COPD Foundation. It was from these sources that I learned more about COPD, and ways to manage it through diet, exercise, breathing techniques, education, pulmonary rehabilitation, and support groups. This was the start of a new journey for me, with managing my ACO. It's a journey that I am still on to this day, though it has gotten much better.

I cannot emphasize enough the importance of pulmonary rehabilitation for COPD and its common comorbidities. Since attending pulmonary rehabilitation, I have had zero hospitalizations. The few flares I have experienced were treated at home with a call or visit to my pulmonologist/doctor. I can do so much more now.

We all know the benefits of toning and building muscle mass and exertion tolerance, how important they are to the cardiopulmonary system. The surprise was how beneficial it was to my mental health. The camaraderie and relationships formed through pulmonary rehabilitation and support groups is something I am forever grateful for. I encourage other patients who may be suffering from mental health issues to seek out that support, which is crucial to recovery and well-being.

Despite all the support I've found, the anxiety still creeps up now and again – particularly when dealing with weather anomalies and the effects of climate change. Recently, we've had poor air quality days due to wild-fire smoke from Canada and that's made me quite worried about how I'm going to manage that with my illness. I have air conditioning, but it unfortunately vents from the outside, which makes me anxious about potentially bringing in bad air from the outdoors... still, I am in a much better space than I was some years ago.

I encourage anyone who may be reading this to be mindful of the whole patient. What comorbidities may be at play in the patient's presentation? Are depression and anxiety preventing the patient from fully engaging in treatment? What resources can be drawn upon, medications, non-pharmaceutical therapies, other specialists? Talk with the patient to determine if there are any obvious cultural or socioeconomic barriers.

We all benefit from being seen as multifaceted human beings, rather than as a patient with a disease to treat. ●

Chronic Obstructive Pulmonary Disease (COPD)

Chronic Obstructive Pulmonary Disease is a preventable and treatable lung disease. People with COPD must work harder to breathe, which can lead to shortness of breath and/or feeling tired. Some other facts about COPD are:

- Although the most common cause of COPD is tobacco smoke, there are several other factors that can cause or make COPD worse, including environmental exposures and genetic (inherited) risk.
- Common symptoms of COPD include feeling short of breath while resting or when doing physical activity, cough, wheezing, fatigue, and/or mucus production that does not go away.
- Some general classes of medications to treat COPD include those that aim to widen the airways (bronchodilators), reduce swelling in the airways (anti-inflammatory drugs, such as steroids), and/or treat infections (antibiotics).



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Garrie Farrow

Sarcoidosis

I came to sarcoidosis through swollen feet and ankles. I now know this is a benign sarcoidosis symptom. It took four years and three different primary care physicians to learn this isn't normal. That a Black woman in her early 30s, even with extra weight, shouldn't have swollen feet and ankles. A chest x-ray resulted in an appointment with a pulmonologist. After a mediastinoscopy with biopsy, I had my diagnosis of sarcoidosis of the lungs – Stage 1.

When I was first diagnosed, I was more concerned about survivability and got a little depressed because there wasn't much research about that aspect that I could find, or that was easily accessible. I wasn't quite sure what to expect – what was I supposed to be doing to deal with this rare disease?

I was initially told that with Stage 1 sarcoidosis, there was nothing for me to worry about and sarcoidosis would have very little impact on my lungs; just to watch for long term coughing or trouble breathing. Reading through some of the medical journals looking for information on sarcoidosis, I realized that the information that I was finding was not written for a patient, I stopped researching and went back to my regular life.

“When I was first diagnosed, I was more concerned about survivability and got a little depressed because there wasn’t much research about that aspect that I could find, or that was easily accessible.”

I already had thrombotic thrombocytopenia purpura (TTP), which I’ve since learned can be a symptom of splenic sarcoidosis. It was a tough pill to swallow; that I could be lucky – or unlucky – enough to have not one, but two rare diseases.

As I was undergoing my sarcoidosis journey, my sister Sharon – sadly – joined me on the trip. She had had breathing issues for years, so after my initial appointments with my sarcoidosis specialist, I'd call her and encourage her to talk to her primary care physician about her symptoms. Unfortunately, Sharon was diagnosed with sarcoidosis after a biopsy. She lived far away and was financially disadvantaged, which meant that she could not make the trip from her hometown to see my specialist.

I gave her the best help I could. We talked about my medication regimen, and Sharon let me know she was on prednisone. I let her know I was on methotrexate and suggested she discuss steroid alternatives with her physician. I don't know if her doctor didn't think medications other than steroids were an option for her or if she didn't tell them about the medication, but she died in January 2019 from pulmonary sarcoidosis. Her lungs filled up with fluid and they couldn't drain it from her fast enough.

After my sister died, I became very angry and felt guilty. She was only 18 months older than me – why was my sarcoidosis experience so drastically different? I decided that I was going to find anything I could on sarcoidosis and dug through the scientific journals again. I found the Foundation for Sarcoidosis Research, and joined their Patient Advisory Committee. My hope is that all clinicians, not just sarcoidosis specialists, become

educated on sarcoidosis and its impact on the entire body. Despite being an introvert, I felt the need to add my voice to others and joined their Speaker's Bureau. I wanted to get the word out about sarcoidosis.

