



# ATS PATIENT VOICES 7

A PUBLICATION FROM THE ATS PUBLIC ADVISORY ROUNDTABLE.

# Public Advisory Roundtable

## Public Advisory Roundtable

### Public Advisory Roundtable

#### Public Advisory Roundtable

##### Public Advisory Roundtable

###### 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*<sup>®</sup>  
PULMONARY • CRITICAL CARE • SLEEP

# Table of Contents

Foreword 2

Polly E. Parsons, MD  
President, ATS

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

Chair's Message 3

Kerri Connolly  
Chair, ATS PAR

Si Baker Goodwin, Ed.D. 4  
Obstructive Sleep Apnea

Nina Beaty 6  
Lung Cancer

Carmen Camacho 8  
Hermansky-Pudlak Syndrome

Karen Erickson 10  
Alpha-1 Antitrypsin Deficiency

Hali Felt 12  
ARDS

Bobbi Filipiak 14  
Lung cancer

Chris Kvam 16  
Cystic Fibrosis

Bill Gluba 18  
ARDS

Donna Matlach, D. Min. 20  
Asthma

Angela Merkens 22  
Alpha-1 Antitrypsin Deficiency

Patricia Ortiz 24  
LAM

Marcia O'Bryan 26  
NTM

Misty Rushing 28  
Scleroderma

Traci Waters 30  
Sarcoidosis

Epilogue 32  
Courtney L. White, CAE  
Director, ATS  
Patient Outreach and Tobacco Control

## Foreword

Since 2001, the ATS Public Advisory Roundtable has helped highlight the patient experience and weaved patients into the fabric of the American Thoracic Society. Along with PAR partners, comprised of various patient advocacy groups, PAR has opened up the Society to include those most personally affected by the diseases we research and treat: patients and their caregivers. 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, and their recoveries. These patients have spoken at ATS conferences and in patient advocacy organizations, serving as a reminder to the many others suffering from similar diseases that the fight continues.

In addition to Patient Voices, throughout the year PAR, in conjunction with PAR partners, promotes awareness, public education, advocacy and research. Such activities include patient programs, like the Meet-the-Expert patient and family forum, PAR Symposium, and several dozen scientific sessions that feature patient speakers at the annual ATS International Conference. The outcomes of those presentations are expansive, and stretch from inspiring investigators and potentially even stimulating new research, into shaping ATS advocacy programs.

We're proud of this aspect of ATS, and we're glad to bring you another edition of this book. We hope that it can serve as a tangible reminder of the impact your work with patients has every day.

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. ■



**Polly E. Parsons, MD**  
President, ATS  
(2018-2019)



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

## Chair's Message

In 2001, vision turned into reality as the American Thoracic Society (ATS) leadership formally partnered with patients and their families. This partnership is known as the ATS Public Advisory Roundtable (PAR). As the patient arm of the Society, PAR is a central component of the ATS, and continues to be one of the only patient-centered groups woven into the fabric of a medical membership association.

For the past several years, the ATS PAR has identified and assigned patient speakers to scientific sessions during the ATS International Conference. During this global gathering in May of 2018, some of the best minds in pulmonary, critical care, and sleep medicine came together in San Diego, California. Fifteen well-informed and engaging patients stood at the podium and courageously shared 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 advance scientific research toward better patient outcomes.

This booklet, *ATS Patient Voices 7*, 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. ■



Kerri Connolly  
Chair, ATS-PAR

## Si Baker Goodwin, Ed.D.

OBSTRUCTIVE SLEEP APNEA



Though I've complained about sleep disturbances since age seven, the first time any doctor asked me about sleep was in the early 90's. I told him that I never slept well, but nothing more was said. I started specifically asking for help with trouble sleeping in the mid-late 90's. My doctor's only question related to how much coffee was I drinking. I quit drinking caffeine and lost the last thing propping me up.

At the time, I had a career that I absolutely loved, and I had gone to graduate school, and earned a doctorate in psychology. I had a step-family. I had money in the bank. I had a retirement account.

As a result of the direct consequences of untreated sleep apnea, I lost all of those things. Despite the stereotype of the typical OSA patient being an overweight, middle-aged male, people who suffer sleep apnea are sometimes young and fit women.

It is important for you to know I never once complained of "sleepiness." It was always exhaustion, "I can't think my way out of a paper bag," "my brain is foggy." Years of subsequent doctor visits investigated allergies, allergy medication changes, thyroid issues, anemia, even a cardiac workup and trial of beta blockers. None of these things were very useful.

*Si Baker Goodwin, Ed.D. was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“Despite the stereotype of the typical OSA patient being an overweight, middle-aged male, people who suffer sleep apnea are sometimes young and fit women.”

---

My primary care physician did not think I had apnea and gave me a trial of Lunesta, which did little.

By 2007 I was back in the office, crying, incoherent, and threatening to take heroin if it would help me sleep. I would have done ANYTHING to get sleep. I got the sleep study, but I didn't get a CPAP until months later when a friend shipped me hers.

In 2012, I moved to take care of my ailing mother and step-father, and discovered I was eligible for Medicaid. I went to a sleep doctor for the first time. He told me I wasn't giving the CPAP enough time, and made some changes to my treatment plan. They all made me feel worse.

By 2015, I was desperate. I told my doctor that I needed help, and that if I couldn't find it, I was giving up the fight. She gave me a referral.

I had a sleep study done, and the doctor gave me a new treatment, which combined my straight CPAP with enhanced expiratory rebreathing space (EERS). It made a huge difference. Now, after years of misdiagnosis, I am finally recovering. ■

## Obstructive 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. Apnea means not breathing. In OSA, you may stop breathing for short periods of time. Even when you are trying to breathe, there may be little or no airflow into the lungs.

Common symptoms you may have during sleep include:

- Snoring that is usually loud and bothers other people trying to sleep near you.
- Gasping or choking sounds.
- Breathing pauses.
- Sudden or jerky body movements.
- Restless tossing and turning.
- Frequent awakenings from sleep.

