



ATS Patient Voices



A PUBLICATION FROM THE 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.



We help the world breathe®
PULMONARY • CRITICAL CARE • SLEEP

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Foreword

Lessons learned from patients leave long-lasting impressions, often beyond what is learned in the classroom. The patient perspective is paramount to our work at the American Thoracic Society, and since 2001, the ATS Public Advisory Roundtable (PAR), along with PAR partners, comprised of various patient advocacy groups, has opened up the Society to those most personally affected by the diseases we research and treat: patients and their caregivers.

This focus is perhaps most evident at the annual ATS International Conference where PAR facilitates patient programs, such as the Meet-the-Expert patient and family forum, PAR Symposium, and several dozen scientific sessions that feature patient speakers. We're very proud of this unique aspect of our conference, and the outcomes of these experiences stretch from inspiring investigators and stimulating new research, into shaping ATS advocacy programs.

Patient Voices is a particularly important part of this effort. In this edition, you'll hear from patients in their own words, not just about the disease and its treatment, but about their reactions to diagnoses, their fears, their recoveries, and what they think it's important for medical professionals to know. These patients have spoken at ATS conferences and to patient advocacy organizations, serving as a reminder to the many others suffering from similar diseases that the fight continues.

Together with patients and their families we will seek cures, and the opportunities for discovery have never been greater. We have the tools to unlock the mysteries of lung disease and advance pulmonary health through innovative research, clinical care, advocacy, education, and training. And thanks to our PAR partners, our members have access to the many resources, from disease-specific grants and publications to patient registries developed by those groups.

Thank you to all the contributors for your stories, and for making Patient Voices possible, as we work together toward ever more treatments, therapies, and ultimately, cures. ■



James Beck, MD, ATSF
President, ATS
(2019-2020)



Karen J. Collishaw, MPP, CAE
Executive Director, ATS

Chair's Message

Since 2001, the American Thoracic Society (ATS) leadership has formally partnered with patients and their families through the ATS Public Advisory Roundtable (PAR). PAR continues to be one of the only patient-centered groups woven into the fabric of a medical membership association. The patient arm of the Society, PAR is a central component of the ATS providing the patient perspective in all aspects of the organization.

Each year, ATS PAR identifies patient speakers to scientific sessions during the ATS International Conference. During this global gathering in May of 2019, some of the best minds in pulmonary, critical care, and sleep medicine came together in Dallas, Texas. Fifteen compassionate and inspiring patients stood at the podium and with tremendous courage explained their disease-related experiences with the audience of professionals.

Their goal was to share their journey — to put a “face” to their diagnosis. As a result, respiratory professionals including physicians, clinicians, scientists, and researchers received an intimate look into disease impact on patients’ lives. Understanding the patient perspective is essential for conference attendees to innovate and to advance scientific research toward better patient outcomes.

This booklet, ATS Patient Voices 8, was created to expand the reach of those stories beyond the conference. Today, we continue to align our work with the unique and urgent needs of individuals living with sleep disorders, critical illness, and respiratory diseases. Together, we’re creating a more unified and powerful research and advocacy community. As our patients gain more knowledge and insight about their diseases and how it affects their quality of life, they remain invaluable resources to us all.

It is a great honor and privilege for the ATS PAR to be the “patient voice” of the ATS. ■



Kari Rosbeck
Chair, ATS-PAR

Michael Hurley

ACUTE RESPIRATORY DISTRESS SYNDROME (ARDS)



I was 17 when I was rushed into St. Vincent's Hospital, admitted to the Pediatric Intensive Care Unit, and placed into a medically-induced coma, breathing only with the assistance of mechanical ventilation. What my primary care doctor had diagnosed as walking pneumonia had become ARDS. As I was being sedated, I remember thinking, "I'm not ready to die. I refuse to die like this."

I was treated with broad spectrum antibiotics and experienced a significant pneumothorax of my right lung upon being intubated. I was placed on ECMO as the last hope to save my life, and remained on it for 24 days, sedated with a cocktail of fentanyl and lorazepam.

Even once I was taken off ECMO, I remained on a ventilator. I was given a tracheostomy and taken out of deep sedation, which sent me into severe, acute opioid withdrawal. It went undiscovered until one of my nurses proposed that I was not being properly tapered off the medications that had kept me sedated for so long.

Michael Hurley was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

Acute Respiratory Distress Syndrome (Critical Care)

“I remember thinking, ‘I’m not ready to die. I refuse to die like this.’”

My symptoms improved as soon as I received methadone and my lorazepam tapering scheduled was slowed.

I still struggled physically. My muscles were atrophied, I suffered peripheral neuropathy in my legs which left me unable to stand or walk, and I had endured some excruciating days of breathing out-of-sync with the ventilator. I began physical and occupational therapy in the PICU until being discharged to a rehabilitation facility, where I spent an additional month.