Helping others helps me to deal with the emotions I've been compartmentalizing all these years. When something impacts your physical well-being, your emotions and mental health are also impacted. A lot of those feelings I just put in a nice little box and just didn't address. But it does accumulate over the years. Opening myself up and the experiences I have been through with this disease empowers me and I hope the experiences I have been through with this disease uplifts others.

“Helping others helps me to deal with the emotions I've been compartmentalizing all these years. When something impacts your physical well-being, your emotions and mental health are also impacted.”

What I hope to highlight is that this disease isn't centered on just one organ, and so having a central point of sarcoidosis care is important. Most patients experience one specialist at a time, and some may not find that one sarcoidosis specialist who helps them put it all together. I think it is urgent to establish a paradigm for multidisciplinary care in sarcoidosis.

I've been fortunate to have a team of doctors actively working together on my health. I would meet with my rheumatologist and sarcoidosis specialist, usually within an hour or two of each other. They collaborate on my treatment and speak with each other immediately before or after my appointments. That's the level of care I hope all sarcoidosis patients can access; that I wish my sister would have been able to receive. ●

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells in various organs and tissues of the body. Sarcoidosis most often affects the lungs and its hilar lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart.

- When sarcoidosis affects the lungs (pulmonary sarcoidosis), the disease can reduce the amount of air the lungs can hold and cause abnormal stiffness, called "restriction," of the lungs. This results in breathing problems that can interfere with daily activities.
- Since sarcoidosis can affect one or more parts of the body, the signs and symptoms depend on the tissue/organs involved. Some people with the disease do not have any symptoms and it may be noticed by chance when they are being seen for other problems. For other people it may be hard to diagnose because the symptoms they have are not very specific. But certain clinical features such as the erythema nodosum, rash or eye findings may lead a healthcare provider to suspect sarcoidosis.

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Amy Gietzen

Scleroderma



I was diagnosed with systemic scleroderma 22 years ago at the age of 19. Over the last two decades, I have developed several more issues because of scleroderma: interstitial lung disease, heart failure, and – as of 2018 – pulmonary hypertension. I have spent 85 percent of each day in bed for the past five months due to the side effects of medications I am taking to try to stop progression and relieve the symptoms I am experiencing which, up until last year, had been effective.

I haven't decided if my current state is worth staying on these meds. Right now, these symptoms of dizziness and lightheadedness make my life unenjoyable, and when dealing with a chronic illness that has no cure, enjoying what life you have left is paramount. When you're chronically ill, you sit in this tough emotional space where you're trying to be positive, but whenever there is a health issue, it sets you back to square one.

You can't help but wonder sometimes, in your darkest moments, what you did to deserve something like this. I've had those conversations with myself plenty of times. I was just a teenager when I was first diagnosed, entering my twenties really, so I wrestled a lot with acceptance. I didn't feel very sick at the time – with scleroderma, I just had issues with my hands and skin, but I could still pretty much live my life like a “normal” human being. So, initially I was just in denial that I was sick.

When you deal with a disease that just progressively gets worse, that doesn't really go away, it's almost like you're living through the stages of grief – as if someone you love died. Because that “someone” is you – who you used to be, a healthy person. The goals and dreams that you used to have and your aspirations. All of that is no longer there, and so you must go through that grief.

I had a lot of anger toward letting go of the life that I had thought I was going to have. I felt kind of isolated, like I didn't really know anybody that was young like me living with all these comorbidities and I just felt like I couldn't connect. On a deeper level, I was dealing with all these emotions and not knowing where to put them.

It is scary as a young adult to have such a debilitating disease. I should be reaching all these milestones and achieving my ambitions such as graduating college, embarking on a career, getting married and having kids. I didn't get to do any of that or really live my life the way that I had envisioned it

growing up. On top of my physical issues, I was dealing with so much on an emotional level and this also took a toll on my mental health.

However, I still have a life to live and so I had to wrestle with the denial, the anger and then moved forward through to acceptance. A big part of that process was dealing with the question of, “What do I want to do now?” Given that I have this illness, what is it that I can do with this new reality? Where can I find my purpose? That led me to social media. I started using it to find information like most other people do. However, it morphed into a tool that helped me to connect with others by sharing my story and that has given me purpose. To be able to use my voice and communications skills to speak out and advocate for patients is a path I willingly accepted.

In order to walk this path, however, I had to become more vulnerable and more honest with the feelings I was going through as well as much of my life and struggles I was willing to share. Connecting with other people who live with the same illness helps me climb my way out of that helpless space of asking, “what did I do to deserve this?” to, “what can I do to help others who feel as alone as I do?”

“I was just a teenager when I was first diagnosed, entering my twenties really, so I wrestled a lot with acceptance.”

I feel like living with these diseases has offered me an opportunity to give back. I get to educate clinicians, students, and other patients about my perspective and hopefully enable other patients to feel empowered enough to share their own experiences. All our voices count.