*Learn more: ATS Patient Education Series. "Sleep Apnea" New York, NY. [www.thoracic.org/patients/patient-resources/resources/obstructive-sleep-apnea-in-adults.pdf](http://www.thoracic.org/patients/patient-resources/resources/obstructive-sleep-apnea-in-adults.pdf)*

## Nina Beaty

LUNG CANCER



Until I got small cell lung cancer, I'd been quite healthy. I was born and raised in Manhattan in an artistic but unfortunately, a heavily smoking family. I started smoking at 15 but by age 30, I realized that I was getting bronchitis every year, and that it was probably due to my smoking, so I quit. I didn't know then that I was still vulnerable.

It's really because my mother had lung cancer that I even got tested.

My mother happened to be one of the first, if not the actual first, to get an early detection low dosage CT scan and only because her internist was aware of her four pack a day smoking history and thought early screening would be of value. It was. My mom did have lung cancer; it was removed surgically, and she went on to live another 16 years, being re-scanned on a regular basis.

In January of 2014, I was visiting her for lunch when her radiologist decided to pop by for a visit. She recommended that, like my mother, I get the early CT scan because I had smoked and had grown up around smokers. Even though I had no symptoms, I decided to get that scan.

*Nina Beaty was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“It’s really because my mother had lung cancer that I even got tested... I’m sure we’ll know more in the future.”

---

The biopsy showed I had a SCLC tumor sitting on top of my left lung in the mediastinal area. Tests showed that was the only spot, so I was staged as “treatable.”

I was determined to survive as long as I could, by getting the best treatment possible. First, at Mt Sinai where I’d had the scan and standard chemoradiation and prophylactic whole brain radiation. Then, after a second tumor showed up in my abdomen, the Mt Sinai doctors sent me to get into a clinical trial at Sloan Kettering.

I’ve been in an immunotherapy trial with Nivolumab for over two years now with no symptoms to speak of.

I’m sure we’ll know more in the future. In the meantime, I will continue to get my infusions every two weeks and live my life as meaningfully as I can. ■

## Lung Cancer

Lung cancer is the leading cause of cancer deaths in the United States and will claim more lives this year than cancer of the breast, prostate, and colon combined. Lung cancers are generally divided into two major types, small cell lung cancer and non-small cell lung cancer, classified based on how it looks under a microscope. Non-small cell lung cancer (NSCLC) includes squamous cell carcinoma, large cell carcinoma and adenocarcinoma. Small cell cancer (SCLC) tends to grow more quickly than non-small cell cancer. Because it grows more quickly, SCLC is often found when it has spread outside of the lung. Symptoms of lung cancer can vary from person to person. Symptoms of lung cancer include:

- A cough that gets worse or does not go away.
- More trouble breathing (shortness of breath) than usual.
- Coughing up blood.
- Chest pain.
- Hoarse voice.
- Frequent lung infections.
- Feeling tired all the time.
- Weight loss for no known reason.
- Swelling of your face or arms.

Learn more: *ATS Patient Education Series. "Lung Cancer" New York, NY. [www.thoracic.org/patients/patient-resources/resources/lung-cancer-intro.pdf](http://www.thoracic.org/patients/patient-resources/resources/lung-cancer-intro.pdf)*

## Carmen Camacho

HERMANSKY-PUDLAK SYNDROME



My name is Carmen Camacho. I am 53 years old, I am legally blind, a mother of two, one of them with autism, and the main breadwinner at home in Massachusetts. I have a MA in psychobiology and work as a social worker doing clinical work with individuals with chronic mental and physical illness. I have pulmonary fibrosis from Hermansky Pudlak Syndrome, Type 1.

I may not look like your typical palliative care referral but I am, even though I have not had to deal with the intensity of the symptoms of the fibrosis. As part of my job as a social worker, I work with families waiting for transplants. Seven years ago, I was at an HPS client-turned-friend's bedside. She qualified for a transplant and there was a big storm in the Northeast. Her family was two hours away, so she asked me to stay with her until they got there. Her transplant coordinator came over to talk to me about the case, but then looked at the two of us and said, "Wow, this must be like looking in the mirror." I had never thought about that before, but it was. Since then I have seen over 25 of my fellow HPs'ers pass away.

*Carmen Camacho was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“ I may not look like your typical palliative care referral, but I am.”

---

About four years ago I needed to have my ovaries removed due to the bleeding of HPS. At that time, I needed to get Human Leukocyte Antigen matched platelets which were really difficult to match because my plasma renin activity was so elevated. I didn't think about it until I came to an ATS Patient Day. They were talking about factors that might disqualify a patient for a lung transplant, among them, antibodies. At the end of the talk, I approached the doctor about high PRA levels, and the chances for a lung transplant. He answered very candidly that anyone with a PRA as high as mine had been would be disqualified immediately. I just looked at Donna Appell, the president of the HPS network, and tears burst out of my eyes. Donna just held me and let me have my moment. I guess she was my palliative care team.

I may not look like a typical palliative care referral, but I am. ■

## Hermansky-Pudlak Syndrome

Hermansky-Pudlak Syndrome (HPS) is a rare inherited disease, named after two doctors in Czechoslovakia who, in 1959, recognized similar health conditions in two unrelated adults. Since the discovery of HPS, the condition has occurred all over the world but is most common in Puerto Rico. The most common health conditions associated with HPS are albinism, the tendency to bleed easily, and pulmonary fibrosis. A growing number of gene mutations have been identified causing HPS (including numbers HPS1 to HPS10). A breakdown of common issues HPS patients experience are:

- Albinism is an inherited condition that reduces pigmentation (coloring) present in the body. People with albinism are often with fair-skinned with light hair. Low vision and various degrees of nystagmus is seen in all cases.
- HPS patients have normal numbers of platelets, but they are not made correctly and do not function well, so the blood does not clot properly. As such, persons with HPS may bruise easily or have frequent nose bleeds.
- The exact cause of pulmonary fibrosis in HPS patients is uncertain. However, there is inflammation present and over time the lungs become scarred which limits the ability for oxygen to enter the blood.