While I feel fortunate about my care overall, it did have its frustrations. Perhaps the most troubling were those in which decisions were made, or information was conveyed, within my earshot. Possessing hardly any agency over my body, feeling excluded from these conversations compounded my powerless psychological state.

ARDS split my life into “before” and “after.” I have physically recovered, but the impact on my mental health was profound. After years of suffering, I finally sought professional help, and found support with other survivors.

I am grateful for the medical professionals who worked tirelessly to save me, and for my family and friends for their support. To know that organizations such as the ATS are studying treatments for severe respiratory illnesses, and conditions like ARDS, inspires in me a sense of hope that perhaps, one day, nobody need suffer through such a catastrophic life event. ■

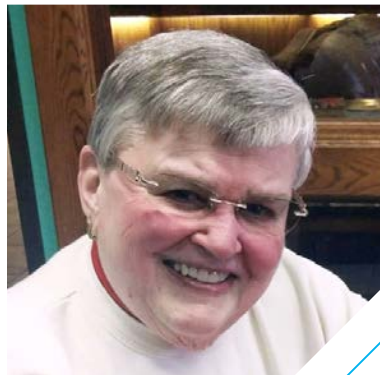
Acute Respiratory Distress Syndrome is a life-threatening problem in which the lungs are severely injured. Inflammation (swelling) occurs throughout the lungs. In the lung tissue tiny blood vessels leak fluid and the air sacs (alveoli) collapse or fill with fluid. This fluid buildup keeps the lungs from working well. People with ARDS generally have one or more of the following symptoms:

- Shortness of breath.
- Cough (often with white or pink frothy sputum).
- Fatigue.
- Fever.
- Abdominal pain (in pancreatitis).

Learn more: ATS Patient Education Series. “What is Acute Respiratory Distress Syndrome?” New York, NY. www.thoracic.org/patients/patient-resources/resources/acute-respiratory-distress-syndrome.pdf

Jean Rommes

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)



Like many men from WWII, my Dad smoked. Cigarette smoke was part of the “Dad smell” and I remember sitting in his lap, feeling as safe as I could be, enveloped in his arms.

I started my own 30-year smoking history in college and finally quit in 1992, when I was 48. I worked in a health-related field and I knew in 1985 that I had COPD. I had all the classic symptoms and all the classic excuses. In 2000, I was officially diagnosed with COPD, and I pretty much let things go.

By December 2002, I was on oxygen 24/7 and in February of 2003, I landed in the hospital with respiratory failure. My doctor told me that if I could lose weight, my problems wouldn’t go away, but they’d get better. I was sure he didn’t think I could or would, and I got angry about that. And I was scared, because I wasn’t able to breathe properly even with oxygen. My husband was also beginning to show signs of Alzheimer’s and I wanted to be around for him.

With my doctor’s wholehearted approval, I started on an aggressive diet and exercise program. Losing weight was my

Jean Rommes was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

Chronic Obstructive Pulmonary Disease (COPD)

“Over 18 months, I lost over 100 pounds, got off oxygen completely, cut my medication down significantly, put the C-pap machine in the closet . . . and got a whole new wardrobe.”

priority, so I did the most intense workouts I could manage on my treadmill and bike. I didn't think about the effect that this exercise would have on my breathing until about four months later when I realized that taking a shower was no longer a breathtaking experience. Making the bed took 3 minutes instead of 15 minutes with rests in between.

Over 18 months, I lost over 100 pounds, got off oxygen completely, cut my medication down significantly, put the C-pap machine in the closet, got my FEV₁ back up to 35 percent, where it was when I was diagnosed, and got a whole new wardrobe. I was able to work full-time until my planned retirement. I still work part-time and spend a lot of time on COPD advocacy work.

Making the life-style change is hard and the hardest part is finding a motivating factor. Once I actually got started and began to see results, everyone I knew was cheering me on. People I knew casually would tell me they could see the differences. That's really motivating, and to be told you look a lot younger is even more so! ■

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. Early in the disease, people with COPD may feel short of breath when they exercise. As the disease progresses, it can be hard to breathe out or even breathe in. A person with COPD may have obstructive bronchitis (bron-kee-oh-lite-is), emphysema, or a combination of both conditions. The amount of each of these conditions differs from person to person.

- Obstructive bronchitis is a condition in which chronic inflammation and swelling cause the inside of the breathing tubes (airways) to be smaller than normal. This narrowing interferes with how well and how easily air empties out of the lungs (expiration).
- Emphysema loosely defined is “air trapping” or the inability to fully exhale, leading to abnormal expansion or hyperinflation (hi-per-in-flay-shun) of the lungs. Constantly having trapped air in the lungs combined with the extra effort needed to breathe results in a person feeling short of breath.