I am now a columnist for a scleroderma-related publication, as well as a patient advocate, public speaker, co-founder of a national podcast, as well as being involved in several other business ventures. Being able to share my story, as I look back on my body work, has been quite cathartic for me. When I go back and read through my columns, it is like a narrative of the emotional journey that I have been on while living with illness. ●

Scleroderma

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as an autoimmune disease. The word “scleroderma” comes from the Greek word “sclero”, meaning hard, and the Latin word “derma,” meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease varies from individual to individual. Scleroderma is not contagious, infectious, cancerous, or malignant.

The exact cause or causes of scleroderma are still unknown, but scientists and medical researchers are working hard to make those determinations. It is known that scleroderma involves an overproduction of collagen

Currently, there is no cure for scleroderma, but there are many treatments available to help particular symptoms. Some treatments are directed at decreasing the activity of the immune system. Some people with mild disease may not need medication at all and occasionally people can go off treatment when their scleroderma is no longer active. Because there is so much variation from one person to another, there is great variation in the treatments prescribed.

Learn more
scleroderma.org



Katie O'Grady

Cystic Fibrosis



I was born in relatively good health in New York in 1995. As a child, I had some gastrointestinal (GI) issues that just seemed to get worse, with no explanation. They thought it was Crohn's Disease (because an aunt of mine had it), then thought it might be lactose intolerance when the tests came back negative. Eventually, I was diagnosed with cystic fibrosis (CF) at the age of six.

Early on, I felt like a normal kid. My symptoms were limited mostly to just GI issues. But then I started missing a lot of school because of my health issues. I couldn't leave the bathroom, pretty much. I started getting all these medical treatments and I didn't really understand it. My thinking at that age was that I had this problem, and a doctor would give me medicine that would make me better – much like treating a cold. But I soon realized how invasive treatments could be. It was frustrating when I'd have to do my nebulizer and other medical treatments, sometimes for hours.

As a child and adolescent, I remember being very embarrassed by my disease. Early on when my symptoms were mostly GI, I felt ashamed as I thought CF was a bowel movement disease. I did not tell any of my classmates and never talked much about my medical condition. If I had friends or family over, I just would just refrain from doing my treatments. But as I started to get older and moved into middle school, I started to get a lot of chronic sinus infections. These sinus infections then became lung infections for which I was hospitalized several times. That was a very confusing and disorienting time for me as no one else I knew needed to go for surgery. I felt isolated and very alone.

There was one instance when my science teacher was talking about CF, and I remember I immediately froze up. No one in class knew about my disease except my teacher. At one point, she said, “Right, Katie?” indicating to everyone that I had it. And I sat there in silent embarrassment with everyone staring at me. It was mortifying. Kids came up to me afterward asking if I was okay, if I was going to die.

In another incident on the school bus, a classmate mentioned that his mom underwent an ultrasound to see her baby. I chimed in that I had had an ultrasound (for surgery), but the other kid didn’t understand and then all the kids started laughing at me. Situations like those were hard to deal with as a youth as I tried to navigate my health issues while also dealing with the emotional challenges of fitting in.

When I started high school, my mom was unfortunately diagnosed with Stage 4 colon cancer. In my senior year of high school her health really started to deteriorate. She was my best friend, and I never left her side other than when I went to school and after-school sports. As she got more ill, my health also deteriorated. My doctor ended up telling me that since I was under so much stress and anxiety my body could not handle it anymore. While my mom was in hospice, I came down with pneumonia. Thankfully, because we had a hospice nurse at our house, I was also able to get IVs at home so I could be with her. It was the most ill I had ever been, and I can only imagine how my dad must have felt having to take care of my mom and I.

Stress and anxiety are so much more powerful than I think a lot of us realize. Having a support system is important for your mental health but also your physical wellbeing, especially when you have a chronic illness. I didn't get mental help during this time, but my family was always supportive. The other thing that really helped me cope was discovering my passion for running. I started running in middle school and subsequently joined the track and cross-country team and ended up being good at the sport – often coming in first place in competitions.

I kept running throughout high school and beyond. It was not without its challenges and there were times when I placed last in some competitions, which coincided with my symptoms getting worse and the stress of my mother's worsening health. But running did enable me to be a more

empowered and confident version of myself than I would have been without it.

Running changed everything for me. It improved my symptoms and cleared out a lot of the congestion I had to deal with in living with CF. It gave me something to look forward to and it enabled me to connect with others with CF. I even participated in the Boston Marathon in October 2021, on a team of 10 runners to raise funds for the CF Foundation. It was an amazing experience—everything from pre-race training to the post-race activities. I am still in touch with many of my fellow runners today. I would encourage anyone living with CF to get the mental help they need, find a passion they love, and develop a support system that works for them. ●

Cystic Fibrosis (CF)

Cystic fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. While there is no cure, life expectancy has steadily improved in the United States. Some other facts about cystic fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
- CF individuals have abnormally thick mucus, which blocks the airways (obstruction) and leads to repeated infections and damaging inflammation in the lungs. Treatments are directed at trying to prevent.

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Marsha Henderson

Sarcoidosis



I was diagnosed with pulmonary sarcoidosis in 1995 and then neuro-sarcoidosis in 2002 while working as an emergency medical technician in Washington, D.C. Since my diagnosis, I have faced incredible physical changes and emotional challenges that have interfered with my life and the lives of my family, friends, and colleagues.

