

ATS Patient Voices 6

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, the ATS PAR has been a core component of the Society and a mutually beneficial partnership wherein organizations that represent persons affected by respiratory diseases, illnesses requiring critical care, and sleep-related disorders collaborate with the ATS to advance their shared educational, research, patient care, and advocacy goals.

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



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PULMONARY • CRITICAL CARE • SLEEP

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Disclaimer

This publication includes stories of patients with lung disease as told to the American Thoracic Society by the patients or their representatives. The views expressed in these stories do not reflect those of 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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Foreword

The ATS Public Advisory Roundtable (PAR) bridges the patient's perspective to the Society and provides the ATS Board of Directors with strategic guidance to keep patients and families as a central focus of all ATS activities and programs. Through PAR, we enable unparalleled synergy with patients—providing support, shaping policy, and stimulating research—as a team.

Since 2001, PAR has represented the patient voice of the Society and has helped to bring patients and families to the forefront. The ATS and PAR's patient advocacy groups collaborate on issues of disease awareness, public education, advocacy, and research. Now everyone, including a patient, is able to participate in the activities of the Society and join the ATS as a member.

Perhaps most importantly, PAR facilitates patient programs, such as the Meet-the-Expert patient and family forum, PAR Symposium, and several dozen scientific sessions that feature patient speakers, at the annual ATS International Conference.

Patient Voices highlights the stories of patients who have presented at our past conferences. You will hear stories of pulmonary disorders such as COPD, asthma, ARDS, idiopathic pulmonary fibrosis, pulmonary hypertension, sepsis, pneumonia, lung cancer, sleep disorders, and others.

Many patients have struggled all their lives with disease, and often times they experience life-threatening conditions. The vulnerability of their narratives helps shed light on pulmonary diseases and inspires the millions grappling with lung disease all over the world.

We look forward to continued inclusion of the patient and family perspective in our work. We empower patients and their stories to be told, and we hope that this booklet is valuable to clinicians and scientists seeking their viewpoints.

Thank you to fearless voices who make this sixth edition possible. Your contributions are needed at the bench and the bedside, and together we can achieve our fiercest dreams of treatments, therapies, and cures.



A handwritten signature in black ink that reads "Marc Moss".

Marc Moss, MD
ATS President
2017-2018



A handwritten signature in black ink that reads "Steve Crane".

Steve Crane, PhD, MPH
ATS Executive Director

Introduction

In 2001, vision turned into reality as the American Thoracic Society leadership formally partnered with patients and their families. This 15-year partnership is known as the ATS Public Advisory Roundtable (PAR), which continues to be one of the only patient-centered groups woven into the fabric of a medical membership association. PAR is a central component of the ATS.

At the ATS 2017 International Conference, Washington, D.C., in May, some of the best minds in pulmonary, critical care, and sleep medicine came together. Among them were 14 well-informed patients who ascended the podium to share engaging, disease-related experiences.

As in years past, their goal was to put a “face” to their diagnosis. As a result, respiratory professionals including physicians, clinicians, scientists, and researchers, received an intimate look at the impact of disease on patients’ lives.

This ATS PAR Patient Voices booklet was created to expand the reach of these stories, these stories, and in so doing we aim to create a more powerful and unified advocacy community. We trust that this leads to an outpouring of advances and ultimately—improved patient outcomes.

It is an honor and privilege for the ATS PAR to embody the “patient voice” of the Society.



Kerri Connolly,
Chair, ATS-PAR

Alex Flipse

OBSTRUCTIVE
SLEEP APNEA



“How could sleep or lack of quality sleep be the reason why my heart wasn’t working properly? This scared me enough to get more studies done.”

Alex Flipse...

In 1996 soon after I delivered my third daughter I started having strange symptoms. Shortness of breath, palpitations, and extreme exhaustion plagued me day and night.

For three years while I was misdiagnosed I kept being told: it was all in my head, I was being too lazy, and that I should stop playing around. Then I was told I have a terminal progressive and very rare condition called primary pulmonary hypertension. I was given two years to live.

