



ATS Patient Voices 4

A publication from the American Thoracic Society 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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Disclaimer

This publication includes stories of lung disease patients as told to the American Thoracic Society by the patients or their representatives. The views expressed in these stories do not reflect those of the 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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The American Thoracic Society (ATS) has long held the inclusion of the patient perspective as a core component of its mission. For more than a decade, the ATS Public Advisory Roundtable (PAR), which represents the patient voice of the Society, has played an invaluable role in helping the organization shape its policies to keep families and patients as a central focus of all ATS programs and activities.

Nowhere has this been more evident than at the annual ATS International Conference where PAR has facilitated patient programs such as the Meet-the-Expert patient and family forum, the PAR Symposium, and the many patient speakers integrated throughout scientific sessions.

Patient Voices highlights the stories of some of the patients who have spoken at past ATS International Conferences on their experiences with pulmonary disorders such as sleep apnea, COPD, lung cancer, pulmonary hypertension, hypersensitivity pneumonitis, alpha-1 antitrypsin disease, and idiopathic pulmonary fibrosis, among others. These brave patients, many of whom have had lifelong struggles with diseases, put faces and voices to their oftentimes life-threatening conditions. Their stories serve as an inspiration to many others who have pulmonary diseases and illustrate that a full life can go on after diagnosis, and that patient voices will be heard.

Patients and their families are seeking cures, and the opportunities for discovery and research have never been greater. We now have the tools to unlock the mysteries of lung disease. The ATS is advancing pulmonary health through innovative research, clinical care, advocacy, and training of tomorrow's leaders who will translate discoveries to patients. Indeed, the ATS partners with patients and patient advocacy organizations to find these cures, and on issues of disease awareness, public education, and advocacy. The ATS also opened its membership criteria—anyone,

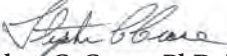
including a patient, is able to join and participate in the activities of the Society. The ATS continues its commitment to funding cutting edge research through the many grants awarded to deserving investigators by the ATS Foundation Research Program in partnership with PAR. This booklet is another manifestation of our efforts to strengthen the relationship between patients, their families, and the ATS.

We greatly appreciate the efforts of the ATS Public Advisory Roundtable, as well as the patients who have given talks at the ATS International Conference that have inspired us and made this booklet possible. We hope that this booklet will be valuable to clinicians who are seeking the patient perspective and to other patients and their families. The ATS will continue its firm commitment to working with patients and its PAR members on advocacy, research, and educational issues. We look forward to continued inclusion of the patient perspective in the work of the Society as we progress toward cures for many lung and airway diseases.




Atul Malhotra, MD
ATS President 2015-16




Stephen C. Crane, PhD, MPH
ATS Executive Director

Because patients are central to what pulmonologists and other medical professionals do, the American Thoracic Society established the Public Advisory Roundtable (ATS PAR) in 2001 to enable patients and their advocates to interact directly with the ATS and help clinicians and researchers understand their perspectives.

ATS PAR is known for its unique ability to respond to patient needs, mobilize efforts to improve patient care, increase research efforts in lung disease, build advocacy and awareness of lung disease, and promote lung health on a national level. ATS PAR members are patients, family members, and advocates who understand the real needs of patients and the lung diseases from which they suffered. Following in the footsteps of the founders, they articulate those needs and help bridge the gap between patients and physicians.

Never before has a medical association elevated patient voices to a level of such an important function within its organization. ATS leadership has shown that ATS PAR remains a vital part of the organization and is held in high esteem. The ATS PAR chair is a standing member of the ATS Board of Directors, with a direct line of communication to ATS leadership.

The implementation of ATS PAR through the vision of Dr. Bill Martin, an ATS past president, not only created opportunities to strengthen medical care but also opened doors for collaboration and partnership. This in turn has helped to increase understanding of lung diseases and fund research that draws us closer to cures. To date, ATS PAR-affiliated member organizations have supported the ATS Foundation with more than \$5 million in funding for innovative and cutting edge medical research in lung disease.

For the past several years, ATS PAR has had the privilege of assigning patient speakers to medical sessions at the ATS International Conference, which draws approximately 12,000 pulmonary, critical care, and sleep medicine researchers and clinicians annually. These patients share their journeys through life with lung diseases that attendees are currently treating and researching.

Within these pages you will find many compelling patient stories that provided the “patient voice” during the International Conference and have inspired attendees to continue research and clinical care without losing sight of the patients.

It continues to be an honor and privilege for ATS PAR to be “the patient voice of the ATS.”



Gregory R. Porta
Chair, ATS PAR

Caroline Moassessi

Asthma



“Patient care and research are the keys to better understanding the health effects of climate change. I’m hopeful these discoveries will improve lives in communities everywhere.”

I appreciate this opportunity to share the realities of climate change on my family's health. I have adult onset asthma, and both my 12-year-old daughter and 16-year-old son have had severe asthma for most of their lives.

As parents, we tell our children there are no ceilings, and the sky is the limit. My daughter, Leila, dreams of working to pass laws that improve the quality of people's lives. Asthma is the one road block that might prevent her from this dream. As our climate changes, controlling her asthma becomes more challenging.

My son was diagnosed with asthma at the age of two after a frightening trip to the emergency room. Around this time, I learned about the bucket theory, which holds that it's not just one trigger that causes an asthma attack but a buildup of many factors. Cold air, exhaustion, mold, and smoke are toxic combinations if dumped into the asthma bucket all at once. When the bucket is full, the bucket tips over. Although I can help control my family's asthma by limiting exposure to their triggers, I can't control our air.

Reno, Nevada, has changed dramatically since we settled here 20 years ago. The city council recently identified climate change as a threat the city should address in its strategic planning.

Strange weather patterns are creating premature pollination. Hay fever season is no longer a season, it seems never ending. Drought conditions continue. Summers are hotter with extreme heat and triple-digit temperatures. Wild fires in the Western United States are becoming more frequent and intense. One particular wild fire, the Yosemite Rim fire, which burned for over two months in 2013, had a calamitous impact on my community. I was out of town during the rim fire. My daughter texted, saying that she felt like sharks were circling her, as she worried about a looming asthma attack. Although the fire was



ASTHMA

Asthma is a chronic disease that swells the airways, or breathing tubes, of your lungs. This swelling (inflammation) causes the airways to make thick, sticky secretions called mucus, and it causes the muscles in and around your airways to get very tight or constrict, which makes it very hard for you to get air into and out of your lungs.