*Learn more: ATS Patient Education Series  
What is Hermansky-Pudlak Syndrome? New York, NY. [www.thoracic.org/patients/patient-resources/resources/hermansky-pudlak-syndrome.pdf](http://www.thoracic.org/patients/patient-resources/resources/hermansky-pudlak-syndrome.pdf)*

## Karen Erickson

ALPHA-1 ANTITRYPSIN DEFICIENCY



My 2000 diagnosis with Alpha-1 antitrypsin deficiency was delivered with a prognosis of living for two years.

I stayed active and fit for my journey with AATD and to prevent the surgical intervention for as long as possible. I was confident I would slide into transplant in the nick of time. That all changed one day late in 2012.

As I took then-foster dog, Sasha, out to train, I readied myself with my portable oxygen. Upon my first breath of a new tank, I felt an indescribable pain throughout my body.

I thought I would succumb to the incident. I remember smiling, and I was at peace at that moment. The foster pup greeted me with her wet nose, and I knew I had to get up, if only to get her inside. I took a couple of steps and realized I would not make it far without more oxygen. I hoped to find another source of O<sub>2</sub> but was unsuccessful, so I resorted to a second breath from the same system. Almost everything is blank after that, but I do have some recollection of a 911 call.

*Karen Erickson was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“ I was confident I would slide into transplant in the nick of time. That all changed one day late in 2012.”

---

I was unresponsive upon my arrival at the emergency department, with present and worsening respiratory distress and seizures. Multiple emergency interventions were required to prevent further deterioration. Labs and radiologic evaluation followed. Indication of both renal and hepatic insufficiency were noted. I took my history of shattering prognoses, added a little extra fight, and I was able to make it home.

I worked on regaining my strength and some much needed weight. It was evident that I had a tough journey to travel to be healthy enough for transplant. By my next visit, three months later, my lung function had not recovered at all but I had added some fitness and weight to my body. Five days later, I was called for a double lung transplant.

I just celebrated my fifth anniversary, and I am pleased to say that Sasha has been by my side through all of it. ■

## Alpha-1 Antitrypsin Deficiency

Alpha-1 antitrypsin deficiency is an inherited form of emphysema. People with the condition, also known as AAT Deficiency or alpha-one antitrypsin deficiency, do not have enough of a protein called alpha-1 antitrypsin (AAT) in their blood. This protein is made in the liver, and it protects the lungs so they can work normally. Without enough AAT, the lungs can become damaged by chemical enzymes in the tissue that cause emphysema. Alpha-one antitrypsin deficiency also can also cause liver damage. Alpha-one antitrypsin deficiency testing is recommended for certain groups of people, including those who have:

- Family history of alpha-one antitrypsin deficiency.
- Early-onset emphysema (less than 45 years old).
- Emphysema without an obvious risk factor such as smoking or occupational exposure to a substance known to cause the disease.
- Emphysema that is worse at the bottom of the lungs.
- Difficult to control asthma.
- Recurrent pneumonia or bronchitis.
- Unexplained liver disease.
- Patients diagnosed with COPD should consult with their health care provider to see if they would benefit from being tested for alpha-one antitrypsin deficiency.

*Learn more: ATS Patient Education Series  
What is Alpha-1 Antitrypsin Deficiency? New York, NY. [www.thoracic.org/patients/patient-resources/resources/alpha-1-antitrypsin.pdf](http://www.thoracic.org/patients/patient-resources/resources/alpha-1-antitrypsin.pdf)*

## Hali Felt

ACUTE RESPIRATORY DISTRESS SYNDROME (ARDS)



I was 32 years old when I got the flu, pneumonia, and ARDS and was put into a week-long induced coma after two sternotomies. As I woke up, I remember someone saying my name and asking me to lift my hands off the bed. The next time I woke someone asked me to wiggle my toes, and the time after that I was able to open my eyes. Then began the ICU delirium. During that period, I was certain a sign taped to the door of my room announced I was DNR, that HGTV's Property Brothers (on the tv in my room) were holding a telethon to keep my life support machines on, and that the haze I saw during a breathing treatment was a toxic gas meant to kill me.

Before I got sick, I was an assistant professor of creative writing, working hard on my second book as well as a magazine article about the ways women's bodies have been historically neglected in scientific research. While I've spent my entire career communicating scientific information to the general public, I'm still trying to figure out how to convey what I experienced during my month in the ICU.

My recovery didn't end when I was discharged. I hadn't realized how my pre-existing—but managed—PTSD could be triggered by a well-meaning doctor or nurse who didn't explain what they were doing to my body. When I was diagnosed with post intensive care syndrome (PICS), which can include memory, processing, and

*Hali Felt was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“While I’ve spent my entire career communicating scientific information to the general public, I’m still trying to figure out how to convey what I experienced during my month in the ICU.”

---

executive functioning problems, I felt a strange sense of relief. I wasn’t imagining these decreased abilities. I wasn’t imagining how easily my sympathetic nervous system can be activated by mundane things associated with my hospitalization: the smell of bleached sheets, or a yoga instructor telling me to wiggle my toes. How simple things like planning a lecture, remembering what I wrote 10 minutes ago, or listening and taking notes during a meeting can wipe out all the mental energy I have for the day. Unfortunately, while there are ways to prevent PICS, there’s not much that can be done once it exists.

It’s unclear whether I’ll be able to return to full-time work, but I’m already turning my insights into action. I’m writing a book about critical illness and its aftermath. I’m also serving on SCCM’s Thrive Task Force to create a pilot study that will examine how training ICU staff members to deliver trauma-informed care affects outcomes. I’m also working on a program that would bring professional writers into hospitals to help patients and their families craft narratives about their experiences. I wouldn’t have chosen to get ARDS. But there’s a part of me that can be glad that I did, and that I still have the ability to write, giving voice to the millions of other survivors who have been disabled by critical illness. ■

## Acute Respiratory Distress Syndrome (ARDS)

Acute Respiratory Distress Syndrome (ARDS) 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](http://www.thoracic.org/patients/patient-resources/resources/acute-respiratory-distress-syndrome.pdf)*

## Bobbi Filipiak

LUNG CANCER



My journey began in 2013 following the birth of our baby girl. I was considered a high risk pregnancy... apparently, 40 is old! This meant I would be monitored more closely with the help of monthly ultrasounds. Things were going so well that my OB GYN said we could just skip the last ultrasound, but my intuition told me to go. I am so grateful for that. During that ultrasound we realized she had gone from 90 percent in gestational size to 10 percent in just three weeks.