Soon after, I was sent to a specialist for evaluation in a sleep study. What a bizarre test! Tubing everywhere, on my head and face, with straps around my chest, wires taped down to me all over. When they said “Go to sleep!” it was almost impossible to get comfortable! Yet after some time of praying for sleep I was actually able to. Moments later, it felt, I was woken up.

Eventually, the technician said that I had severe obstructive sleep apnea. Finally, my condition had a name, it was not all in my head!

I don’t remember the number of episodes I had per hour, but I remember a feeling of shock. I was asked to return for a second study to be fitted for a CPAP mask. I made the appointment, but I never went.

I couldn’t imagine lying in bed next to my spouse with a contraption over my face. I thought, I was already attached to a pump delivering sodium, a life-saving medication for my pulmonary hypertension that had to be surgically connected with the very tip of the catheter inside my heart. I felt ugly, unlovable, and alien! There was no way I was going to add something else to cover my face.

Ten years later in 2008, I went through a painful divorce that I thought I’d never live through. I moved in with my sister in Washington, D.C., and I started seeing a different doctor at Johns Hopkins Hospital.

After performing a right heart catheterization on me, my doctor informed me that my

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

- 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. “What is Obstructive Sleep Apnea in Adults?” New York, NY. www.thoracic.org/patients/patient-resources/resources/obstructive-sleep-apnea-in-adults.pdf

Alex Flipse...

cardiac output was extremely low. He believed my sleep apnea, which had worsened over the years, was the cause.

Again, I was shocked. How could sleep or lack of quality sleep be the reason why my heart wasn't working properly? This scared me enough to get more studies done. Soon, a rep from a respiratory therapy company arrived at my house to drop off my new CPAP machine, show me how to use it, and how to wear the mask.

I wore the mask every night, but I'd wake up to go to the bathroom and find the mask either on the floor or on the bed beside me. I must have yanked it off in my sleep. This happened without fail for nearly three weeks. Then one day I woke up wearing the mask. Now I have been wearing the CPAP mask during the night, as well as any time I need a nap, for nearly 10 years!

Alex Flipse was a patient speaker at the ATS 2017 International Conference in Washington, D.C.

Charday Eury

ASTHMA



“It’s heartbreaking when you’re a parent and the hurt that your child suffers from asthma is out of your control.”

Charday Eury...

My name is Charday Eury. I am the single mom of five beautiful children growing up in the busy District of Columbia. My son, Haven, is a 10-year-old well-mannered boy with severe asthma. Haven first presented with asthma-like symptoms at about five to six months of age. At eight months old he was officially diagnosed with asthma. From that moment, our lives changed drastically.

Haven and I would go to the emergency room or primary care doctor for sick visits at least once a week, sometimes more than that. At this point I had become the unemployed, welfare benefit recipient, college dropout that I had promised myself never to be! I went through a short bout of depression before being referred to the Asthma IMPACT DC Clinic at Children's National Medical Center.

It was there where I would learn about my son's triggers and how to properly clean his inhalers. I learned how and when to give him a controller medication versus a rescue medication. His asthma symptoms would improve and then come back with a vengeance every time.

Sadly, today, Haven's asthma is still a huge problem! This time around it's his schooling and social life that are being affected by the constant inflammation in his lungs. I've watched asthma steal my son's dreams twice this year. Once was when he earned his first "F," and the second time was when he wasn't cleared to play sports.

It's heartbreaking when you're a parent and the hurt that your child suffers is out of your control. Asthma not only affects my son's way of breathing, it affects his mental and physical health!

I hope that someday researchers will come up with a better way to control asthma, to lessen the side effects of medication, and better manage the condition itself. I hope that someday children with asthma will be able to enjoy their childhoods without any restrictions.

I'm hoping my son lives to see this day happen.