In the beginning, I tried to act as normally as I could, continuing to work and meet my social obligations. But it was just an act because the reality was that I felt far from normal. I was struggling to breathe and dealing with extreme fatigue. It was draining to be physically limited in all my daily activities and difficult trying to explain to others what I was going through. As hard as it was to manage my physical symptoms, I found it even harder to cope with the impact sarcoidosis had on my emotions.

Living with sarcoidosis has had a significant impact on my mental and emotional well-being. The constant battle has led me to feel anxious and depressed. Many times, social isolation has rendered me unable to participate in activities or spend time with family or friends. This always leaves me feeling a profound sense of loneliness. I feel a sense of loss or grief for the life I had before my illness. I practice self-care techniques such as meditation and breathing exercises to help improve my state of mind. My biggest hurdle has always been dealing with the uncertainty and unpredictability of my condition. I must constantly manage my illness, follow treatment plans, and make lifestyle adjustments. All that leaves me feeling utterly overwhelmed - even angry and resentful.

My family and friends have experienced a range of emotions themselves, including worry, stress, and even guilt. Their constant concern for my well-being has often left them emotionally drained. Many of them have taken on unassigned caregiving responsibilities for my children, which can be both physically and emotionally demanding. I realize that I may be the one diagnosed with a respiratory illness, but what I am going

“Living with sarcoidosis has had a significant impact on my mental and emotional well-being.”

through also impacts them. My friends have tried their best to balance my health issues with their own obligations to work and other commitments, although a few were not successful at it. Sadly, these friendships did not endure because of a lack of understanding about my illness.

“Their constant concern for my well-being has often left them emotionally drained.”

Respiratory illness has also impacted my livelihood. It became very challenging trying to ask for special accommodations, time off, or workload adjustments due to sarcoidosis. My physical limitations and health-related absences affected my productivity at work, which ultimately forced me to retire early and go on disability. I had to leave a job that I loved. I missed the support and friendship of my coworkers. I felt profoundly sad and isolated, not to mention worried about the financial burden of being unable to afford as much as I used to. The loss of income, coupled with increased medical expenses related to hospital visits, medications, and tests, caused major financial instability.

Taking care of my mental and emotional well-being has been crucial for me. My family and I see a therapist who specializes in chronic illness. She helps us to navigate emotional challenges and develop coping strategies. Plus, she provides a safe space for us to express our fears and concerns. Also, I connect with others who are facing the same challenges as I am. These groups provide me and my family with a sense of belonging, understanding, and encouragement, as well as help to alleviate my feelings of isolation.

After years of many doctor appointments and searching for answers, I connected with the Foundation for Sarcoidosis Research (FSR). The FSR is an international patient advocacy organization dedicated to finding a cure and better treatments. The FSR was a breath of fresh air, and I am grateful that the American Thoracic Society has partnered with them to help advance the health of those impacted by sarcoidosis and respiratory diseases. Currently, I'm an FSR Patient Advocate.

I encourage anyone suffering from respiratory illness to get in touch with a patient advocacy organization. These organizations are dedicated to supporting individuals with specific illnesses or conditions and provide informational resources, connect individuals with support groups, and advocate for patient rights. Some even offer financial assistance programs. But what I find most helpful is the sense of community they provide. Through my involvement, I am reminded that I am not alone in this journey.

Whether it is dealing with physical challenges, emotional struggles, or financial burdens, there are resources, support systems, and people who genuinely care about the well-being of patients. I would encourage anyone suffering from sarcoidosis or any respiratory illness to reach out for help when they need it. Building a dedicated support network can make a world of difference. You are stronger than you think, and there is always hope for better days ahead. It is that hope that anchors my heart. ●

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells in various organs and tissues of the body. Sarcoidosis most often affects the lungs and its hilar lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart.

- When sarcoidosis affects the lungs (pulmonary sarcoidosis), the disease can reduce the amount of air the lungs can hold and cause abnormal stiffness, called “restriction,” of the lungs. This results in breathing problems that can interfere with daily activities.
- Since sarcoidosis can affect one or more parts of the body, the signs and symptoms depend on the tissue/organs involved. Some people with the disease do not have any symptoms and it may be noticed by chance when they are being seen for other problems. For other people it may be hard to diagnose because the symptoms they have are not very specific. But certain clinical features such as the erythema nodosum, rash or eye findings may lead a healthcare provider to suspect sarcoidosis.



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LaJoy Johnson-Law

Chronic Obstructive
Pulmonary Disease (COPD)

My daughter, Abria, was born at just 23 weeks in utero. She was just one pound and six ounces. The doctors diagnosed her with chronic lung disease and epilepsy as well as a developmental delay, due to her extreme prematurity. New motherhood is a difficult time for anyone, but with a daughter with special health care needs, I was running on fumes. We had no car at the time and lived in an older building in Washington, D.C. that lacked an elevator. Imagine carrying this precious baby and her health equipment around—medications, oxygen, as well as diaper bags and other necessities, up three flights of stairs. Oftentimes this was my daily routine, and it was a lot for me to deal with. Physically and mentally, I was overwhelmed.