I was rushed to the hospital for five hours of rapid fire tests which revealed HELLP syndrome (Hemolysis, Elevated Liver Enzymes, Low Level Platelets). As they prepped me for an emergency C-section, I was anxious but somehow I knew she would be just fine. After a five hour surgery, I finally met our tiny but mighty baby girl, Katherine Grace Filipiak or "Kate the Great".

During recovery, I experienced tremors and severe headaches. After three days, we called for a neurologist, who ordered a CT scan. The next day we were told that the scan identified something of concern that had nothing to do with my brain. The CT tech had misread the orders and inadvertently scanned not only my brain but also my chest which revealed a spot on my right lung just one centimeter above the base of the scan. That led to a bronchoscopy biopsy.

I never imagined I would hear the words, "YOU HAVE CANCER." I had stage 3b adenocarcinoma non-small cell lung cancer. What?! Adno-what? Lung cancer? How could this be?!

*Bobbi Filipiak was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“ I never imagined I would hear the words, ‘YOU HAVE CANCER’ .”

---

The doctor told me my treatment plan would be aggressive. I thought, “Perfect.... I’ve got this!” My initial biopsy didn’t reveal anything of substance relative to mutations that available therapies targeted , so for the next six months, with a newborn at home and the world’s most amazing husband, I began six weeks of daily radiation, nine weeks of chemo, and a wedge-resection surgery to extract part of my lung. That was followed by a few more weeks of chemo, which kept me in remission for 18 months.

During a follow up scan on my two year cancer-versary, my cancer was found to have spread to my kidney, the left lung and my brain. This time, a CT guided needle-biopsy of the lung determined it had metastasized. It was now stage 4, inoperable lung cancer with a high (70) PDL-1 expression, making me a great candidate for immunotherapy.

I began my first clinical trial at Cleveland Clinic. This course of treatment was eventually FDA approved and worked for me for two years. In early 2017, my cancer spread again and another biopsy was performed. This time we identified a new mutation that made me eligible for a new Poziotinib trial at MDA in Houston. I began the treatment Aug. 2, 2017.

In summary, I’ve learned to partner with my medical team, strive for a plan B, never underestimate intuition, and stop to acknowledge all the silver linings along the way. I believe everyone is dealt a card or two in life that will pose our greatest challenges. Knowledge is power so I stay informed. I lean on my team of doctors and I never ever lose hope. I truly believe that stage 4 lung cancer, formerly called “end stage cancer,” is purely a diagnosis, not a prognosis. With the advancements in modern medicine and the commitment to research and development, the future looks brighter than ever. ■

## Lung Cancer

Lung cancer is the leading cause of cancer deaths in the United States and will claim more lives this year than cancer of the breast, prostate, and colon combined. Lung cancers are generally divided into two major types, small cell lung cancer and non-small cell lung cancer, classified based on how it looks under a microscope. Non-small cell lung cancer (NSCLC) includes squamous cell carcinoma, large cell carcinoma and adenocarcinoma. Small cell cancer (SCLC) tends to grow more quickly than non-small cell cancer. Because it grows more quickly, SCLC is often found when it has spread outside of the lung. Symptoms of lung cancer can vary from person to person. Symptoms of lung cancer include:

- A cough that gets worse or does not go away.
- More trouble breathing (shortness of breath) than usual.
- Coughing up blood.
- Chest pain.
- Hoarse voice.
- Frequent lung infections.
- Feeling tired all the time.
- Weight loss for no known reason.
- Swelling of your face or arms.

Learn more: *ATS Patient Education Series. "Lung Cancer" New York, NY. [www.thoracic.org/patients/patient-resources/resources/lung-cancer-intro.pdf](http://www.thoracic.org/patients/patient-resources/resources/lung-cancer-intro.pdf)*

## Chris Kvam

CYSTIC FIBROSIS



My name is Chris. I am 37 years old, and happen to have Cystic Fibrosis. I am also an avid cyclist and runner, assistant district attorney, and husband. I ran competitively in high school and college, and continue to push my limits athletically. I have made exercise the keystone in my CF care, and strive to live fully by setting healthy goals.

I was diagnosed with CF in 1984. My doctor told my parents to treat me like a normal kid, and when I got sick, we'd deal with it. I was never sick or disabled. I grew up maximizing health, regardless of what my lung function was. Enzymes, chest physical therapy, nebulized treatments and other drugs became part of my normal, the small price for having the chance to participate and excel.

I spent much of my young adult life trying to avoid hospitalizations. I viewed the prescription of IV's as a failure on my part. My lung function would decline, but I would convince my care team to give me a few weeks before ordering the cleanout. I'd spend that extra time doing everything possible to raise my lung function just enough to prevent the hospitalization.

*Chris Kvam was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“ I realized that my attitudes towards CF, my CF self-care and goal-setting had to change. I became focused on maximizing my health status...”

---

Ultimately, I became very sick, and couldn't climb up two flights of stairs. I realized that my attitudes towards CF, my CF self-care and goal-setting had to change. I became focused on maximizing my health status, and recognized that cleanouts were a tool in that effort.

Today, I direct my own care, and I collaborate with my care team to make my health care decisions. I can't remember the last time a pulmonologist told me something about my lungs I didn't already know.