Learn more: *ATS Patient Education Information Series. “Chronic Obstructive Pulmonary Disease (COPD)”* New York, NY. www.thoracic.org/patients/patient-resources/resources/copd-intro.pdf

Madeline Williams

LYMPHANGIOLEIOMYOMATOSIS (LAM)



In 2005, when I was 29, I was diagnosed with a rare lung disease called pulmonary lymphangioleiomyomatosis (LAM). I started out with very few symptoms. I had been a runner for many years, and in 2008 I started having continuous lung collapses. After several unsuccessful surgeries, it became painfully obvious that I would need to get on the transplant list in the future. On oxygen for 18 months, I waited to be considered “bad enough” to be listed for a transplant. During this time, I was rushed to an ER in Arkansas for tachycardia then transported to Dallas by plane to begin the process of getting ready for a transplant.

At this time, a family friend offered his new home in Dallas while we waited for the call. In March 2009 I collapsed there and was rushed to UT Southwestern to prep for transplant. My heart gave out twice during the surgery but the dedicated staff hand-pumped my heart. After a long two-month recovery in the hospital, I was released.

Madeline Williams was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

Lymphangioleiomyomatosis (LAM)

“I had been a runner for many years, and in 2008 I started having continuous lung collapses.”

In the 10 years since my transplant I have traveled to Ireland, parasailed in upstate New York, and visited Disney World and New Orleans, among other places. I believe my overall success can be attributed to my commitment not to ever give up, and to enjoy life to the fullest. As long as I can still grab a breath, I will continue to fight. ■

LAM is a rare lung disease that mainly affects women, usually during their childbearing years. LAM occurs in 3-8 women per million in the general population. LAM is caused by mutations in the tuberous sclerosis complex (TSC) genes. These mutations lead to growth of abnormal cells that spread by the blood stream and make their way into the lungs. Once in the lungs, these cells create holes in the lung tissue (called cysts) that can weaken breathing and the ability to take up oxygen.

Symptoms of LAM are similar to other lung diseases. Sometimes patients can be misdiagnosed with asthma, bronchitis, or emphysema. These symptoms include:

- Shortness of breath.
- Fatigue.
- Lung collapse, also known as a pneumothorax.
- Chest pain.
- Cough.
- Coughing up small amounts blood.

Learn more: *ATS Public Advisory Roundtable member The LAM Foundation.*
www.thelamfoundation.org.

Melody Papazis

ASTHMA



My name is Melody Papazis. I am a wife, mom, nurse, and severe asthma fighter.

Severe asthma is waking up in the morning praying it's not raining, too cold, too hot, too humid or too windy.....because asthma.

Severe asthma is taking medications that make you angry, scared, wired, and jittery, like Prednisone. Prednisone keeps us alive but destroys our bodies at the same time.

Severe asthma is being told your lungs are fine because you aren't wheezing, but knowing that you're not wheezing because you're not moving any air.

Severe asthma is watching your twin sister get married and have kids as you quietly cry out to God, "How can I have kids when I can't walk five feet without wheezing?"

Severe asthma is making an extrovert miss out on weddings, parties, and life.

Melody Papazis was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

“To thrive with my severe asthma, I have to fight the good fight every day.”

Severe asthma is not getting your master’s degree, or your dream job as a pediatric pulmonary nurse, because of the exposure to germs.

Severe asthma is countless days in the ICU fighting for every breath while your husband and kids try to maintain a normal life but deep inside they too are scared and afraid.

When I was dismissed from my local pulmonary doctor, my life changed for good. I was placed in the hands of Dr. White and Dr. Hogarth from University of Chicago, who LISTENED to me. Dr. White ran tests that should have been done years before. Because he took the time to listen, I am alive, and I am way more alive than I was 10 years ago. I am blessed.

To thrive with my severe asthma, I have to fight the good fight every day. I have to eat healthy, take my daily asthma medications, exercise and monitor my peak flows daily. I have to drink lots water, listen to my body and when my peak flow is in my caution zone I have to adhere to my doctor’s instructions. I have to realize that my body requires more rest and sleep than the average person and not beat myself up. I have to be okay with calling it quits early on my 11 hour shifts as a telephone triage nurse on days when talking is just too much.

I feel very blessed to have organizations like the American Thoracic Society and Allergy and Asthma network that are fighting with me and giving me so much support and guidance. ■

Asthma is a chronic disease that affects the airways of your lungs. When you have asthma, your airways become swollen. This swelling (inflammation) causes the airways to make thick, sticky secretions called mucus. Asthma also causes the muscles in and around your airways to get very tight or constrict. This swelling, mucus, and tight muscles can make your airways narrower than normal and it becomes very hard for you to get air into and out of your lungs. Frequent lung or sinus infections can cause asthma. Irritants that can also cause asthma are:

- Exhaust fumes from cars, buses, trucks etc.
- Chemicals like garden sprays.
- Molds and dust.
- Strong odors from paint, perfumes, colognes, hair spray, deodorants, and cleaning products.
- Tobacco smoke from cigarettes, pipes, or cigars.
- Temperature or weather changes.
- Stress or exercise.
- Medications, including aspirin and betablockers (heart or blood pressure medicine).
- Sulfites in foods such as dried fruits, wine and beer.