Asthma can be caused by genetics, allergies, respiratory infections, and irritants such as:

- Molds and dust
- Exhaust fumes from vehicles
- Chemicals in garden sprays
- Strong odors from paint, perfumes, colognes, hair spray, deodorants, and cleaning products
- Tobacco smoke
- Weather changes
- Stress or exercise
- Medications
- Sulfites in foods such as dried fruits, wine, and beer

Learn more: ATS Patient Information Series. "What is Asthma?" New York, NY: American Thoracic Society, 2013. patients.thoracic.org

about 200 miles south of Reno, the smoke darkened our skies and dropped fine ash onto our homes and into our lungs.

Health officials warned that the air quality was so bad that even the healthiest of individuals were in danger if they spent too much time outdoors. People with heart and lung disease were urged to stay indoors. Citizens were warned to watch for chest pains, heart palpitations, or trouble breathing. Having managed asthma for some time, our family was prepared. But the rest of my community was not as lucky.

People with asthma were certainly in danger, but even more at risk were the number of non-asthmatics rushed to the hospital for respiratory issues. Pediatric wards overflowed, urgent care facilities juggled long lines, and pulmonologists were working overtime.

Friends complained of headaches and the inability to focus and work. People left town simply to avoid being hospitalized. I worry about our children's asthma forcing us to move one day. I worry about those I love being placed in harm's way each summer, and I pray that nothing tragic happens.

Patient care and research are the keys to better understanding the health effects of climate change. I'm hopeful these discoveries will improve lives in communities everywhere. We are all at risk in our changing climate.

Jon Bernhard

NONTUBERCULOUS MYCOBACTERIAL DISEASE



“It was like the disease fueled a new fire to live, and I wanted to approach every moment with genuine intention. I rode my bicycle across the U.S., stood atop the tallest peaks of Alaska, and climbed the faces of El Capitán in Yosemite.”



I have lived over 30 years of battles and incredible achievements. I was first diagnosed with nontuberculous mycobacterial disease (NTM/MAC) in 1987 when I was 22 years old. My life as a top-end athlete in road bicycle racing came to a complete halt. I was devastated with facing the end of my life, right when I felt my life was only beginning. Through the support of my doctors and heaps of medications, I have clawed my way back to a semblance of my former self.

My journey is marked by countless medication regimens and numerous horrific side effects. Today I am working my way through cryptogenic organizing pneumonia as a result of the scarring and damage due to bronchiectasis, and other effects of the disease.

Childhood memories of backpacking, canoeing, and exploring helped me remember 'life's true meaning,' and kept me from giving up. My brother introduced me to rock climbing and brought me back to pursuits of the outdoors. It was like the disease fueled a new fire to live, and I wanted to approach every moment with genuine intention. I rode my bicycle across the U.S., stood atop the tallest peaks of Alaska, and climbed the faces of El Capitán in Yosemite. Instead of seeing limits with my physical ability, I worked with a new range of focus. I still viewed the world and my place in it as a great adventure.

In the three decades of living with NTM/MAC, I have been fortunate to participate actively in my treatment plans and rehab routines. I even co-authored a peer-reviewed paper on the prevalence rates of the disease in the U.S., and I created a foundation for pediatric patients.

The medical, physical, and emotional struggles of NTM/MAC are daunting. Patients and their families obsess over the day-to-day questions of:

Nontuberculous Mycobacteria (NTM) is a naturally occurring environmental pathogen which impacts tens of thousands of people every year in the United States alone. The bacteria are widely found in the environment, including soil and tap water.

An estimated 50,000 to 90,000 people in the United States have pulmonary NTM disease at any given time, and between 12,000 and 18,000 people become infected each year.

Underlying pulmonary problems and prior pneumonia are but a few risk factors, and a number of genetic diseases including Cystic Fibrosis, COPD, and Alpha-1 Antitrypsin Deficiency have a statistically demonstrable link with NTM. Slender Caucasian women are particularly vulnerable to infection.

Learn more from ATS Public Advisory Roundtable member Nontuberculous Mycobacteria Info and Research (NTMir) at ntminfo.org.

“How am I breathing today?”

“Am I well or am I sick?”

“Will this small cold turn into a full-blown infection?”

“Will being active today lead to overall health conflicts?”

“Will I be able to keep up with the demands of work and my relationships?”

Often our questions and doubts win the day. But by surmounting these fears, we go to a place of ownership and civil disobedience against the disease.

I believe each patient should be treated in a way that activates and unlocks their hidden potential. I climb, adventure, bicycle, and much, much more to prove that we need to adjust our vision, and I aim to show to my physician team that as an NTM/MAC patient we can reach for success well outside the mean.

Jeff Goldstein

PULMONARY FIBROSIS



“Lung transplant should be more than just about surviving. It should also be about living and giving.”

I am a double lung transplant recipient, with chronic myelogenous leukemia that is currently in remission. I have undergone approximately four dozen Moh's surgeries, four courses of radiation therapy, a complete right auriclectomy with removal of lymph nodes and partial parotid gland, and tumor surgery with removal of left side lymph nodes and all of my parotid gland.

One humid summer evening in Miami, I collapsed in my driveway while dragging trash to the curb. I couldn't catch my breath and thought, "Will my wife realize I am not in the house and get to me in time to save me?" I was finally able to control my breathing and thus began my relationship with IPF, idiopathic pulmonary fibrosis.

How could I have a diagnosis of "end stage lung disease?" When I think back I realize there were symptoms I didn't recognize but rationalized as being out of shape, overworked, or tired from not getting enough sleep. This is the *modus operandi* of IPF, and in fact of many of the fibrotic lung diseases. Unless you are able to detect it early by some serendipitous opportunity, you don't know it or feel it until there is significant lung damage.

I was transplanted, just barely in time, on July 6, 2003. My transplant went well, and I considered myself fortunate. It took almost a year and a half to reach my new normal. It was grueling, exhausting, and often uncomfortable. I was grateful, but I felt guilty. I saw others whose transplants didn't work and were rejected within days. Often those patients' bodies were so weak that they couldn't recover or hold on much longer. And for some, their only hope for life—new lungs—didn't come in time. Why has it worked for me? Did I really deserve my new lungs?