Adherence to care is not easy, and at times, life with CF is not easy. Not everybody is passionate about exercise, but everyone with CF can be passionate about something, and can learn to use that passion to drive their adherence to care. This doesn't mean adherence is easy, this means that adherence is worth it. ■

## Cystic Fibrosis

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 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.
- 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](http://www.thoracic.org/patients/patient-resources/resources/cystic-fibrosis-facts.pdf).*

## Bill Gluba

ACUTE RESPIRATORY DISTRESS SYNDROME (ARDS)



*Bill Gluba was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

One Saturday morning in July of 2015, while doing yard work, I pulled on some work gloves and noticed that they were very tight around my wrists. A few minutes later, I felt like something was biting or stinging my wrist. I pulled off the glove but did not see anything, so I finished trimming the hedge.

Afterwards, I noticed my left arm was starting to swell, so I went to a walk-in medical clinic. I told the nurse what had happened. She did not think too much about it, and prescribed me an antibiotic to take every day for 10 days. She also prescribed an ointment that I was to rub into my arm until it got better.

I religiously followed the directions. One night, my wife woke me and asked what was wrong, noting that my breathing was very irregular. I ignored her and went back to sleep.

A day or so later, I went to a local political rally. A number of my friends asked me if something was wrong, noting that I didn't look well. I left the rally and drove to another outpatient clinic. A nurse took my temperature and told me to drive myself to the emergency room of the local hospital.

I went to the emergency room, but was released a few hours later.

Two days later, I could not talk, and by the following morning I was delirious. My wife and oldest son rushed me to the hospital and our parish priest gave me the last rites. I was intubated and air- vacated by helicopter 55 miles to the University Hospital in Iowa City.

---

“One night, my wife woke me and asked what was wrong, noting that my breathing was very irregular.”

---

For the next 21 days I laid in the ICU unit with round-the-clock nurses and medical staff monitoring and checking on me constantly. They even ran tests through the CDC in Atlanta to check to see if I had been bitten by a deer tick, which I hadn't. I spent another 10 days recovering in the hospital. Eventually, I was transferred to Select Specialty Hospital in Davenport.

During that recovery period, I felt great discomfort in the left side of my chest. An x-ray showed that the chest cavity between my lungs and heart had filled with fluid. Doctors put a small hole near the left top of my chest, inserted a small straw like tube and put me on a pumping machine for a few days. That relieved the pressure and I felt much less discomfort until a few days later, when I asked my family doctor to give me something that would help me sleep. During the night I became delirious, and ripped the large band aid off my upper chest where the tube had been. The pressure and discomfort returned until my pulmonary physician drained about a quart of fluid from my lungs. After that, my oxygen level improved and I began to get progressively better.

After loads of tests, the best conclusion the University of Iowa Hospital and Clinics medical staff could come to was that I had had a very severe reaction to the original antibiotic medication that was prescribed by the first walk in clinic. They said it contributed to a cascading effect that almost killed me.

I cannot say enough or give enough accolades to all the people in the health care profession who had something to do with my hospital stay and treatment. From the house keepers, to the food servers, to the aids and orderlies, to the social workers and therapists, to the nurses and doctors, they were all very caring professionals who treated me with the utmost dignity and respect. They truly did save my life and for that I will be eternally grateful. ■

## Acute Respiratory Distress Syndrome (ARDS)

Acute Respiratory Distress Syndrome (ARDS) 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](http://www.thoracic.org/patients/patient-resources/resources/acute-respiratory-distress-syndrome.pdf)*

## Donna Matlach, D. Min.

ASTHMA



I often say my severe asthma is like a firecracker. Once the fuse has been lit, will it explode? Or will it fizzle out? You can never predict how an asthma exacerbation will end. My childhood asthma returned with a “bang” after an episode of bronchitis in 2007. Despite the usual treatments for asthma, it continued to the point where I was home-bound with a nebulizer and other medications for two years.

My husband and I traveled to different hospitals and specialists around the country looking for answers. Finally, I was diagnosed with “complex eosinophilic asthma with autoimmune features.” I received a trial drug and was finally able to have a somewhat “normal” life again. During this time I learned to be my own advocate. I also realized the stigma I felt from asthmatic episodes in public, use of medications around others, as well as the psychological stress that this disease had inflicted on me and my family.

Learning to control my symptoms and living with the risk of experiencing a debilitating flare-ups are intricate parts of my journey with severe asthma. Speaking at conferences and medical events is all part of my mission to educate not only the public but the medical

*Donna Matlach, D.Min. was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“Through my journey, I refuse to let asthma define who I am, rather I define asthma as a part of my life I WILL control.”

---

community about severe asthma and the profound effect it has on all involved. I am now on the board of a global organization that is doing this type of education for children, adults, athletes, and the medical world.

My story can be summarized with a few key messages: Keep track of your asthma’s frequency, severity, and its effect on you and your family, (physically, emotionally, and financially by journaling), and TALK to your medical professional about your disease. CREATE an asthma action plan, for both you and your family, for quick reactions when exacerbations do occur. UTILIZE your medications properly and in the manner prescribed even when you feel well.

Through my journey, I refuse to let asthma define who I am, rather I define asthma as a part of my life I WILL control. ■

## Asthma

Asthma is a chronic disease that affects the airways of a person’s lungs and causes airways to become swollen. This swelling (inflammation) causes the airways to make thick, sticky secretions called mucus. Asthma also causes the muscles in and around airways to get very tight or constrict. The swelling, mucus, and tight muscles can make airways narrower than normal make it difficult to breathe. Frequent lung or sinus infections can cause asthma. Irritants that can also cause asthma include:

- Exhaust fumes from cars, buses, trucks etc.
- Chemicals, such as 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](http://www.thoracic.org/patients/patient-resources/resources/asthma.pdf).*

## Angela Merkens

ALPHA-1 ANTITRYPSIN DEFICIENCY



When I was 30 years old, I lived in Flagstaff, Arizona and I loved to hike, bike ride, and run. I had my dream job, I was working for a biotech company doing research and product development in the lab. One day in the lab I had a chemical exposure to a severe lung irritant. The chemical exposure caused an inhalation injury, which led to a huge inflammatory response in my lungs.