ASTHMA



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

Frequent lung or sinus infections can cause asthma. Irritants that can also cause asthma are:

- Exhaust fumes from cars, buses, trucks etc.
- Chemicals like garden sprays
- Molds and dust
- Strong odors from paint, perfumes, colognes, hair spray, deodorants, and cleaning products
- Tobacco smoke from cigarettes, pipes, or cigars
- Temperature or weather changes
- Stress or exercise
- Medications, including aspirin and beta-blockers (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

Christa Warden

NONTUBERCULOUS
MYCOBACTERIA



*“We are so much more
than a set of lungs.”*

Christa Warden...

I'm Christa Warden, age 69, and I have nontuberculous mycobacteria (NTM). I am a mother of three and a grandmother. I was a military wife, educator, school counselor, and a middle school administrator for 28 years. My professional goal was to retire after 30 years. Disappointingly, my career ended abruptly after a two-year series of repeated and debilitating bouts of pneumonia and worsening asthma.

My recurring respiratory infections fell into a cycle of a new infection every three to four months. I rarely saw my primary care physician, as my pneumonia would begin abruptly. It still does. Urgent care through my medical group was referred to the nurse practitioner or one of the physician assistants. In retrospect, I feel that this lack of continuity of care, and the lack of knowledge of NTM, led to missing the pattern of my infections or exploring their cause.

In 2009, I had a CT scan indicating bronchiectasis. I had no idea what this diagnosis would mean. Few pulmonary physicians were familiar with the impact this would have on my lungs and health. I felt that I had to be my own advocate and find a physician willing to explore the cause of my repeated infections.

My life has been and continues to be highly impacted by NTM. I have life-changing fatigue and limited stamina. I even break into a sweat doing tai chi. I live what I call an “every other day” life. When I undertake a physical activity, social activity, or even the caring of my grandchildren, I must spend the following day recovering.

My forced retirement is not what I dreamed about. I hesitate to make travel plans. My family and friends understand that making social plans too far in advance is based on the fact that I cannot predict how I will feel that day. My experience has been that if I try to “push through” the fatigue and ignore my body, I can become seriously ill requiring hospitalization and IV antibiotics.

One night recently, I was tucking my precocious nine-year-old granddaughter into bed and, she asked if I would be alive in 20 years. I was caught off guard. I reassured her that I

NONTUBERCULOUS MYCOBACTERIA



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:

- cough with sputum production
- tiredness (fatigue)
- fever
- coughing up blood (hemoptysis)—a late sign of illness
- unplanned weight loss

Learn more: ATS Patient Education Series. “What is Nontuberculous Mycobacteria (NTM) Disease?” New York, NY. www.thoracic.org/patients/patient-resources/resources/ntm.pdf

Christa Warden...

was doing everything possible to be strong and healthy. Her question went straight to my heart. The truth is, I do worry, “Will the next pneumonia or infection be the end of me?”

The unpredictable nature of my illness fills me with sadness. I have always been an optimistic and social individual. Now I struggle with a big secret, the anxiety and depression surrounding my chronic illness. I fear that even with doing everything suggested, it might not be enough.

I love my family and friends, and I want to do some of the things I said I would do when I retired...I have places to go and people to see! I don't want to wait. There might not be time later.

Regaining some control through action lessens my anxiety. Managing my disease requires time and consistency with medications, inhalers, and general lung hygiene. It also requires getting an hour of strenuous physical activity, building strength, and doing cardio every day. I am currently participating in a great pulmonary rehabilitation program three times a week. I take tai chi on alternate days. Managing NTM is my part-time job.

After a long and bumpy search, I have been extraordinarily fortunate to have found my current physician at Georgetown University Hospital. In addition to the kind and attentive care she provides, she participates in drug trials. When I qualified to enter a trial, I felt hopeful for the first time. I felt the possibility that these trials might directly impact me. Of course, I prayed that I would not get the placebo. It turns out that I received the actual medication, and there was a momentary break in my cycle of flare-ups.