Learn more: *ATS Patient Education Series. "What is Asthma?"* New York, NY. www.thoracic.org/patients/patient-resources/resources/asthma.pdf.

Sandra Detter

SARCOIDOSIS



Living with sarcoidosis is like living by traffic light.

When I am “green,” life is great! I am alert and productive at work. I have no limits when it comes to exercise. I can do anything I want.

“Red” is when the symptoms are so severe that I can’t work full-time or do any exercise. It is obvious to everyone that I am not well, and I’ve never managed to get out of a red state without medical intervention.

At “yellow,” fear and uncertainty cause me to be anxious. I am functioning, but I feel sick. I can only meet the minimum requirements of my life. I force myself to exercise because it is the only thing that makes me feel better.

I do my best to hide this because I cannot afford to show a doctor too much anxiety because, if I do, that ends up being the diagnosis. You’ve heard of people carrying baggage from old relationships? I still have baggage from my doctors/patient experiences during the years when I was sick with sarcoidosis and misdiagnosed. So when I do slide into “yellow,” I give it two weeks to go away, or improve. If it doesn’t, I need to see a doctor. But which one?

Sandra Detter was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

“I cannot afford to show a doctor too much anxiety because, if I do, that ends up being the diagnosis.”

If I start with my primary care physician, she will help me figure out the specialist I need to see, though she can't treat me herself. That will delay the process by two weeks and cost a half day of work when I am already struggling to keep up. Another option is my pulmonologist, who is sarcoidosis-proficient, but sometimes my lungs are fine.

No matter what I do, I am still far from treatment. It will take several weeks to see a specialist, and then medical tests will take another few weeks. That's a long time when I am not feeling well, and my batteries are draining. I often think I should just give up, but again, if I show a doctor too much hopelessness, depression ends up being the diagnosis.

Physicians, if I sense that you are taking me seriously, you will be my hero and I will trust you. You will be my hero even if you do not know what is wrong with me. I will appreciate your support in ruling out possible causes and pointing me in the right direction. ■

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. These lumps are called granulomas. 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. Sarcoidosis varies in how active and how severe it is for each person and over time. The granulomas, when active, can cause short term and/ or long-term damage to the organ involved. Some signs and symptoms of Sarcoidosis are:

- Lungs: Shortness of breath, wheezing or dry cough.
- Lymph nodes: Enlarged and sometimes tender lymph nodes.
- Eyes: Burning, itching, tearing, redness, sensitivity to light, dryness, seeing black spots, blurred vision, reduced color vision, and, in rare cases, blindness.
- Skin: Bumps, ulcers, or rarely, flat areas of discolored skin that appear mostly near the nose or eyes or on the back, arms, legs and scalp.
- Bones and joints: Bone lumps (nodules), and/or swelling of ankles or other joints.
- Spleen and liver: There can be pain in the upper abdomen.
- Heart: Shortness of breath with activity and swelling in the legs. One may have an irregular or fast heart beat at times or pass out without warning.
- Nervous system: Headaches, vision problems, numbness, weakness, or loss of movement of arms or legs, drooping of one side of the face, pain or a “pins and needles” feeling.

Learn more: ATS Patient Education Series *What is Sarcoidosis?* New York, NY. www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf.

Jennifer Eisenmann

CYSTIC FIBROSIS



I'm 48 years old and I have cystic fibrosis. When I was 12 months old, doctors told my parents they would be lucky if I lived to my teens.

Despite having two protein-processing mutations, I was not very sick as a child. My mom did hand percussion on me to loosen mucus and I took enzymes to help digest my food. I started noticing deficiencies in my breathing when I was in college, and I got scared. I attended my first real cystic fibrosis clinic when I was 22, and began twice-daily breathing treatments as well as frequent hospitalizations to deal with infections.

In 2014, I had a typical blast of IV antibiotics, but I still got worse. It took weeks to get over. I decided it was time to accept I needed a double lung transplant, so my husband and I moved to North Carolina to be close to two great transplant centers. It took another bad infection in July of 2016, which nearly cost me my life, to be deemed "sick enough" to start the listing process. I received my transplant that December. Those five months were the longest of my life. Sometimes I wasn't sure I would live long enough to get a transplant. I worried about what the surgery recovery would be like. But most of all, I dreamed of what it would be like to take a full breath.

Jennifer Eisenmann was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

“I dreamed of what it would be like to take a full breath.”