From that day on, my life has never been the same. I now have a chronic cough, dyspnea and fatigue. The elevation of Flagstaff is 7,000 feet, and within four weeks, I had to move to a lower elevation because I couldn't breathe. My family had to come out from California to pack my apartment and move me down the mountain to Phoenix, where the elevation is closer to sea level. I was no longer able to work, and I eventually lost my job.

I became so deconditioned that I had to use an electric scooter at the grocery store. I had to choose whether to go grocery shopping or go to lunch with friends, because I couldn't do both in the same day. I was on a daily dose of prednisone (20-40 mg) for over two years, four nebulizers a day of Albuterol and several steroid inhalers. Nothing helped my dyspnea.

I was evaluated by five pulmonologists over two years and they all missed an Alpha-1 diagnosis. One pulmonologist suggested that I have an open lung biopsy, and another suggested that I go on a chemotherapy drug. Luckily, I did not do either. Two of the five said that there was nothing wrong with my lungs and attributed my shortness of breath to psychological issues.

*Angela Merkens was a patient speaker at the  
ATS 2018 International Conference in San Diego,  
California.*

---

“When I had the chemical exposure, it caused a huge immune response in my lungs and my lungs were deficient of the Alpha-1 protein, so I was unable to turn off the inflammation in my lungs.”

---

At 32 years old, I was diagnosed with COPD and I had become so deconditioned that my physician recommended that I attend a pulmonary rehab program. There, a respiratory therapist told me about a rare genetic disorder called Alpha-1 Antitrypsin Deficiency. I decided to take advantage of the testing the program offered. It was a simple blood test.

Two weeks later, I received a call from my pulmonologist. He confirmed the Alpha-1 diagnosis and explained that this was the missing piece as to why I was not improving. He went on to say that while there is a treatment to slow down the damage, Alpha-1 is a chronic progressive disorder, and there is no cure. In the end-stages, it can require a lung transplant.

I soon learned that the Alpha-1 protein, Alpha-1 Antitrypsin, is made in the liver and goes through the bloodstream to the lungs to turn off an inflammatory process, and that the Alpha-1 protein inhibits neutrophil elastase in the lungs. Alpha-1 is also known as the genetic form of COPD and/or liver disease and can cause panniculitis.

When I had the chemical exposure, it caused a huge immune response in my lungs and my lungs were deficient of the Alpha-1 protein, so I was unable to turn off the inflammation in my lungs.

The treatment for Alpha-1 is a weekly IV infusion for life of an FDA approved Alpha-1 proteinase inhibitor plasma product. I am now 38 years old, and I have been receiving weekly IV Alpha-1 proteinase inhibitor infusions for about 5 years. I am not as short of breath, I am able to exercise longer, I no longer use an electric scooter, and I do not get as many respiratory infections. However, I still use oxygen when I fly or go above 3,500 feet.

For the past four years, I have had the privilege of being a support group leader for two Alpha-1 Foundation Support Groups. The support groups are for patients with Alpha-1 and their family members in San Diego and Los Angeles, California. ■

## Alpha-1 Antitrypsin Deficiency

Alpha-1 antitrypsin deficiency is an inherited form of emphysema. People with the condition, also known as AAT Deficiency or alpha-one antitrypsin deficiency, do not have enough of a protein called alpha-1 antitrypsin (AAT) in their blood. This protein is made in the liver, and it protects the lungs so they can work normally. Without enough AAT, the lungs can become damaged by chemical enzymes in the tissue that cause emphysema. Alpha-one antitrypsin deficiency also can also cause liver damage. Alpha-one antitrypsin deficiency testing is recommended for certain groups of people, including those who have:

- Family history of alpha-one antitrypsin deficiency.
- Early-onset emphysema (less than 45 years old).
- Emphysema without an obvious risk factor such as smoking or occupational exposure to a substance known to cause the disease.
- Emphysema that is worse at the bottom of the lungs.
- Difficult to control asthma.
- Recurrent pneumonia or bronchitis.
- Unexplained liver disease.
- Patients diagnosed with COPD should consult with their health care provider to see if they would benefit from being tested for alpha-one antitrypsin deficiency.

*Learn more: ATS Patient Education Series What is Alpha-1 Antitrypsin Deficiency? New York, NY. [www.thoracic.org/patients/patient-resources/resources/alpha-1-antitrypsin.pdf](http://www.thoracic.org/patients/patient-resources/resources/alpha-1-antitrypsin.pdf)*

## Patricia Ortiz

LYMPHANGIOLEIOMYOMATOSIS (LAM)



It was a devastating day when I was diagnosed with Lymphangioleiomyomatosis (LAM). LAM is a rare progressive lung disease leading to the cystic destruction of the lungs over time. Being an athlete for most of my life, none of my physicians had ever suspected anything was seriously wrong with me, even when I started presenting with respiratory symptoms and unexplainable chest pains back in 2009. Other symptoms that I now know are related to LAM started as far back as 2005.

Right before I was diagnosed in January of 2012, I was at the peak of my athletic capacity. I had received my category upgrade that allowed me to compete alongside professional athletes and had just returned from the National Championships for road cycling when suddenly everything changed. On December 29, 2011 I was admitted to the hospital with a large lung collapse. A lung biopsy revealed that I had LAM. My once bright future as an elite athlete seemed over. I thought I would never be able to compete again, and soon found myself not even strong enough for most recreational rides in my area.

Looking healthy and being athletic is a true gift but when it comes to having a rare disease, it can lead to missing important early signs. Some oxygen testing such as the "six-minute-walk test" were not as applicable to me, as I might not have de-saturated during a walk test but would have benefitted from oxygen therapy at a higher level of activity. My journey of

*Patricia Ortiz was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“Looking healthy and being athletic is a true gift but when it comes to having a rare disease, it can lead to missing important early signs.”

---

misdiagnoses included everything from asthma to bronchitis to a possible anxiety attack. After that, I truly thought that the strange symptoms I was experiencing were all in my head.

Being under the care of the multidisciplinary team at USCD was a blessing. I think what made the difference for me was that the pulmonologist who correctly diagnosed me looked beyond my otherwise healthy appearance and spent a lot of time asking me a million questions.