I ask that physicians and researchers please continue their research, and participate in drug trials and education programs to increase knowledge regarding NTM. As a patient, I would encourage them to “be present.” Look for patterns. Look at the whole patient. We are so much more than a set of lungs.

Christa Warden was a patient speaker at the ATS 2017 International Conference in Washington, D.C..

Christine Lentz

SEPSIS/CRITICAL CARE



“My mom asked if I wanted to keep fighting or let go. I don’t remember this, but I said ‘I choose life.’”

On Dec. 27, 2013, with a high fever and feeling very ill, I went to the emergency room.

When I entered the ER, they drew blood. The ER doctor did an examination and determined, like all the other patients in the ER that night, I had the flu. I explained that seven weeks prior I had abdominal surgery, shared the details of my surgery and my complications post-op. But this information did not seem to be taken into consideration. I insisted on a flu test to confirm the doctor's diagnosis, and it came back positive. Unfortunately, the diagnosis masked the other condition I had at the time, which was sepsis. A more diligent review of my history should have resulted in a blood test that would have revealed sepsis.

I left the ER with a packet on how to care for the flu, not knowing my body was septic. Over the next three days, thinking I was recovering from the flu, I was actually going into septic shock.

Early on Dec. 31, suffering from unbearable leg pain, my husband took me to the ER for the second time. This time, however, after they drew blood and tested it, the results showed significant bacterial growth. I was admitted to the hospital for further evaluation. During this period, my blood pressure dropped and my heart rate rose dramatically. I was rushed to the ICU and put on life support.

For the next 16 days, the doctors in the ICU worked diligently to save my life. I don't remember anything from those days. It was determined I was in septic shock from a Strep-A bacterial blood infection and diagnosed with toxic shock syndrome. Unfortunately, the result of using presser drugs for a prolonged period of time is necrosis of the extremities.

On Jan. 17, I was transferred to Presbyterian/St. Luke Hospital on the advice of the infectious disease specialist. At the time I did not know the real condition of my limbs. Within several days of being in the ICU at PSL, my family was informed that both hands and both feet needed to be amputated. Although I was mostly conscious during this time, I was, in fact, unaware of what was happening. My mom asked if I wanted to keep fighting or let go. I don't remember this, but I said "I choose life."



Sepsis is a severe and toxic response to infection and inflammation. Sepsis occurs when your body is trying to fight infection and that fight is having negative (bad) effects on your body. The problems that develop with sepsis can affect multiple organs in the body. Sepsis can be life-threatening and requires prompt and skilled medical care.

Common signs and symptoms include:

- Shivering, fever, or chills
- Pain and discomfort: usually aching all over the body
- Pale, clammy skin, that can change colors
- Difficulty breathing
- Feeling sleepy, "appearing like you are drunk," agitated, or confused
- A feeling of dread that "I'm going to die"

Learn more: ATS Patient Education Series. "What is Sepsis?" New York, NY. www.thoracic.org/patients/patient-resources/fact-sheets-az.php

Christine Lentz...

One leg was amputated first. It was still believed I was not going to survive much longer, and surviving this surgery was the test. To the amazement of all, not only did I survive, I started getting better!

The next three amputation surgeries were completed, and on Feb. 3, I was transferred to an acute care hospital. This would be my recovery site for the next five months.

During the first three months in acute care, I was not very coherent due to the pain and medications. I couldn't eat or drink anything for weeks. My protein levels were dangerously low, and my weight dropped down to 70 pounds. I also lost all of my hair. My husband scaled back at work, with the support of his boss, to be by my side during late afternoons and evenings for much of my recovery. My parents moved to a nearby hotel so they could remain with me constantly for the first month. I was extremely lucky to have so much support. I was in the hospital for seven months, and I was rarely without family by my bedside. I emphasize this, because I believe this was key to my successful recovery.

I was transferred to a rehabilitation hospital for the final six weeks of my recovery, where I learned to use my prosthetics and perform the activities of daily living.

Finally, on Aug. 1, 2014, I returned home.