While I am very grateful for my transplant, it truly is trading one set of problems for another. I have struggled with my weight, undergone multiple surgeries. All of this, and the average life expectancy five to nine years after transplant is only 50 percent. I've seen many of my friends die from rejection, pneumonia, kidney failure, and cancers that are common to post-transplant recipients.

The average life expectancy for someone born with CF in the U.S. is now 44-46 years old, but it is still widely known as a pediatric disease. I hope this perception changes. I am happy to report that I have been feeling well for several months now and enjoy time doing “normal” things like spending time with my family, going out with friends and taking my dog to the park. Most of all, I enjoy being able to take deep breaths once again. Without the medical and research community I would not be here today. ■

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. Those with only one CFTR mutation are carriers and do not have it. If both parents are carriers there is a one in four chance their child will have the disease. While there is no cure, life expectancy has steadily improved the median survival exceeding 45 years in the United States. Some other facts about cystic fibrosis are:

- There are now more adults than children with CF in the U.S.
- 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.
- Older children and adults are usually diagnosed based on symptoms, such as frequent respiratory infections, malnutrition, and/or male infertility.
- 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 and treat these problems.

Learn more: *ATS Patient Education Series 20 Facts about Cystic Fibrosis*. New York, NY. www.thoracic.org/patients/patient-resources/resources/cystic-fibrosis-facts.pdf.

Heather Kagel

IDIOPATHIC PULMONARY FIBROSIS (IPF)



I'm 51 years old and was diagnosed with idiopathic pulmonary fibrosis (IPF) in February of 2013. My symptoms before diagnosis included a persistent dry cough that would not go away. I went to the doctor thinking I had lingering bronchitis. She took an x-ray and told me she was referring me to a pulmonologist because it was not normal.

Because my dad and my granddad both had IPF, the first words out of my mouth were, "Please tell me it is not scarring." It was, in fact, scarring.

My diagnosis of IPF was confirmed shortly after that. I began using supplemental oxygen in June 2015. The three most common challenges I've faced are travelling with oxygen, getting the appropriate oxygen for home use, and exercising with oxygen.

Most oxygen providers will provide a home concentrator and either tanks or a portable oxygen concentrator (POC). Initially I ended up purchasing a POC out of pocket because it was difficult to get through insurance. Tanks are very heavy and, depending on your flow rate,

Heather Kagel was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

“I went to the doctor thinking I had lingering bronchitis.”

you may have to carry more than one tank with you. Last fall I was prescribed a POC with a low continuous flow capability and it took over two months, and several follow-up calls by me, in order to get the machine. In addition to that, oxygen deliveries can be unreliable and sometimes require that you be home for a full day.

Plane travel requires a battery-operated POC. Most POCs have little to no continuous flow option, which prohibits those with continuous flow needs from air travel. If you don't own a POC or get one through insurance, the rental fee for a POC is almost cost prohibitive. Oxygen companies also require advance notice in order to access home concentrators and tanks while traveling, and if you give less than two-weeks-notice, there is a significant charge to arrange for the oxygen. I have also been required to pick up and drop off oxygen during weekday business hours. Otherwise, there are significant charges for delivering and picking up the oxygen. This requires factoring into travel the extra time and scheduling to pick up and drop off oxygen.

My hope is that oxygen companies will realize that oxygen needs are not a “one size fits all” across patients and will work more closely and compassionately with patients to ensure their oxygen needs can be met in a way that allows as much quality of life and as little frustration as possible. ■

Pulmonary fibrosis describes a group of lung diseases in which thickening of the walls of the air sacs (called alveoli), caused by scarring, can result in cough, shortness of breath, fatigue and low blood oxygen levels. Pulmonary fibrosis can be caused by an identifiable irritation to the lungs, but in many cases the cause is unknown. In cases when the cause of PF is unknown, the diagnosis is idiopathic pulmonary fibrosis.

- Most people with IPF develop symptoms of cough and shortness of breath between the ages of 50 and 70 years.
- IPF is not common under the age of 50 years.
- Historically, more men have been diagnosed with IPF than women, but IPF in women appears to be on the rise.
- Occasionally, IPF occurs in members of the same family. When this happens, the disease is called Familial Pulmonary Fibrosis.

Learn more: ATS Patient Education Information Series. Idiopathic Pulmonary Fibrosis (IPF). www.thoracic.org/patients/patient-resources/resources/idiopathic-pulmonary-fibrosis.pdf

Charnette Darrington Zaskoda

ASTHMA



My name is Charnette Darrington Zaskoda and I have severe asthma, which was aggressively triggered by Hurricane Harvey.

Asthma is a respiratory condition marked by spasms in the bronchi of the lungs, causing breathing difficulty. It usually results from an allergic reaction or other sensitivity.

I will never forget Hurricane Harvey. We suffered from extensive rain and street flooding. Once Harvey went into a tropical depression, the flooding stopped and I went back to work on the recovery team at the hospital.