At first, I managed by just going into active warrior mom mode. I had no time to worry about myself because my baby needed to be taken care of. My motto was, “Abria comes first.” I would just pray to God to take care of the rest. The financial challenges felt impossible. I lost several jobs due to putting my daughter and her health care needs first. Between inpatient visits, outpatient doctor visits, therapy appointments, and her being too sick to go to school, it was a struggle to balance it all.

At one point, things got so bad that we even got a writ of eviction and were facing homelessness. My dad also passed at that time, and I was also going through a divorce on top of everything. That was the time of the biggest financial strains. Thankfully, Medicaid kicked in and I was able to cover most of the costs for her medications and treatments, however, the anxiety I felt then was crushing and seemingly inescapable.

I dealt with it by reasoning with myself: Am I stressed? Yes. But am I also fighting for my life? No – my daughter is, though. She was literally walking that fine line between life and death. It was heartbreaking. There were times when her doctor would say to me, “Abria is very weak right now. We’re not sure she’s going to make it.” They even had me plan a funeral for her in case things took a turn for the worse. There was just no telling which way it could go for my baby. In those moments, I leaned on my faith and my family. My mother and my godmother were an amazing support system for me. My mom would step in and care for Abria for a weekend

“I dealt with it by reasoning with myself: Am I stressed? Yes. But am I also fighting for my life? No – my daughter is, though.”

every so often just to give me a break. My godmom would pick her up and take her to school sometimes. I was so grateful as every little bit and every act of kindness helped.

It has been a long journey, but Bria is now 12 years old and so much has changed. She is in much better shape now and so I call her my “miracle baby.” She is doing so well thanks to the health care and therapeutic providers, her school and the world of support we received from them and my family and friends. Despite having to take daily medication, she’s active and just a joy to be around. She is now enrolled in taekwondo classes and just started swimming classes. She has so much energy and curiosity and I am incredibly proud of and inspired by her every day.

My life has also changed a lot. As Abria started to get older, I decided that the best way I could help myself was to be of service to others. There is a whole community of support available for parents in situations like mine. I got involved a few years ago with an organization called Parents

Amplifying Voices in Education and I am currently on their board. I am also involved in various other social services organizations in a volunteer capacity.

It truly does take a village to raise children, especially when they have special needs. It is a team effort that includes doctors and clinicians, teachers, church groups, neighbors, family, and friends. I was not able to do this alone. What I want other families who may be going through similar situations to know is there are teams of people in place to be able to assist you and get your children what they need to thrive. Amazing people are out there who will wrap their arms around you and your family. You are not alone. You don't have to do it alone. We are your community and we support you. ●

Chronic Lung Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is a preventable and treatable lung disease. People with COPD must work harder to breathe, which can lead to shortness of breath and/or feeling tired. Some other facts about COPD are:

- Although the most common cause of COPD is tobacco smoke, there are several other factors that can cause or make COPD worse, including environmental exposures and genetic (inherited) risk.
- Common symptoms of COPD include feeling short of breath while resting or when doing physical activity, cough, wheezing, fatigue, and/or mucus production that does not go away.
- Some general classes of medications to treat COPD include those that aim to widen the airways (bronchodilators), reduce swelling in the airways (anti-inflammatory drugs, such as steroids), and/or treat infections (antibiotics).



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Kathy Page

Sleep Apnea



Nighttime was never relaxing for me. When others were getting a good night's rest, I was struggling with restless leg syndrome. Several years ago, a doctor suggested that it might be stress and hormones preventing me from getting good sleep. Following that, I made several lifestyle changes, but to no avail. I was tired and emotionally drained from not being able to get a decent night's rest, so I decided to participate in a clinical sleep study. I wanted to see if anything could be done for my restless leg syndrome.

Results are usually given a week after the participant concludes the study, but in my case, the doctor was ready and waiting to give me the results right away. It was sleep apnea. I was in total shock – and so began my journey with this illness. I was advised to begin using a continuous positive airway pressure (CPAP) machine, which I felt anxious about. I had seen

pictures of people strapped to these contraptions and had heard stories from those who had used them. My first thought was, “Nope – this is absolutely not happening.” I was scared and, in some sense, ashamed.

I didn’t want my husband to see me wearing the mask. I didn’t want family or friends to know I needed to use the machine. I tried to reason myself out of using it, thinking that maybe I could live with sleep apnea after all. But it didn’t take me long to realize the folly in that. Not getting good sleep can affect your blood pressure, heart, lungs, brain, as well as how you feel about yourself. Not only are you physically tired, but it can leave you emotionally drained, as well. Sleep is an essential function that allows your body and mind to recharge. Good rest enables your immune system to function optimally, to stave off disease and keep you healthy.

Despite my initial misgivings, I started using the CPAP machine. I had no other choice. Regardless of whether I wanted to use it or not, I had to use it to get better. I’ve now gotten used to wearing it and in fact don’t sleep well without it. But I still dislike wearing it. It’s bulky and uncomfortable. It makes rude noises when it leaks. And then there are the strap marks it leaves on my face, which I’ve had to endure strangers commenting on.