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. It can be caused by an identifiable irritation to the lungs, but in many cases the cause is unknown, which is described as idiopathic pulmonary fibrosis (IPF). Idiopathic means there is no known cause at this time. Symptoms include:

- Dry cough or shortness of breath
- Abnormal breath sounds—crackles (like Velcro) can be heard by your health care provider when you take a deep breath
- The ends of your fingers and/or toes have changed to a club shape (called "clubbing")

Learn more: *ATS Patient Information Series. "Idiopathic Pulmonary Fibrosis (IPF)"* New York, NY: American Thoracic Society 2015. thoracic.org/patients/patient-resources/resources/idiopathic-pulmonary-fibrosis.pdf

Perhaps there wasn't an answer. Then a timely letter from my donor's family relieved me of that burden of guilt. I knew the statistics all too well: 65 percent of transplant recipients do not survive the first year, 50 percent of those do not survive to year three and of those that do, 50 percent do not survive to year five. I decided that my transplant was a gift, and I adopted a line from my favorite movie, *Shawshank Redemption*, "Get busy living!"

My brother is an important part of my story. In April 2012, Dan was diagnosed with "likely" IPF. What followed were regular visits to a local pulmonologist to monitor his health status. In December 2013, he was diagnosed with IPF and non-small cell lung cancer. We struggled heavily with the diagnosis.

There was nothing we could do to keep Dan comfortable. He underwent chemotherapy with some positive results, but he continued to suffer from pneumothoraces, and his health declined precipitously. On May 8, 2014, my brother, Dan, died.

Lung transplant can be a lifesaving and transforming experience for those fortunate enough to receive them. But lung transplant should be more than just about surviving. It should also be about living and giving.

Along with a group of other transplantees I started the national nonprofit Lung Transplant Foundation, of which I'm the current president. Our mission is to raise funds to promote research in post-transplant rejection and successful post-transplant adjustment. For other families, there's still hope.

Barbara Pusey

ALPHA-1 ANTITRYPSIN
DEFICIENCY



“I have been so amazed at the positive attitude of patients in this community. They have taught me to cope, and they inspire me to keep going.”

I live in Fort Collins, Colorado, with my husband. I am surrounded by my family of six children and eight grandchildren. I have a bachelor's degree in nursing and a master's degree in education. I spent most of my nursing career in hospitals working in the ICU or ER. I also taught nursing for several years. I started four urgent care/occupational medicine clinics, and I am most proud of starting a proprietary school to train paraprofessionals.

I was diagnosed with alpha-1 antitrypsin deficiency in 2003. I had never heard of this diagnosis –whether through our teaching curriculum or in the emergency room. I was totally blindsided. I remember driving home to look up alpha-1 in my nursing textbooks and found no information there. This was the pre-Google era.

I had a personal health history of bronchitis at least twice a year, which I either ignored or handled with antibiotics. In late 2002, I had pneumonia, and in early 2003 I had more severe pneumonia.

The doctor I worked with sent me to a hospital for a CT scan. When the radiologist called and stated I had emphysema, I defiantly told him he had the wrong films. I had never smoked.

It all went downhill from there. Once tested, I learned I was a ZZ. (Alpha-1 is caused by mutations in the SERPINA1 gene, and a ZZ is an individual with two copies of the Z allele.) I received a recommendation to start augmentation therapy, but I was in so much denial that I didn't. After about six months, I went to a Denver Education Day and observed other alphas. I decided I should help myself and began therapy. Since, I have only had three upper respiratory infections.

Barbara Pusey

ALPHA-1 ANTITRYPSIN DEFICIENCY



Alpha-1 antitrypsin deficiency is an inherited form of emphysema. Patients with the disease 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 emphysema. It also can cause liver damage. There is no cure for alpha-1 antitrypsin deficiency.

Testing is recommended for those who have:

- Obstructive lung disease.
- Family history of alpha-1.
- Early-onset emphysema (younger than 45 years old).
- Emphysema without an obvious risk factor.
- Emphysema that is worse at the bottom of the lungs.
- Chronic asthma (in adolescents and adults).
- Recurrent pneumonia or bronchitis.
- Unexplained liver disease.

Learn more: ATS Patient Education Series. "What is Alpha-1Antitrypsin Deficiency?" NewYork, NY. 2014. thoracic.org/patients/patient-resources/resources/alpha-1-antitrypsin.pdf

On the one hand, getting the diagnosis was awful. On the other, the diagnosis helped answer a lot of questions in the back of my mind: Why could I tap dance for two hours but get out of breath going up two flights of stairs to the studio? Why could I ride my bike for miles until I came to a hill and have to get off and walk? Why did I feel out of breath when going up to Copper Mountain to ski?”

Living with alpha-1 means I can no longer do all the things I want to do. Some of my daily activities are a real struggle. I wish I had been tested and diagnosed earlier in life so I could have made better choices. Most alphas estimate that it takes seven years and three doctors to receive a proper diagnosis.

When I finally came to grips with my diagnosis and began therapy, I also took a position with AlphaNet as a coordinator. Founded in 1995, AlphaNet’s mission is “Alphas Helping Alphas.” The group employs over 40 coordinators with alpha-1. These coordinators make monthly calls to patients and help implement disease management programs. I have been so amazed at the positive attitude of patients in this community. They have taught me to cope, and they inspire me to keep going.

Candice and Crystal Sipe

HERMANSKY-PUDLAK SYNDROME



“We were so overjoyed to find the network; it was as if a huge burden was lifted from us. We were no longer alone.”

We are identical twins, adopted at the age of one from Hyderabad, India. It might surprise you that we are Eastern Indian, but we have albinism because of Hermansky-Pudlak Syndrome type 4. HPS is a genetic metabolic disorder. It causes legal blindness, albinism, platelet dysfunction and in our case, inflammatory bowel disease, severe osteoporosis, acid reflux, kidney disease, and pulmonary fibrosis. Approximately 1,200 people are on the HPS patient registry, and there is no cure at this time.