Upon my diagnosis, I became very active in the LAM community. The LAM Foundation and scientific community provided me with a wealth of information, and I had the opportunity to connect with the NIH, enrolling in one of their natural history studies of LAM. I have also become an advocate for improved oxygen delivery technology and accessibility. The oxygen needs of LAM patients appears to be higher than the majority of oxygen users, yet oxygen delivery technology severely lags behind the need, so I'm passionate about changing that.

The work done at the NIH gives me hope. I realize that a cure for LAM may not be found in our lifetime, but I do continue to hope that in the future there are more answers for the next generation. ■

## Lymphangioleiomyomatosis (LAM)

Lymphangioleiomyomatosis (LAM) is a progressive cystic lung disease typically manifesting in women of reproductive age. LAM can be either sporadic or associated with tuberous sclerosis complex (TSC). LAM involves smooth muscle proliferation that contributes to parenchymal cysts formation in the lungs. While LAM is considered an interstitial lung disease, clinically, it is essentially a cystic lung disease and shares significant physiological features of emphysema including bilateral multiple cysts and airflow obstruction.

- Symptoms may include shortness of breath, collapsed lung, chest pain, cough, fatigue.
- Women with LAM may be misdiagnosed with asthma, emphysema, or bronchitis.
- Median survival in patients with LAM has varied from 10 to 30 years.

*Learn more: ATS Public Advisory Roundtable member The LAM Foundation.  
[www.thelamfoundation.org](http://www.thelamfoundation.org).*

## Marcia O'Bryan

NON-TUBERCULOUS MYCOBACTERIAL  
PULMONARY DISEASE (NTM)



Living with NTM is not easy, but it is possible. Originally, I was diagnosed with asthma. I didn't think I had asthma, so I asked my doctor for a CT scan and a sputum test, just to be sure. After he did these tests, he agreed with me. I didn't have asthma. I had bronchiectasis and non-tuberculous mycobacterial pulmonary disease, NTM.

With my diagnosis came a severe cough and fatigue so extreme that it made it difficult to get out of bed. My routines changed. For example, showers are no longer a good idea because of germs in the showerheads, so I take baths instead. I use nasal washes daily, and every morning I put on my vest.

My vest isn't your ordinary, go-to-work vest. It has hoses and Velcro, and it helps to get mucous out of my lungs. It's an important part of my lung hygiene process, which also includes nebulizers and other gadgets to help loosen the mucous and allow it to be coughed out. It's a good thing, but it is time consuming and tiring.

*Marcia O'Bryan was a patient speaker at the  
ATS 2018 International Conference in San Diego,  
California.*

---

“Living with NTM is not easy, but until there is a cure for this stubborn disease, I will live my life to the fullest.”

---

These routines take several hours every day and are very important. Additionally, I use oxygen, have a picc-line for IV antibiotics and take three antibiotics by mouth, sometimes for months at a time. I've also had a lobe of my lung removed.

Other routines have changed, too. While I've had to stop kayaking and mountain biking, I've found new activities I enjoy, such as learning to play the piano. Living with NTM is not easy, but until there is a cure for this stubborn disease, I will live my life to the fullest. ■

## Nontuberculous Mycobacteria (NTM)

Nontuberculous Mycobacteria (NTM) are bacteria that are normally present in the environment. NTM comprise more than 160 different species of bacteria that are found naturally in the environment. Inhalation of these bacteria may cause disease in both healthy patients and those with compromised immune systems. NTM disease most often affects the lungs in adults, but it may also affect any body site. NTM pulmonary disease causes symptoms similar to a chronic and non-resolving pneumonia. Common symptoms include:

- 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 Nontuberculous Mycobacteria (NTM) Disease?" New York, NY. [www.thoracic.org/patients/patient-resources/resources/ntm.pdf](http://www.thoracic.org/patients/patient-resources/resources/ntm.pdf)*

## Misty Rushing

SCLERODERMA



In the fall of 2012, I began experiencing severe fatigue and shortness of breath. I thought I was just anemic, stressed and overweight, but in March 2013, I received a diagnosis of severe PAH or Pulmonary Arterial Hypertension secondary to Scleroderma (Limited Systemic Sclerosis). I began oxygen therapy and medications. The medications worked well to reduce the Pulmonary Arterial Hypertension and I was able to wean off of continuous oxygen therapy a few months later.

Throughout 2015 and into 2016, I suffered from severe GERD or Gastro-Esophageal Reflux Disease, difficulty swallowing, and chronic cough. A high resolution CT scan of the chest in February 2016 showed PF or Pulmonary Fibrosis with ILD or Interstitial Lung Disease consistent with Scleroderma. An endoscopy performed in the same month was also consistent with Scleroderma gut changes.

I searched and found Functional Medicine practitioners who created a personalized diet and nutrition program for me, I attended physical therapy, I learned healthy coping skills to reduce stress and I began prioritizing sleep. I also started seeing a psychotherapist to help cope with the changes in my life. I sought the support of complementary practices in addition to my conventional care.

*Misty Rushing was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“I thought I was just anemic, stressed and overweight, but in March 2013, I received a diagnosis of severe PAH or Pulmonary Arterial Hypertension secondary to Scleroderma (Limited Systemic Sclerosis).”

---

I am happy to report that I feel better now than I have in many years. In October 2017, with the support of my physicians, I was able to slowly wean off the three medications because the routine tests showed great improvements. My cardiologist has stated I no longer have PAH but will continue to monitor me for changes.

I started a FB group called Scleroderma and Functional Medicine a year ago which has grown to over 3,000 members worldwide. I also have a website called Scleroderma FM. [www.sclerodermaf.com](http://www.sclerodermaf.com). ■

## Scleroderma

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word “scleroderma” comes from two Greek words: “sclero” meaning hard, and “derma” meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called “progressive systemic sclerosis,” but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient. Some facts about scleroderma are:

- Scleroderma is not contagious, infectious, cancerous or malignant.
- It is estimated that about 300,000 Americans have scleroderma.
- One-third of those people have the systemic form of the disease.
- Localized scleroderma is more common in children, whereas systemic is more common in adults.
- Female patients outnumber male patients about four to one.
- The onset of the disease is most frequent in people between the ages of 25 to 55.