There’s a social stigma to having to use a CPAP machine: it flags to others that there is something “wrong” with you. I remember being quite embarrassed whenever I had to go through an airport and unpack the machine.

It would invite stares and whispers from onlookers, and inevitably I'd feel the stress of having to explain my condition to TSA agents. Fortunately, I'm TSA pre-certified now and don't have to take it out of the bag anymore, but I empathize with people who must experience this.

It's why I say I have a love-hate relationship with my machine: I rely on it for adequate rest, but I hate using it otherwise. What keeps me positive is just recognizing that there are a lot of people out there like me and that there are scores more who have it worse off.

Over the last few years, I've gotten involved with a group called ASAP, the Alliance of Sleep Apnea Partners. We started out just as a grassroots organization, a group of people that have sleep apnea and wanted to share information with each other and others who may suffer from the condition. We've grown into a nonprofit with a virtual community of over 20,000 patients.

“There's a social stigma to having to use a CPAP machine: it flags to others that there is something 'wrong' with you.”

Before my diagnosis, I had no idea so many people had this illness. As a past president of ASAP's board of directors, I've now had the opportunity to guide the organization in its mission to empower patients with information and opportunities to connect. We now have an executive director and a social media lead, which has helped our cause tremendously and enabled us to do more work in the advocacy space.

Getting involved with ASAP has been just as beneficial for me as it has been for the organization. It's given me a sense of empowerment over this illness and enabled me to help others through their own feelings of being helpless and overwhelmed. I encourage anyone who may be going through this to get involved and realize that they are far from alone. ●

Sleep Apnea

Obstructive sleep apnea (OSA) is a common problem that affects a person's breathing during sleep. A person with OSA has times during sleep in which air cannot flow normally into the lungs. The block in airflow (obstruction) is usually caused by the collapse of the soft tissues in the back of the throat (upper airway) and tongue during sleep. There are many clues that can make one suspect that you may have OSA. You may not be aware that you have OSA, but these symptoms may be more obvious to a spouse, other family member, or close friend.

Common symptoms you may have during sleep:

- Snoring that is usually loud and bothers other people trying to sleep near you. Snoring can come and go through the night.
- Gasping or choking sounds.
- Breathing pauses observed by someone watching you sleep. Sudden or jerky body movements.
- Restless tossing and turning.
- Frequent awakenings from sleep.



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Niraj Patel

Cystic Fibrosis

My journey with cystic fibrosis began with a persistent cough that plagued me throughout childhood. By the time I was 12, I had developed a severe cough that disrupted not just my life at home but also my interactions at school. Teachers were often forced to move me to the hallway during tests because my coughing proved a distraction. Other students did not want to befriend me for fear of contagion.

I was one of those kids who sat at the back of the cafeteria, off to the corner, with just a few friends – only those willing to endure my fits of coughing. Adolescence is already a self-conscious age; my coughing made it doubly so. It was an emotional stressor as much as a physical burden; drawing unwanted attention to me, leading me to miss classes, and causing me to avoid social situations entirely.

During a family visit to the United Kingdom when I was 14, my symptoms worsened with the appearance of blood in my sputum. The sight of it was frightening and led to a rushed trip to the emergency room. I was admitted and isolated, and after a series of tests and scans, I was diagnosed with bronchiectasis and then CF.

For my parents, the diagnosis was not a relief but a call to action. Together with my doctors they implemented a strict treatment regimen, which was a daunting prospect for me as a teenager. I wanted greater freedom and to spread my wings, yet I was told that I would have to be put on a demanding routine of frequent chest physiotherapy and multiple medications. I struggled to cope with all of this as what I longed for most was to be normal.



This emotional turmoil led me to poor decision-making throughout early 20s. I would let treatments slide, drink alcohol, and party knowing full well there would be consequences but choosing instead to do things I thought would make me happy. What I did not realize then was that happiness is inextricably linked to good health. After years of self-neglect, I landed back in the hospital with a severe infection that left me gasping for air. My lung functioning was so low that I was on the verge of a lung transplant.

Laying there in the hospital, I felt 14 again – unable to breathe well, uncertain of the future, and anxious about what was to come. Even worse was the realization that I had done this to myself. Fortunately, the doctors were aware of my condition and able to quickly offer me targeted treatments that led to a fast resolution. I was lucky and I would never take my health for granted again.

It took hitting rock bottom to really help me turn my life around. During that time, I remember thinking a lot about my family, who were impacted almost as much as I was by CF. My parents shouldered a lot of stress having to care for me throughout my adolescence and early adulthood, grappling with the disease as best they could, while putting up with me when I was not as cooperative as I should have been.



Recognizing their efforts really helped me get out of the emotional funk I was in that was causing me to behave so self-destructively as an adult. Better health led me to start thinking about my future. I pulled myself together, got a degree, and landed a well-paying job. I worked my way up the corporate ladder and today am in a much better place than I was several years ago – physically, financially, and most importantly, emotionally.

I also started going to therapy after that second hospital stay, and that has singularly been the best decision I've ever made. It enabled me to see patterns of behavior that weren't serving me well and to connect the dots between physical health and emotional well-being. I recommend it to anyone with a respiratory illness who has ever

experienced what I have felt, as part of a holistic approach to treatment. I hope sharing my story will be a source of inspiration to others, emphasizing both the importance of early diagnosis and the need to bring attention to the emotional and mental health aspects of cystic fibrosis.