As babies we were very white with blond curls, and our eyes were in constant movement due to the nystagmus. At 15 months old, we saw a pediatric ophthalmologist and were fitted with glasses. We both had eye surgery a few years later to help slow down the nystagmus. If we had known about HPS at the time, we would have held off on surgery because bleeding was a considerable issue, and we both bled profusely.

We can't think of a time in our lives when we weren't battling a health challenge. We saw many doctors who made various diagnoses. As children we dealt with many asthma attacks and constant difficulty breathing. Now as 34-year-old women, our asthma has been well controlled with the help of steroid and rescue inhalers. We both have had upper respiratory infections, including pneumonia and bronchitis. Candice has had Valley Fever, and she was on treatment for many years.

We have seen several pulmonologists throughout the years. Since HPS is so rare, most doctors don't know about it. We have to educate them, and very few are willing to research and learn about the disease. In the process, we have become our own advocates and researchers. We have chest CT scans every other year and pulmonary function tests regularly (our FVC is at 60 percent). I am thankful to say neither one of us has

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 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).

- HPS gene causes pulmonary fibrosis in gene types 1, 2 and 4; therefore, it can be followed prior to patient reported symptoms.
- HPS is characterized by a platelet bleeding disorder. In the past, the standard of care supported platelet transfusions to prevent bleeding during surgical and dental procedures. Because of the formation of antibodies that can cause difficulty matching lungs for transplant, the recommendation is to keep platelets on standby until needed rather than transfusing liberally.
- Postoperatively, platelets and medications that enhance clotting are routinely prescribed after surgeries. Careful use of this therapy with attention to dosing and timing is necessary as DVT's and unwanted clotting have occurred from possible overcorrection.

Learn more: ATS Patient Information Series. "What is Hermansky-Pudlak Syndrome?" New York, NY: American Thoracic Society 2015. thoracic.org/patients/patient-resources/resources/hermansky-pudlak-syndrome.pdf.

Candice and Crystal Sipe

pulmonary fibrosis yet, but we know it could happen at any time because of our age.

Singing is our love and our passion. We take zumba classes three times a week. Physical activity is tough, but we have been very faithful with our exercising and both feel that staying active helps keep our lungs strong. It's important for us to stay as active as we possibly can.

At age 12, I finally saw my first pediatric GI specialist, who was concerned that I wasn't responding to the medications like a normal Crohn's patient should. He sent our family to Cedars-Sinai Medical Center, where we were diagnosed with HPS. Our family was devastated to learn this news, and we had no idea what HPS was, or where to begin. Our doctor told us that he knew of a colleague in New York with an HPS patient. The patient's mother was Donna Appell, founder and president of the HPS Network. We were so overjoyed to find the network; it was as if a huge burden was lifted from us. We were no longer alone.

Meeting Donna allowed us the opportunity to get to know our HPS family. In November 1995, Crystal and I were invited to open the HPS protocol for research at the National Institute of Health. Accompanying us was Donna's daughter, Ashley. Our team is wonderful, and we continue to follow up with one another regularly. We are thankful to have the support of such a tight-knit group of people.

Audrey Knipe

LYMPHANGIOLEIOMYOMATOSIS
(LAM)



“LAM has changed my life in so many ways, but I won’t stop fighting back. The dedicated scientists and doctors who are researching the disease won’t stop either.”

I was diagnosed with a rare disease called lymphangioleiomyomatosis (LAM) when I was 35.

I never really suspected that my chronic cough was related to a lung disease because I did not smoke. By the time I was referred to a pulmonologist, I was miserable. I was coughing for about 18 hours a day. The workup included my very first PFTs and a chest X-ray. The results showed my FEV1 was 52 percent of the predicted amount, with a 16 percent improvement from a bronchodilator. The specialists found nothing in the X-ray, so I was diagnosed with asthma.

Fast forward five months: I'm in a hospital connected to four liters of oxygen and waking up from a Nissen fundoplication with severe, stabbing chest pain. A high-resolution CT clearly showed the LAM cysts all throughout my lungs. The pulmonologist told my family about my diagnosis before he told me, so when my family came into the room I could tell some of them had been crying. I was wondering, "What's going on? Am I dying?" The next day a nurse came into my room and said, "I'm sorry about your diagnosis, but look on the bright side, at least you'll get to have a double lung transplant."

I left the hospital a week later, on oxygen 24/7. With time, I was able to stop using oxygen during the day, but I needed it from then on when I slept or exerted myself. In retrospect, I was lucky to be diagnosed with LAM at the time that I was. Results of the MILES trial were published eight months later. Sirolimus was found to stabilize FEV1 and slow the progression of the disease. I started sirolimus shortly thereafter, and my FEV1 has been stable since. This has definitely staved off my need for a lung transplant—hopefully forever!

Audrey Knipe



LYMPHANGIOLEIOMYOMATOSIS

LAM is a progressive lung disease that usually strikes women during their childbearing years, which results in the destruction of healthy lung tissue caused by cyst formation and abnormal growth of smooth muscle cells not usually found in the lungs. Symptoms may include:

- Shortness of breath
- Collapsed lung
- Chest pain
- Cough
- Fatigue.

As many as 40 percent of women with LAM have a benign kidney tumor called angiomyolipoma. Women often go undiagnosed for years, and are frequently misdiagnosed with asthma, bronchitis, or emphysema. LAM does not usually appear on an X-ray. A high-resolution CT scan of the chest, and often the abdominal area, is required for accurate diagnosis. Lung capacity in LAM patients progressively declines, sometimes resulting in the need for supplemental oxygen.

Learn more from ATS Public Advisory Roundtable member The LAM Foundation. thelamfoundation.org

Each day I learn to live with this life-sucking disease. It sucks away my energy and leaves me chronically fatigued. It also produces anxiety and insomnia, so when I'm seeking restful, restorative sleep, it will not come. To make matters more difficult, LAM is believed to be estrogen-mediated, and each month I'd have ten days where my shortness of breath worsens dramatically. I talked to my doctor about trying leuprolide in addition to sirolimus, just to see if that made any difference. It certainly did. I had wonderful success decreasing my shortness of breath for those ten days per month. Interestingly, my FEV1 also improved by about 10 percent over the next year. Ultimately, I chose to have an oophorectomy in the hopes of improving my lungs permanently.