During my many months in the hospital, it was surprising how far reaching my sepsis diagnosis was. There were my three teenaged boys, and their mom was absent for seven months. Rumors surrounded us on social media and spread in the hallways of school.

My life at home involved many changes. We have a den on the main level of our house with an attached full bathroom. It has since become my bedroom. I've knocked holes in the walls, pulled down railings, scratched every piece of wood, you name it.

Christine Lentz...

I also got my driver's license, but what a process. I had to jump through so many hoops, but it was worth it. I had modifications done to my car, and the biggest help is the driving ring. Really nothing else was needed because I can "feel" my pedals.

However, life as a quad amputee is not easy. My energy level has been zapped. I now get "complex migraines." Most of the time the medication will keep them from becoming severe, but a few times they have become so violent they mimic the symptoms of a stroke or seizure. The worst symptom I deal with is losing the ability to speak. However, this is becoming less frequent.

I was a very athletic person, and my leisure activities always involved some kind of sport. When I became disabled, I lost a big part of my identity and ability to keep myself entertained, as well as a big way to connect to my boys.

Now I am keeping myself busy with volunteering. I work with organizations involved in raising sepsis awareness. I also work with many groups, in various capacities, involving limb loss. My goal is to do more public speaking and someday—to get back on the ski slopes.

Christine Lentz was a patient speaker at the ATS 2017 International Conference in Washington, D.C.

Sarah Collins

ACUTE RESPIRATORY DISTRESS SYNDROME



“ARDS is vicious and fast moving. Setback after setback occurred, and my loved ones were glued to the monitors and hardly slept through the night in fear of a phone call with bad news.”

Sarah Collins...

Imagine waking up in a hospital room, unable to move or speak. Then you find out two months have passed.

My journey on the roller coaster of acute respiratory distress syndrome (ARDS) began when I was intubated after contracting pneumonia due to swine flu (H1N1). I had no idea that when I went to the ER—with what I thought was just a bad cough—that I would be starting the fight of my life.

Forty-eight hours after I was admitted to the hospital, I was transferred to the ICU of a larger local hospital, intubated and placed into a medically-induced coma. My husband was told that I likely wouldn't make it through the day. After exhausting all local options, I was survival-flown to the University of Michigan, where they had more options to treat my condition. My husband and his parents and brother moved to Michigan, and our five children were sent to live with other family members, while doctors worked diligently to save me.

ARDS is vicious and fast moving. Setback after setback occurred, and my loved ones were glued to the monitors and hardly slept through the night in fear of a phone call with bad news. Kidney failure, multiple cardiac arrests, lack of oxygen to the brain, and secondary infections took a toll on me. It was one step forward, two steps back for a long time. But my family never gave up hope.

After two months in a coma and four months on a ventilator, I began inpatient rehab. I had to learn to walk, feed and dress myself, and regain the strength that I lost in my battle to stay alive. I finally went home, and after a year that included outpatient cardiopulmonary rehab, I weaned off supplemental oxygen.

In spite of lingering cognitive issues, decreased lung function, and recurring pneumonia, I am so lucky to be alive. I am a survivor. I am a true miracle and feel most blessed when I am able to provide support for patients going through similar situations. My take away from all this is: "Slow and steady wins the race."

Never give up!

Sarah Collins was a patient speaker at the ATS 2017 International Conference in Washington, D.C.

ACUTE RESPIRATORY DISTRESS SYNDROME



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

Kathleen Fennig

LUNG CANCER



“Things in the lung cancer world have come a long way... Besides established lung cancer screening programs, we now have molecular testing, targeted therapies, and many more clinical trials.”

Kathleen Fennig...

I am a 68 year-old wife, mother, grandmother, and registered nurse. I am also a lung cancer survivor because I recognized my risk factors and requested a screening.

My personal relationship with lung cancer began six and a half years ago, before most institutions had established lung cancer navigators and screening programs. So, when I was diagnosed with lung cancer, it was typically found in one of three ways: by luck, by diagnosis after symptoms developed and often too late to save the life of the individual, or by the paranoia and perseverance of someone who felt they were at risk for developing the disease.