When I arrived at work, I got out of my car and inhaled pollen that made my nose start to burn and itch. Then my chest started feeling constricted. By the time I got off the elevator to walk to my department I was wheezing and I knew it was time to take my inhaler.

I used my inhaler and then needed it again two hours later. I then had a sudden and severe asthma attack, which left me incapable of working anymore. I barely made it back to the department office, and then my co-workers rushed me down to the ED in a wheelchair. They put me on a steroid IV and continuous nebulizer treatments. My breathing was still subpar, so I was admitted to the hospital for three days.

Charnette Darrington was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

“Never in a lifetime would I believe some super pollen from [Hurricane] Harvey would have set off my asthma so severely.”

Sometimes you wish you would have called in sick! Never in a lifetime would I believe some super pollen from Harvey would have set off my asthma so severely.

Unfortunately, in addition to a hospitalization, this episode delayed my bronchial thermoplasty. The delay caused me to get sick several times, and I was not able to complete my final surgery until November 2018. Since my bronchial thermoplasty was completed, I have noticed small improvements in my life. Speaking in a regular rhythm had become a problem for me. I can do that now without sounding breathy. I cough less. I enjoy being outside longer. I still get asthma exacerbations, but they are better managed. I'm even attempting to exercise more.

In addition to my asthma, I have many health issues related to the steroid that keeps my asthma under control, such as Cushing syndrome, which resulted in osteopenia and a broken foot, as well as diabetes. I'm hopeful that a new drug or treatment can be developed in the future.

I am appreciative of all the progress that you all have made but I look forward to more advances. ■

Asthma is a chronic disease that affects the airways of your lungs. When you have asthma, your airways become swollen. This swelling (inflammation) causes the airways to make thick, sticky secretions called mucus. Asthma also causes the muscles in and around your airways to get very tight or constrict. This swelling, mucus, and tight muscles can make your airways narrower than normal and it becomes very hard for you to get air into and out of your lungs. Frequent lung or sinus infections can cause asthma. Irritants that can also cause asthma are:

- Exhaust fumes from cars, buses, trucks etc.
- Chemicals like garden sprays.
- Molds and dust.
- Strong odors from paint, perfumes, colognes, hair spray, deodorants, and cleaning products.
- Tobacco smoke from cigarettes, pipes, or cigars.
- Temperature or weather changes.
- Stress or exercise.
- Medications, including aspirin and betablockers (heart or blood pressure medicine).
- Sulfites in foods such as dried fruits, wine and beer.

Learn more: ATS Patient Education Series.

"What is Asthma?" New York, NY.

www.thoracic.org/patients/patient-resources/resources/asthma.pdf

Billy Anton

PRIMARY CILIARY DYSKINESIA (PCD)



On the outside I look pretty normal, but there's a battle going on in my lungs: primary ciliary dyskinesia.

I had most of the classic PCD phenotypes shortly after birth which allowed for early diagnosis and treatment. Many PCD patients go decades without a definitive diagnosis. At first, PCD didn't prohibit me from being a kid. Though I did get sick and required antibiotics, I always bounced back quickly. I was very active, playing upwards of 100 basketball games per year, and never felt that I was physically inferior to other kids.

My teen years didn't come as easily. I was almost willfully ignorant to PCD, not always complying with my treatments. Then I stopped playing sports, and I started getting sick more often. I missed school, had more courses of antibiotics and got increasingly frustrated. I refused to accept PCD as a part of my life, so I pretended that it didn't exist, allowing it to take over my life on its own terms.

I was hospitalized for the first of 7 times when I was 17. I felt physically depleted. My doctors insisted this was just the cycle of PCD, even though my rapid decline was atypical. With college approaching and my health in question, I decided to stay local, missing out on the "college experience." I finally sat back and considered how much PCD was affecting my life.

Billy Anton was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

“On the outside I look pretty normal, but there’s a battle going on in my lungs: primary ciliary dyskinesia.”

I began doing my treatments with a purpose, twice a day, and saw small improvements. I incorporated physical activity again. I gained confidence in my ability to fight and find stability in my health care. In 2015, I got involved with the PCD Foundation as a volunteer, and I now serve as vice chairman of the board.

Currently, my lung function hovers around 50 percent, and I have a chronic cough. I have sinus issues, and moderate pain caused by severe bronchiectasis in my lower lobes. I often consider how quickly my health will deteriorate or how PCD will affect my quality of life. I know what potentially lies ahead: sinus surgery, hospital admissions, PICC lines with IV antibiotics, oxygen supplementation, and potentially a double-lung transplant. Hopefully some of those things are many years away. I try my best to stay present, but you can imagine how easy it is to look back and question some of my past health choices.