I miss the old days when I felt good and had energy. I loved walking around the lake in the evenings, unencumbered and free. I now have to walk carrying a nine-pound concentrator. I used to love going to the mountains for a long weekend with my family. Now it is too much effort bringing all of my medical equipment with me. I take vacations at sea level instead, learning what I can and can't do in a day and not overdo it. LAM has changed my life in so many ways, but I won't stop fighting back. The dedicated scientists and doctors who are researching the disease won't stop either.

Judy Moore

PULMONARY FIBROSIS



“IPF requires a creative doctor, who is able to talk openly with the patient and not discourage him or her. It takes someone who is able to encourage patients to keep working at exercise and health, and getting out of bed in the morning.”

I am a third generation idiopathic pulmonary fibrosis (IPF) patient. I was first diagnosed about nine years ago when my brother said, “You sound like mom.” An X-ray suggested pulmonary fibrosis, only the second case my doctor had seen in her practice. Other tests, including a lung biopsy, confirmed the diagnosis.

My grandmother died of IPF in 1968 and my mother in 1990. Imagine my surprise that there was still no cure, not even a treatment! Since as many people die from IPF a year as they do from breast cancer, I was shocked at the lack of progress.

My first doctor was brilliant, but he did not communicate well with patients. Before my biopsy he said, “Well, what we don’t want is IPF.” After the operation he came into the room, grinned and said, “Well, you’ve got it! See you in the office in three days.” When my family and I returned, we were told, “You need to go home and get your affairs in order because this can go quickly.” He did get me to National Jewish Health, where I have an attentive, caring pulmonologist whom I can approach with any question.

Early on, I attended an IPF convention where two newly diagnosed men were sent by their doctors to learn more about the disease. After the first session one of the men collapsed; no one had told either of these men that IPF was an incurable disease with no workable treatment. But now there are some tools and some hope. In October 2014, the U.S. Food and Drug Administration approved two medications for pulmonary fibrosis. I was in one of the trials, and I am now on one of the drugs. These treatments do not stop or cure the disease, but they often seem to slow the progress. My last CT did not show any additional damage.

I work at fighting the disease in several ways. Since I am third generation patient,

PULMONARY FIBROSIS



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. It can be caused by an identifiable irritation to the lungs, but in many cases the cause is unknown, which is described as idiopathic pulmonary fibrosis (IPF). Idiopathic means there is no known cause at this time. Symptoms include:

- Dry cough or shortness of breath
- Abnormal breath sounds—crackles (like Velcro) can be heard by your health care provider when you take a deep breath
- The ends of your fingers and/or toes have changed to a club shape (called “clubbing”)

Learn more: ATS Patient Information Series. “Idiopathic Pulmonary Fibrosis (IPF)” New York, NY: American Thoracic Society 2015. thoracic.org/patients/patient-resources/resources/idiopathic-pulmonary-fibrosis.pdf

my main reason for participating in research has been for my three children and four grandchildren. National Jewish Health has discovered several genes of interest for this disease, and I assume other research labs have done the same.

Besides taking my medications, I take supplements. I have been in pulmonary rehabilitation for eight years. This has served as a support group, a place where other patients and I see one another at our best and our worst! My Pilates for Cancer Survivors group started over ten years ago, and the exercise helps support the lungs. I am active in two other support groups, and they are my go-to sources for new research and patient information. I see my respiratory doctor at least every three months. Of course, my strongest support is my faith in God.

IPF requires a creative doctor, who is able to talk openly with the patient and not discourage him or her. It takes someone who is able to encourage patients to keep working at exercise and health, and getting out of bed in the morning. I struggle with constant cough, extreme tiredness, at times the need for oxygen, breathlessness, and rib pain. One summer my cough was so severe that I damaged the cartilage between my ribs.

I'd like to tell other patients that I've heard it said that you need to GET UP, GET DRESSED, SHOW UP! Attitude affects your life and those around you each day.

Millie Camp

ACUTE RESPIRATORY DISTRESS SYNDROME (ARDS)



“Pumped full of fluids, I was so swollen that my wedding rings would not come off. My husband of 41 years began the arduous process of cutting them off. You can imagine his pain and sorrow with this difficult task.”



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.

- It is estimated that ARDS affects about 150,000 Americans per year.
- ARDS can occur in many situations, though it often affects people who are being treated for another serious illness.
- A person can develop ARDS even if he or she has not had lung disease or a lung condition in the past.

Learn more: ATS Patient Education Series. "What is Acute Respiratory Distress Syndrome?" New York, NY. 2013. thoracic.org/patients/patient-resources/resources/acute-respiratory-distress-syndrome.pdf

I'm a survivor. In 2012, I was perfectly healthy and celebrated the Christmas holidays with my children and their families (all 15 of them). My life was filled with children and singing, and my pillbox held vitamins.

My life changed on Jan. 8, 2013. I was admitted to Vanderbilt Hospital and diagnosed with idiopathic thrombocytopenic purpura, a rare blood disorder that destroys platelets. Pheresis, the prescribed treatment, did not work. So I was treated with high doses of steroids and the cancer drug Rituxan, which resulted in steroid myopathy and a depressed immune system.

Ten weeks later I was readmitted, moved to the ICU and diagnosed with pneumonia, acute respiratory distress syndrome (ARDS), and sepsis. Pumped full of fluids, I was so swollen that my wedding rings would not come off. My husband of 41 years began the arduous process of cutting them off. You can imagine his pain and sorrow with this difficult task.

ICU illness impacts the whole family. I was intubated for 17 of the 30 days I spent in critical care. I could not speak, much less sing, and lost all of my muscle. My husband and family vividly recall images and emotions of which I have little memory. One thing I do remember was watching the nurses and knowing that I had no way to communicate or move. I didn't even have the strength to press a nurse call button, but I thanked God for my life. At one point my oxygen level dropped, and my doctor said there was nothing more they could do. My family gathered around me, and my friends gathered in the waiting room praying for us all. I am so thankful for the whole team at Vanderbilt, who not only took care of me but also my family.

Millie Camp

I was moved to a step-down hospital in April where I spent five weeks and began physical therapy. I focused on one day at a time, inching forward one step at a time. I could barely roll to my side, when the physical therapist told me I was going to stand. I laughed. Nose over toes, rock forward, lock knees, and I was standing! It was May 2, 2013.