*Learn more: ATS PAR Partner, The Scleroderma Foundation. What is Scleroderma?*  
[www.scleroderma.org/site/PageNavigator/patients\\_what\\_is.html#.WziZStJKgDU](http://www.scleroderma.org/site/PageNavigator/patients_what_is.html#.WziZStJKgDU).

## Traci Waters

SARCOIDOSIS



I was diagnosed with sarcoidosis at the age of 31. At the time of diagnosis I had no symptoms, I was athletic and completely healthy.

I had no idea the impact it would come to have on my life. As the years went on I began to have flair-ups. These flair-ups forced me to make many physical and psychosocial adjustments.

I began to feel isolated and ostracized because of the cough. I was embarrassed by the shortness of breath. I was irritable and suffered from insomnia because of the Prednisone that I was on to control my symptoms, and I was depressed about the weight it caused me to gain. The pain and distressing fatigue made it difficult to exercise, as well, which led to decreased function and more weight gain. I felt trapped in a distressing cycle of illness.

In 2008 I contracted a fungal infection that caused so much damage to my lungs that I later had a lobe of my right lung removed. Fortunately, I had enough reserve lung function remaining that I didn't need to be on supplemental oxygen after the surgery.

*Traci Waters was a patient speaker at the ATS 2018 International Conference in San Diego, California.*

---

“The pain and distressing fatigue made it difficult to exercise, as well, which led to decreased function and more weight gain. I felt trapped in a distressing cycle of illness.”

---

The damage to my lungs from the sarcoidosis has left me with many limitations but I try not to allow these limitations to stop me from living my best life. I work full-time, I travel, I exercise and interact with my friends and family. There are occasions when I can't participate in events because I'm too fatigued and I've learned that it's important to pay attention to my body when it's telling me to rest.

Through the years I have remained prayerful and had the benefit of family and friends who prayed for me. I am determined not to let this disease steal my life. I have shortness of breath and a chronic cough and I'm not able to walk as fast or as far as I used to, but that's okay because I'm grateful to be here to share my story. ■

## Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells, called granulomas, 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. 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, most often in the neck and chest.
- 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. Painful and tender reddened bumps called *erythema nodosum* can suddenly appear on the ankles and shins.
- Bones and Joints: Bone lumps (nodules), causing pain in the hands and feet, and/or swelling of ankles or other joints.
- Spleen and Liver: There can be pain in the upper abdomen, under the ribs on the right (liver) or left (spleen).
- Heart: Shortness of breath with activity, leg swelling, irregular or fast heart beat, or passing out without warning.
- The Nervous System: Headaches, vision problems, numbness, weakness, or loss of movement of arms or legs, drooping of one side of the face, pain.
- Fatigue is a common problem, seen in more than half of patients.

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

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 much to learn from patients. The experience of living through, or living with a disease like many of our patients have faced, have well equipped them to remind us of the realities of survival.

However, taking the time to read their stories reminds us that to them and to their communities, they are not asthma patients, or COPD patients, or even lung cancer survivors. They are parents, friends, or neighbors who have asthma, or COPD, or who have 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 is 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 also inform our own work. Where do they see a need for innovation? What do they see that we may not because of their proximity to the disease?

Patient Voices is a great way to remind ourselves of their expertise in their own disease and treatment. But once a year is not enough. That is 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.

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



## Save the Date: Lung Disease Week

Each year, the American Thoracic Society Public Advisory Roundtable presents [Lung Disease Week at the ATS](#), a series of weeks that focus on specific lung disorders for which ATS PAR member organizations provide support and guidance to patients and their families.

Find links to [information for patients and experts](#), including disease definitions, clinical trial updates, support group information, ongoing legislative efforts, patient stories, testimonials, interviews, videos, and photos.

Attend live events or watch and listen online to webinars with experts in disease research and clinical care presented by ATS PAR partners.



Join the Society-wide initiative at [thoracic.org/patients/lung-disease-week/](http://thoracic.org/patients/lung-disease-week/).

# Meet the Experts

Each year, the American Thoracic Society Public Advisory Roundtable (ATS PAR) holds its patient-focused Meet-the-Experts forum as part of the larger ATS International Conference. This free event is open to lung and airway disease patients and their families. Attendees learn the latest research, clinical trials, and clinical care, and network with other individuals who share their experiences with lung diseases.

More than 20 expert speakers are usually available, as well as a number of breakout sessions to give patients and families a chance to interact with prominent pulmonologists and experts in critical care and sleep medicine. Lunch, oxygen, and parking is provided free of charge.

To learn more, contact Mr. Courtney White at [cwhite@thoracic.org](mailto:cwhite@thoracic.org).



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

ATS Annual International Conference each May

# Get the Facts! ATS Patient Information Series

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:

- Asthma
- COPD
- Critical Illness
- Lung Problems and the Environment or Work
- Lung Problems in Babies, Children, Teens
- Lung Problems from Bacteria, Virus, Molds, Fungi
- Lung Cancer
- Lung Problems that are Uncommon or Rare
- Lung Problems that are Seasonal
- Lung Problems and Smoking
- Sleep Problems
- Tobacco Series
- Surgery and Transplantation for Lung Problems
- Tests, Procedures and Monitoring for Lung Problems

Browse the entire selection of Patient Information Series fliers at [thoracic.org/patients](http://thoracic.org/patients).



# Previous Voices



View all past  
editions and  
many more patient  
resources at:  
[thoracic.org/patients](http://thoracic.org/patients).



“I never imagined I would  
hear the words,  
‘YOU HAVE CANCER’.”

— BOBBI FILIPIAK

# ATS PATIENT VOICES 7

A PUBLICATION FROM THE ATS PUBLIC ADVISORY ROUNDTABLE.



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