It’s an honor to represent the PCD patient community and I also want to express how grateful I am for researchers who work tirelessly to better understand PCD. PCD is a serious disease. It’s not “similar to asthma or allergies,” or even a “milder CF.” It’s a progressive respiratory disorder that can be debilitating. ■

PCD is an inherited disorder, meaning that people born with the disease receive a mutated (abnormal) gene from both parents. In PCD, mutations in the genes responsible for building cilia and controlling their function result in cilia that do not work effectively. PCD causes frequent respiratory infections starting at a very early age that result in lifelong, progressive lung, sinus, and ear disease.

Symptoms of PCD start very early in life, usually during the first year, and include:

- Neonatal respiratory distress (trouble breathing shortly after birth) in full-term babies, usually requiring oxygen therapy, and often lasting days to weeks.
- Daily, year-round, nasal congestion.
- Daily, year-round, wet (mucus-producing) cough.
- Chronic middle ear fluid and ear infections that can lead to hearing loss or speech difficulties
- Chronic sinus infections.
- “Sidedness” differences (situs inversus totalis or situs ambiguus/heterotaxy), including congenital heart defects.
- Male infertility (inability to make a woman pregnant), since sperm tails use the same genes as motile cilia.
- Reduced fertility in women (inability to get pregnant) related to cilia dysfunction in the Fallopian tubes.

Learn more: *ATS Patient Education Information Series. “Primary Ciliary Dyskinesia (PCD).”*
www.thoracic.org/patients/patient-resources/resources/pcd.pdf

Ralph Gervasio Jr.

ACUTE RESPIRATORY DISTRESS SYNDROME (CRITICAL CARE)



I was a 66 year-old special operations Vietnam combat veteran, and strength and conditioning athlete, when I was admitted to the Nashville VA with acute respiratory failure. During my stay in the MICU, I remained intubated and ventilated for 17 days. I received dozens of necessary procedures, and had last rites administered. I had never been in-patient in my entire life, and I was in one hell of a mess!

One of my doctors promoted early mobility when others thought it too dangerous and risky, as a result of a casual conversation she initiated about my hobbies. I wrote my responses, and she honed in on my commitment to a lifestyle of superior physical fitness. My nurses and others gathered twice a day to walk with me, lap after lap, until I was finally extubated dozens of laps and many days later.

I had survived.

I was wheeled—cannula in nose and tank in tow—to a shared room to begin my recovery.

While in the ICU, I had been deeply sedated while intubated and ventilated. Looking back at my ICU Diary, to which doctors, nurses, and others had

Ralph Gervasio was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

“I give more credit to the ICU Recovery Group for my overall healing than any physical aspect of recovery and reintegration.”

contributed, I deduced that at one point I had been resuscitated. They helped me understand my short-term memory loss, which can happen due to delirium in the ICU. I was unaware of any cognitive issues until my wife asked me something one morning. I answered her precisely and with the right words, but my words were not in the right order!

That June, I attended my first ICU Recovery Group meeting, held in a small room across from the actual MICU. It evoked an unrealistic stress. Would they see me and take me back in the Unit? I was nervous, but forced myself to attend. I have been attending ever since.

After nearly a year, I started giving back. I visited other post-ICU vets, and I spoke to family members regarding delirium, and confusion. I give more credit to the ICU Recovery Group for my overall healing than any physical aspect of recovery and reintegration.

Since my MICU experience, I have not had a single bad memory, dream or nightmare about my critical care experience, and I attribute that to my volunteering.

Today, I watch Wheel of Fortune with my wife to try and solve puzzles, and my speech is mostly in the correct order. I still have memory impairments and sometimes confuse one event with another, but that is a very small price to pay for being alive and otherwise well! God's infinite grace and mercy blessed me with the best care imaginable. I am a better person for the total ICU experience. ■

Acute Respiratory Distress Syndrome is a life-threatening problem in which the lungs are severely injured. Inflammation (swelling) occurs throughout the lungs. In the lung tissue tiny blood vessels leak fluid and the air sacs (alveoli) collapse or fill with fluid. This fluid buildup keeps the lungs from working well. People with ARDS generally have one or more of the following symptoms:

- Shortness of breath.
- Cough (often with white or pink frothy sputum).
- Fatigue.
- Fever.
- Abdominal pain (in pancreatitis).

Learn more: ATS Patient Education Information Series. "What is Acute Respiratory Distress Syndrome?" New York, NY.

www.thoracic.org/patients/patient-resources/resources/acute-respiratory-distress-syndrome.pdf

Rebecca Abel

ACUTE RESPIRATORY DISTRESS SYNDROME (CRITICAL CARE)



When I was 24 weeks pregnant, my obstetrician noted increasing blood pressure, and by 27 weeks, I was having difficulty breathing. After two nights of little sleep, and feeling miserable, I visited a clinic.