I went home in June, equipped with an oxygen tank and a portable canister. I went to outpatient therapy three times a week and exercised at home the other days. My hair was falling out and my skin peeling off, so I bought a wig, put on make-up, and had my nails done. After PT ended, I could climb a few steps and walk short distances. But I wanted more. Soon I hired a personal trainer and carried my oxygen and pulse oximeter to train. On off days I went to Curves or walked in the mall. By the end of September, I was free of oxygen. My rehab journey is ongoing. It has been two years now, and I still work out regularly. I climb stairs, sing, shop, cook, and enjoy my grandchildren, family, church, and friends.

The ICU Recovery Center was a great resource, as was the Vanderbilt Voice Center, which gave me vocal and breathing exercises I needed to improve my overall breathing capacity. In January 2014, I returned to my chorus to sing. I hope that my story pushes you to not just survive, but thrive!

Kirk Mease

SARCOIDOSIS



“This is my new normal. With a positive mindset and the strong support of family and friends, I will continue to take life one shot at a time.”

My first symptoms of sarcoidosis began in June 2000 with a bout of optic neuritis in my left eye. I was a newlywed and avid golfer, teaching the game of golf and looking forward to starting a new life with my new wife.

The morning I awoke with the optic neuritis I quickly scheduled an appointment with my optometrist, who referred me to a neuro-ophthalmologist. The MRIs, CT scans, and blood tests began. My initial diagnosis was multiple sclerosis. There was scarring in the brain and also the spine. I began daily injections of the MS drug Rebif, which sent me to the hospital in an ambulance. The University of Colorado Hospital started to seem like a second home.

I was tested for Rocky Mountain spotted fever, Lyme disease, AIDS; any and all autoimmune system disorders were an option at this point. Following cerebral angiograms and more blood work, my doctor finally said that they needed to do a brain biopsy.

I was taken off Rebif and started on prednisone. I began to gain weight and ate everything in sight. The prednisone worked to restore my eyesight, and I am forever grateful. After more tests and seeing numerous specialists, I was by exclusion diagnosed with neurosarcoidosis.

I continued to work full time. Work was my sanctuary from the disease.

The next step was to start an aggressive drug, cyclophosphamide. I was on a very high dose for nearly three years. One of the side effects was possible bladder cancer. I was already having difficulty passing urine and was on medications for it. Cystoscopies were next on the list of procedures. The bladder battle continued for years until they

SARCOIDOSIS



Sarcoidosis is an inflammatory disease that most commonly involves the lungs but can impact any organ in the body including the eyes, nervous system, liver and heart. For some patients, the disease is mild and for others it may be progressive and devastating. The cause of sarcoidosis remains unknown. However, experts suspect that sarcoidosis develops when a patient's immune system overreacts to some type of exposure—occupational, environmental or infectious—and small clumps of inflammatory cells called granulomas are formed and deposited in affected organs.

Learn more from ATS Public Advisory Roundtable member the Foundation for Sarcoidosis Research. stopsarcoidosis.org

found a benign tumor in my bladder, which was removed. Immediately I was taken off Cytoxan and started on CellCept.

I began to look for any information I could find to help me understand sarcoidosis. One night I found Shirley Holley of the Denver Sarcoidosis Awareness Support Group. Shirley happened to live a few blocks from my house. I joined the next meeting of the local support group, and we soon came up with the idea for Golf in the Darc for Sarc. The tournament raised \$11,000 in the first year, which was ultimately used by the Foundation for Sarcoidosis Research and funded the production of a neurosarcoidosis brochure. The tournament was a continued success for the next six years, raising a total of \$50,000 for the foundation. In the seventh year, the tournament was discontinued because of a life-changing event.

As my body suffered the harsh effects of the chemo drug, I developed a neurogenic bladder. The doctors tried everything they could but reached the last option—the removal of my bladder. It was the second scariest time of my life, next to brain surgery. The procedure, a cystoprostatectomy, the removal of my bladder and prostate, was performed on Oct. 12, 2012. The surgery would also take away my ability to have children.

Looking back on my experiences, I feel I've done OK. I knew I wasn't going to be a quitter. This is my new normal. With a positive mindset and the strong support of family and friends, I will continue to take life one shot at a time.

Annie Costello and Dee Wilson Costello

OXYGEN THERAPY



“The scars on my body and feet make it tricky to put on socks, and my mom gets frustrated when we change them a lot before the bus gets here. But I’m thankful to be alive.”

If you had asked me ten years ago if I thought that we had any hope of having a healthy child, my answer would have been “No way.” But thanks to God, a great medical team of pulmonologists and neonatologists, and support from the world’s finest clinicians and researchers, here we are!

During my pregnancy I developed severe HELLP (Hemolysis; Elevated Liver enzymes; Low Platelet count) syndrome, and Annie was born at 26 weeks gestation, weighing 750 grams. In the delivery room, she received assisted ventilation, surfactant, chest compressions, and resuscitation medications.

I was a neonatal doctor before Annie’s birth, but when I saw her for the first time, I fainted. I felt like all my hopes and dreams evaporated that day, and life was over. When Annie was four weeks old, she nearly died of an infection that caused a huge pneumatocele in her lung. As Annie worsened, debate raged about whether to remove the lung and wean her from ventilation. I recall the sad Christmas Eve when she was on maximal support. All I could think of was, soon everyone will be going home to their families, and my child is going to die, and I’ll be all alone. The low point was when a pediatric pulmonologist named Carolyn Kersmar came in, sat with me, cried with me, then pulled up her sleeves and said, “We’re not gonna touch that lung. We’re gonna do some creative management, get this kid off the vent, and this kid’s gonna make it.” And come Christmas morning, we were all still there! We were on the ventilator for several more months, failed six planned extubations, and spent an eternity in CPAP.

Four months later, we went home with oxygen, feeding tubes, monitors, and more questions than answers. I broke the oxygen tanks on the first night. I was desperate when

Annie Costello

OXYGEN THERAPY



Children with lung disease can have low levels of oxygen in their bodies and some need to use extra (supplemental) oxygen in order to bring their oxygen levels up to a healthier level. Children with lung diseases such as bronchopulmonary dysplasia (BPD) or cystic fibrosis (CF) may require oxygen therapy. Extra oxygen protects their bodies from the effects of low oxygen levels, helps them to function better, and allows them to stay more active.