As a 32-year-old professional who today is thriving despite having CF, I am grateful for every breath I take. It is a gift made possible by the relentless efforts of the American Thoracic Society, researchers, and medical practitioners everywhere. Thank you. ●

Cystic Fibrosis (CF)

Cystic fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. While there is no cure, life expectancy has steadily improved in the United States. Some other facts about cystic fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
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John Torrence

Bronchiectasis



I marked my 50th birthday by coughing. I didn't realize at that time that my whole world would be different than before. I tried all my own little things and after a while I realized, this is beyond me. I spent about a year seeing a general practitioner at a clinic who gave me a little bit of this, a little bit of that – none of which worked. At the end of the third year, I started getting emotional about it.

Usually, I'm a pretty calm, cool, and collected guy; nothing phases me. But at this point I was at my wit's end. I remember getting quite upset, really started having an emotional response, and one day I just went into the clinic without an appointment and told the doctor something is really going on. Eventually I was referred to a pulmonologist who said I had an incredibly rare bacterial infection of the lung that would require a long course of multiple antibiotics. My mother had had similar issues, so she

asked me to inquire about bronchiectasis, which I did. I get the impression the pulmonologist wasn't familiar with it at first...but eventually I was diagnosed with "acute exacerbations of bronchiectasis."

My life as a science experiment began – the bacterial infection required twice weekly blood tests, weekly bandage changes, daily vomiting, weakness, and not-so-fun airway clearance exercises to do. I was anxious about not knowing anything about this rare disease which was affecting my personal relationships. My then-wife wanted to know why I had to get a twelve-syllable disease of which no one had ever heard.

We were living in Maui, HI at the time. Our social structure was built around scuba diving. We went diving weekly, sometimes more. That's hard to do with an IV line attached to my arm. So, the group went on local and faraway trips without me. I felt isolated and alone. I could no longer do the things that I enjoyed most.

My wife grew impatient at the toll this disease was having on my life – and by extension, hers. After lung surgery in Denver, CO, I remember her irritation when I refused to heal as fast as the surgeon had assured her I would. The doctor wanted to keep me for a couple more days. That was too much for her, so she went home alone. I was alone in a hospital room, 4000 miles from home, with tubes coming out of everywhere.

When I made it home a few days later, my wife said all my “laziness” meant that we were now behind financially and that I needed to get to work immediately. I could see my world crashing down around me. I eventually cleared the bacterial infection... but the marriage did not survive.

I lost my wife, our house (that I had built with my own hands), my scuba diving friends, and my mental health. This disease affected so much more than just my lungs. I lost the life that I had so carefully built and was now in uncharted territory. I even moved to the desert of Las Vegas, NV, as doctors said I needed dry air. This was not a place I had ever envisioned myself living in, so far from the ocean I loved.



“I could see my world crashing down around me. I eventually cleared the bacterial infection... but the marriage did not survive.”

Since moving, I have had more NTM infections. Each one is a two-year cycle of drugs, CT scans, blood tests, airway clearance exercises. The great irony is that my current infection is a species unique to the desert southwest, and particularly hard to treat. The toxicity of the medicine damaged my hearing to the point that I now have hearing aids.

But it hasn't been all bad living here. When I first arrived in Nevada, I just had an apartment that I only used to sleep in. Being new here, I went online and there were various websites where you could volunteer for different local activities. I came upon the Cystic Fibrosis Foundation. I figured, children with CF might have NTM and bronchiectasis, too, and be going through the same things physically and emotionally as I am. I've been volunteering with them for some time now.

I've also been working with the COPD Foundation, talking to new patients, moderating a monthly patient support meeting, helping hospitals, pharmacies and industry develop better answers for tomorrow's patients. I want to help others, because in doing so, I help myself.

Being able to help others has given a purpose to my suffering. In a weird way, as much as bronchiectasis has closed doors in my life, it has opened others.

It's been 14 years since that first cough. At least now I have balance in my life. New friends, new hobbies, new routines. I don't fear the disease anymore. I try to do something non-medical every day, so that I don't feel like I am just a science experiment.

I am grateful to my entire care team and many others who have helped me on this lonely journey. ●

Bronchiectasis

Bronchiectasis is a lung condition that causes cough, sputum production, and recurrent respiratory infections. The symptoms are caused by abnormal dilation (widening) of the airways of the lung (bronchi). In some cases, only one airway is affected. In other cases, many are affected. In very severe cases, dilation of the airways occurs throughout the lungs.

- Genetic diseases (such as cystic fibrosis and primary ciliary dyskinesia)
- Problems with the immune system (reduced ability to fight infections)
- Past lung infections
- Problems with swallowing causing aspiration of food or fluids into the lungs



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Epilogue



Courtney L. White

Managing Director, Health Equity
and Community Engagement

For those in roles with high patient-engagement, such as clinicians, or patient advocates, the patient is never far from mind.