Rebecca Abel was a patient speaker at the ATS 2019 International Conference in Dallas, TX.

The nurse practitioner immediately called my obstetrician, who sent me to the hospital for pre-eclampsia. I was given a magnesium sulfate drip to prevent seizures or stroke. My memories are hazy, but I distinctly remember my obstetrician telling me that the baby needed to come that weekend. My daughter was born via c-section at 28 weeks gestation, and to our delight, she cried like a kitten when they pulled her from my belly. She was taken to the NICU for stabilization.

All seemed well until I thought I saw bugs crawling on the ceiling. I began to panic and had difficulty breathing. My oxygen saturation levels dropped enough that I was transferred to the ICU and placed on a Bi-PAP. I began coughing up frothy, pink sputum. The nurses could not get one mask cleaned out before I filled up the next. Around midnight, I was intubated. The last thing I remember was looking fearfully at my husband.

The next memory I have was nearly a week later. While intubated, my brain made up the story that I had given birth, my baby had been put up for

“While intubated, my brain made up the story that I had given birth, my baby had been put up for adoption, and I was being sedated and held prisoner.”

adoption, and I was being sedated and held prisoner. I needed to call my husband. As soon as the nurse came in, she gave me the phone, and my worries faded.

I don't know how to explain what it feels like to have lost time that is peppered with bits of reality. I recall my breasts engorging with milk, and placing my mother's hand on my chest to remind everyone that I had just given birth. Lactation brought a pump, and my husband and the nurses pumped my breasts seven times a day.

My family helped fill in the blanks of what happened, and how I tried to communicate via sign language with my husband to tell him I loved him. At some point, I had been scrawling illegible messages asking if I was going to survive, and how my daughter was.

After I was released, having been diagnosed with peripartum cardiomyopathy and pulmonary edema, I had very little time to focus on the emotions of what happened to me. I was thrust into motherhood 12 weeks earlier than anticipated, and my world was a whirlwind of NICU visits, pumping breast milk, and working while also caring for my own needs. Looking back, I don't know how I did it all, but I am grateful that nearly 10 years later I can share my story to help others. ■

Acute Respiratory Distress Syndrome is a life-threatening problem in which the lungs are severely injured. Inflammation (swelling) occurs throughout the lungs. In the lung tissue tiny blood vessels leak fluid and the air sacs (alveoli) collapse or fill with fluid. This fluid buildup keeps the lungs from working well. People with ARDS generally have one or more of the following symptoms:

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Learn more: ATS Patient Education Information Series. "What is Acute Respiratory Distress Syndrome?" New York, NY.

www.thoracic.org/patients/patient-resources/resources/acute-respiratory-distress-syndrome.pdf

Epilogue

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. ■



Courtney L. White, CAE
ATS Director,
Patient Outreach, and
Tobacco Control

Get the Facts!

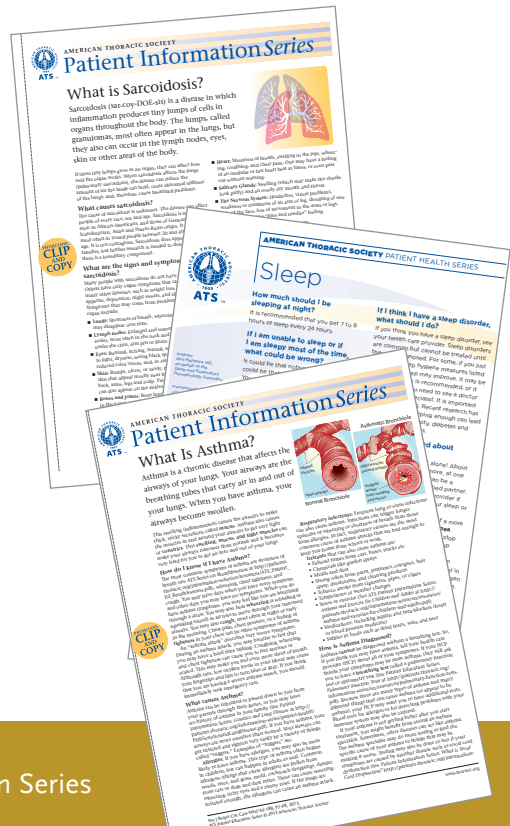
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The American Thoracic Society's Patient Information Series features **FREE** downloadable fliers that describe lung diseases, treatments, and tests in patient-friendly terms.

TOPICS INCLUDE:

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Disclaimer

This publication includes stories of patients with lung disease as told to the American Thoracic Society by the patients or their representatives. The views expressed in these stories do not reflect those of ATS. The ATS makes no claim as to the efficacy of treatments, veracity of diagnoses, or competency of any physician or medical institution referenced herein.

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“I remember thinking, ‘I’m not ready to die. I refuse to die like this.’”

— MICHAEL HURLEY

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