- Oxygen is a medical treatment. Use oxygen exactly as prescribed by your child’s health care provider.
- If your child has any of these symptoms: shortness of breath, morning headache, or seems more tired or drowsy, contact your child’s health care provider.
- Oxygen used properly is safe. Do not smoke near oxygen, or keep oxygen near open flames, or other sources of heat or flames.

Learn more: ATS Patient Information Series. “Oxygen Therapy for Children” New York, NY: American Thoracic Society, 2008. thoracic.org/patients/patient-resources/resources/oxygen-therapy-children-2008.pdf

seven attempts to wean to room air failed. Although you hate the equipment, you bond to it. When we finally did get off of oxygen, I was afraid to leave home because it was too far from the tanks and monitors.

Due to severe bronchopulmonary dysplasia and steroids, Annie had several motor delays. We were terrified of germs. Then one day, after nearly two years of captivity, we went crazy and went to Disneyworld. On the plane, Annie was fascinated with the other children. She had never seen any before.

The road to today has been hard, but Annie is now a vibrant ten-year-old who loves school and life. I'd like to share a few of her words with you:

“My name is Annie. I struggle with small things, like shortness of breath when I run fast, or wheezing when I get respiratory viruses, like I had last week. Every time these things happen, my mom gets scared and relives the NICU all over again. We spend a lot of time working on motor skills, doing activities like riding horses and chasing chickens. It's paying off. I'm getting faster. The scars on my body and feet make it tricky to put on socks, and my mom gets frustrated when we change them a lot before the bus gets here. But I'm thankful to be alive. A lot of people helped save me and my family.”

Alexandra Allred

ASTHMA



“I was not going to remain silent. I thought that by accessing celebrities, legislators, and high-profile lawyers, we could turn this toxic train around and really help people.”

Who knew that asthma would allow me to testify before the Senate, go to the White House, and meet Barack Obama? Or meet Erin Brokovich, write a book, and now a screenplay? Before 2001, I never even thought about asthma. I was was a national champion on the U.S. women's bobsledding team, and my children, Kerri, Katie, and Tommy, were with me for most of my training.

When I retired, we moved to Midlothian, Texas, the “cement capital” of the state. That little town took in hazardous waste from seven other states, and in 2004 nearly 400 tons of various kinds of toxic pollutants were released into Midlothian's air. At the time, industry was legally allowed to call the burning of hazardous waste a “resource recovery” practice. Two months after settling into our new home, Tommy couldn't breathe, but we couldn't figure out why.

Because Midlothian was a small, blue-collar town, no one would talk to us. Only years later, after my son's school was mentioned in a 2008 USA Today special report as being in the upper one percent of the most toxic elementary schools in the nation did school nurses, teachers, and parents come forward. Not only did they tell me that they know what was causing Tommy to be so sick, but that many other children have died from or are suffering from upper respiratory diseases, rare tumors, cancers, and birth defects.

I was not going to remain silent. Having lived in the Olympic Training Center, traveled on the World Cup, been around the HBO Sports and ESPN crowd, and written for Sports Illustrated, I had some fairly good contacts and used them. I thought that by accessing celebrities, legislators, and high-profile lawyers, we could turn this toxic

ASTHMA



Asthma is a chronic disease that swells the airways, or breathing tubes, of your lungs. This swelling (inflammation) causes the airways to make thick, sticky secretions called mucus, and it causes the muscles in and around your airways to get very tight or constrict, which makes it very hard for you to get air into and out of your lungs.

Asthma can be caused by genetics, allergies, respiratory infections, and irritants such as:

- Molds and dust
- Exhaust fumes from vehicles
- Chemicals in garden sprays
- Strong odors from paint, perfumes, colognes, hair spray, deodorants, and cleaning products
- Tobacco smoke
- Weather changes
- Stress or exercise
- Medications
- Sulfites in foods such as dried fruits, wine, and beer

Learn more: ATS Patient Information Series. "What is Asthma?" New York, NY: American Thoracic Society, 2013. patients.thoracic.org

train around and really help people. When I brought Erin Brokovich to town, I was threatened.

In two months, Tommy was hospitalized six times. One time when he turned purple and stopped breathing, and I was flying down the back roads to the hospital, he asked me, “Could a little boy die of this?” I screamed at him not to be so stupid because I could not let him think—not even for a second—that he could. A few months later, I testified before the director of the Environmental Protection Agency. He commented about it “just” being asthma and asked if I couldn’t “just” treat it more aggressively. I replied about “just” putting my foot up his arse and said he could “just” remove it when he felt able. I went home, and two days later read in the Dallas Morning News that limits for mercury levels increased. That’s when I began writing the book, *Damaged Goods*, a fictional account of life in a cement town.

“Just” asthma changed our entire lives. Tommy is much stronger now, but we don’t do outside sports. We had to move, and my kids changed schools. Before relocating, my oldest daughter was diagnosed with asthma, and my middle one had a tumor removed due to sinusitis. We used to be a big soccer family. In the Midlothian soccer fields, you could forget your purse or cell phone and walk back to find them sitting right where you left them. But if you left an inhaler, consider it gone! So many families would not or could not see a doctor, yet they knew enough to steal inhalers whenever possible. Although frustrating, I never once blamed them. I figured they were victims in all this, too.

Bebe Pinter

PULMONARY FIBROSIS



“Comparative research has been used successfully in the study of certain cancers and diseases. Since Westies have naturally occurring PF, they may well be a model to study the disease.”

I believe comparative research is the future of medicine.

Research that compares human disease to naturally occurring disease in animals—in particular dogs—is moving science forward faster and more successfully than ever imagined.

My mother and my West Highland Terrier, Rowdy, both lost their lives to the same deadly disease: pulmonary fibrosis (PF). I've had my heart broken by the disease, watching my loved ones die, feeling helpless that I could do nothing, and being frustrated with the lack of treatments.

I remember my mother, Florence, as a beautiful blonde model during my childhood. She was a mother whom every other child envied. She served as president of the PTA, enjoyed ballroom dancing, and loved me unconditionally. I remember her having hay fever and then asthma as she got older. My father was a heavy smoker, and he died of lung cancer seven years before my mother died of PF.