No matter how many medical advancements we make, we will always have things to learn from patients. The experience of living through, or living with, a disease like many of our patients have faced, has made them well-equipped to remind us of the realities of survival.

Taking the time to read their stories reminds us that to them and to their communities, they are not an asthma patient, or a COPD patient, or even a lung cancer survivor. They are a parent, a friend, or a neighbor who has asthma, or COPD, or who has beaten lung cancer. Their disease does not define them, even when it does define their daily lives.

We remain grateful to the patients who share their stories with us, and who remind us that life with these diseases is more than possible – it’s critical. They remind us that every milestone is important: every treatment that makes their lives a bit more normal, every intervention that makes breathing a bit easier, allows them to focus less on their disease, and more on their lives. By hearing their stories, we can inform our own work – where do they see a need for innovation? What do they see from their proximity to the disease?

Patient Voices is a great way to remind ourselves of patients’ expertise in their own disease and treatment, and once a year isn’t enough. That’s why the ATS, in conjunction with PAR partners, dedicates specific patient education weeks to individual diseases throughout the year. During those times we bring patient advocacy groups together with expert clinicians and researchers to shed light on disease and treatment and facilitate a public conversation. We talk about the existing state of treatment, as well as where treatments are headed. By connecting our members and PAR partners, the ATS not only highlights the patient experience, but also encourages collaboration as researchers are able to connect with the many resources our partners offer, from grants to patient registries.

Thanks to input from all stakeholders, including patients, families, clinicians, scientists, and researchers, we can continue to move forward, together. ●



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What Is Asthma?

Asthma is a chronic disease that affects the airways of your lungs. Your airways are the breathing tubes that carry air in and out of your lungs. There are two main problems in asthma: swelling and increased mucus (inflammation) in the airways, and squeezing of the muscles around the airways (bronchospasm). These problems can make it hard to breathe. Taking medicines and avoiding things that trigger asthma can help control asthma. This fact sheet will address the basics of asthma—what it is, how it is diagnosed, and what are some common triggers. For information on treatment, see part 2, "Treatment of Asthma".

How do I know if I have asthma?

Common symptoms of asthma include:

- Cough—often dry and can have harsh bursts
- Wheezing—a whistling sound mainly when you breathe out through narrowed airways
- Chest tightness
- Shortness of breath which may occur with activity or even at rest

When you are having a problem with asthma, you may feel like you are breathing through a straw because it is hard to move air through your narrowed airways. Cough is often a first symptom of an asthma problem. Cough most often occurs at night or early in the morning.

While asthma is a chronic disease, you may not have symptoms every day. You may have days with cough, wheeze and/or shortness of breath and other days when you feel completely fine. If you have symptoms often and/or they are interfering with your activities, you should talk to your healthcare provider.

An "asthma attack" means rapid and severe worsening of your asthma. If you think you are having an asthma attack, follow the emergency (red zone) Action Plan that you developed with your healthcare provider. If you are not getting better, or getting worse, you should immediately seek emergency care.

Diagnosing Asthma

Asthma is usually suspected by a healthcare provider based on a pattern of symptoms and response to medicine called a bronchodilator that can relieve the squeezing of the muscles around the airways. In people over 5 years of age, a breathing test called spirometry (a type of pulmonary function test—PFT) helps confirm the diagnosis. This test can detect narrowing (obstruction) in the airways. A normal

Figure 1. Normal Airway

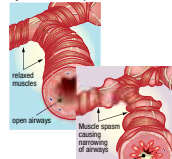
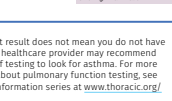


Figure 2. Acute Asthma



breathing test result does not mean you do not have asthma. Your healthcare provider may recommend other types of testing to look for asthma. For more information about pulmonary function testing, see ATS Patient Information Series at www.thoracic.org/patients.

If you have been diagnosed with asthma, but it is not getting better with treatment, you might benefit from seeing an asthma specialist. Sometimes asthma can be difficult to control. At times, other medical problems can make asthma worse or harder to control. Based on your symptoms, your healthcare provider may suggest testing for other problems, such as allergies, sinus disease, vocal cord dysfunction (VCD), inspiratory laryngeal obstruction (ILO), gastric reflux (heartburn), or heart problems.

Work with your healthcare provider to get the tests and treatment you need to be sure you have good asthma control which can improve your quality of life.

What triggers asthma symptoms?

If you have asthma, your airways are more sensitive than normal. Your airways can get irritated easily when exposed to a variety of things, called "triggers." Exposure to triggers can lead to both muscle spasm and inflammation/swelling described above. Sometimes asthma symptoms occur right away after you are exposed. Sometimes your symptoms may occur hours later. You have to be a detective and think about what may be around you that can trigger your asthma. Knowing and avoiding your triggers can help with asthma control. There may be some triggers that you cannot avoid or control and may need treatment to keep them from causing asthma symptoms. Some common triggers of asthma include allergies, respiratory infections, stress, exercise, and medications.

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Patient Voices

Mental and Emotional Health of Patients and Families

A publication of the American Thoracic Society **Public Advisory Roundtable**



“Having a support system is important for your mental health but also your physical wellbeing, especially when you have a chronic illness.”

-Katie O’Grady