As the disease progressed, my mother's lungs became scarred. She had to quit dancing, and later even walking for any length of time.

I remember the violent coughing and hearing her lungs crackling. Her doctors treated her with large doses of prednisone, and she lived out her days on supplemental oxygen. She went to the hospital many times and overtime lost four inches in height from osteoporosis, a side-effect of the drug. She died just before Thanksgiving in 1986 at 71.

In 1988, Rowdy came into my life. When Rowdy was nearly 11 years old, I noticed he was slowing down. He panted whenever he walked, and he stopped playing with his toys. One day I took him to his veterinarian who told me nothing could be done. I never had

Bebe Pinter

PULMONARY FIBROSIS



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. It can be caused by an identifiable irritation to the lungs, but in many cases the cause is unknown, which is described as idiopathic pulmonary fibrosis (IPF). Idiopathic means there is no known cause at this time. Symptoms include:

- Dry cough or shortness of breath
- Abnormal breath sounds—crackles (like Velcro) can be heard by your health care provider when you take a deep breath
- The ends of your fingers and/or toes have changed to a club shape (called “clubbing”)

Learn more: ATS Patient Information Series. “Idiopathic Pulmonary Fibrosis (IPF)” New York, NY: American Thoracic Society 2015. thoracic.org/patients/patient-resources/resources/idiopathic-pulmonary-fibrosis.pdf

an actual diagnosis so I never heard the words pulmonary fibrosis. Rowdy died that night at home.

I am here today because of my mother and Rowdy.

My hope lies in the hands of researchers and scientists. We know that humans and animals share some of the same diseases. Comparative research has been used successfully in the study of certain cancers and diseases. Since Westies have naturally occurring PF, they may well be a model to study the disease.

I am president of the Westie Foundation of America, Inc., which supports research to improve the health of the breed as well as other animals, including humans. In 2007, the WFA held its first conference Looking at Lung Fibrosis in Canines and Humans. Results from this meeting were published in the Annals of the American Thoracic Society.

The WFA's follow-up conference, Fibrosis Across Species, held April 2014 in Louisville, Kentucky, joined clinician investigators, researchers, veterinary doctors, pathologists, geneticists, and patient advocates to discuss the state of knowledge in lung fibrosis in humans and domestic animals. We look forward to incorporating results into white papers and submitting them to medical and veterinary journals. Like the two new drugs recently approved to treat PF, this is only the beginning.

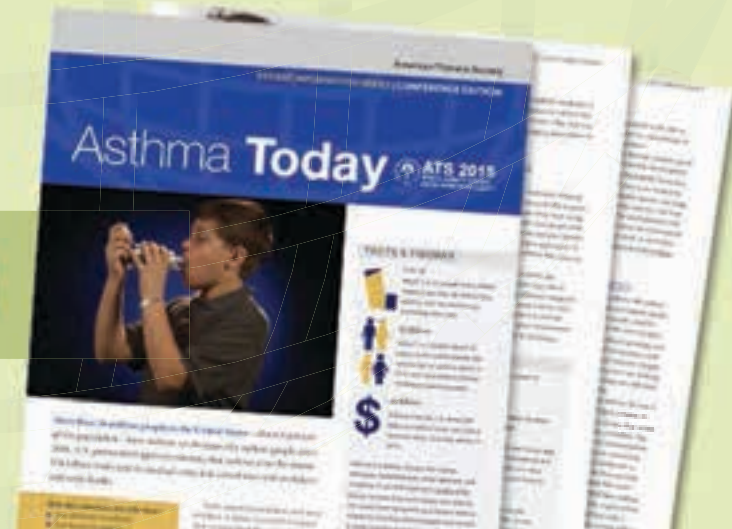
New Patient Resource: Asthma Today

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Featuring highlights from ATS 2015

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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/.



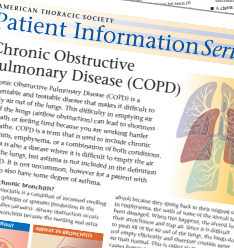
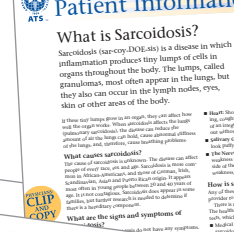
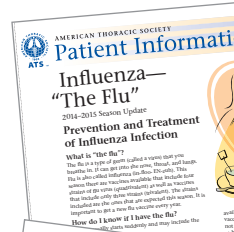
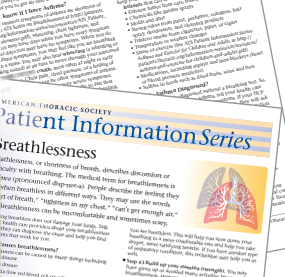
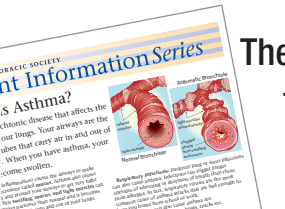
Get the Facts! ATS Patient Information Series

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 patients.thoracic.org.



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 will be 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.



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Previous Voices

Patients and speakers featured in *ATS Patient Voices 3*.

“To this day, I always tell doctors: ‘A patient’s will to live is stronger than a doctor’s opinion. Don’t give up on someone who has not given up on herself.’”

–Heather Snyder
Pulmonary Fibrosis

“Taking critically ill patients as autonomous agents—part of the ‘decision-making team’—fails to respect the precarious position such patients find themselves in.”

–Cheryl Misak, *DPhil*
ICU Delirium and Cognitive Impairment

“My daughter had a great doctor with a great nurse. Involving the patient and caregiver as active participants is key.”

–Donna Bryson
Asthma

“My future is the brightest it has ever been, and I am beyond excited to see where we are heading.”

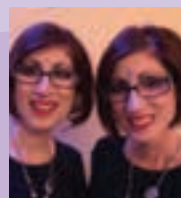
–Emily Schaller
Cystic Fibrosis

“My sepsis attacks go something like this: I wake up to a normal day and the attacks can come anywhere, anytime. All of a sudden I start to shake all over, my heart rate goes crazy, my blood pressure plunges, then the fever and dry heaves set in.”

–Sandra Rock
IPF and Sepsis

Visit bit.ly/PatientVoices3.

ATS Patient Voices 4



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A publication from the American Thoracic Society Public Advisory Roundtable.