What I feel is unique about my experience is that despite all my medical knowledge, my advantages and connections over the 40-plus years working as a nurse at a large health care facility, I still found my lung cancer diagnosis and road to wellness a difficult process to navigate through.

My journey began indirectly as a lung cancer caregiver in July 2010. I had a dear, elderly, cousin who was diagnosed with metastatic lung cancer. He was never a smoker. I dislike differentiating based on smoking history, but it does make a difference in my story. Sadly, my dear Oscar died that November.

I became profoundly reflective. I thought about how Oscar fell victim to a disease that I largely associated with smoking and I began to think that, perhaps, I was at an even greater risk. In addition to 30-plus years of smoking, I now knew I also had a genetic predisposition.

I have always been an assertive individual. In December 2010, armed with my fears, I made the call to my primary care physician's office to request a screening chest CT.

Keep in mind, this was a couple years before the National Lung Screening Trials results were published and I was unaware of the 2004 recommendations from the U.S. Preventative Task Force regarding lung cancer screenings. The nurse asked me if I had any symptoms and I truthfully answered "no." She told me there was no way the doctor would order a chest

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. The type of cancer is based on how it looks under the microscope. Non-small cell lung cancer (NSCLC) includes the following types; 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 which should alert you to see your health care provider are:

- 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*

Kathleen Fennig...

CT based on my fears. My request was denied and I was offered, instead, a chest X-ray. I accepted, even though I had heard that an X-ray was of little value in diagnosing early stage lung cancer.

Fortunately for me, the radiologist was a rock star and reported a potentially “suspicious area” in the upper lobe of my right lung and recommended an oblique. This time, however, I was not settling. I insisted on a chest CT.

The chest CT was performed January 2011, revealing two small nodules: 6mm in the middle right lobe and 8mm in the upper right lobe. I was assured not to worry, that everyone in Ohio has lung nodules and since they were too small to biopsy and I looked great, it was probably nothing. I was told I could be rescanned in three to six months. I chose the three-month route.

On April 18, 2011 a repeat CT showed that the 6mm nodule had stayed the same, but the upper 8mm nodule was now 10mm. A PET scan was ordered, and a hot spot showed up in the upper right lobe. I was sent to a pulmonologist who ordered a biopsy, and on June 2 the interventional radiologist performed the procedure indicating that I had non-small cell adenocarcinoma of the lung.

I kept the news to my family and a few close friends and co-workers. I was ashamed and did not want to be judged. I knew the first questions people would ask would be about my smoking history.

I read and re-read all the depressing statistics on the Internet. Sixteen percent: five-year survival. I felt defeated, and that was not typical for me. Before this, I had always been upbeat. But I never had to face such devastation. I had so many negative feelings...guilt, regret, remorse, and most of all, extreme sadness.

Kathleen Fennig...

I had a traditional thoracotomy, upper right lobectomy, and partial right middle lobectomy. Because of early detection, there was no lymph node involvement; only two primary tumors. One was well-differentiated and the other moderately differentiated. I was staged at 1A and told there was a 33 percent chance that it would return.

Here I am, over six years later and I consider myself to be the luckiest woman alive. I am older, wiser, and a whole lot stronger than I ever thought I would need to be.

Things in the lung cancer world have come a long way since I first set foot on this road. Besides established lung cancer screening programs, we now have molecular testing, targeted therapies, and many more clinical trials. Most large health care organizations have lung cancer navigators. My wish is to see more patients diagnosed at an earlier stage of lung cancer when the chances of cure and survival are greatest. And with the rise of lung cancer screening programs, I know there will be many more like me.

The best advice I can give is that you need to be your own health care advocate. Understand your risk factors, and take advantage of screening programs. Research is paving the way to brighter futures for lung cancer patients, but personal awareness is key.

Cancer changes everything. For me, I love a little harder, forgive a little easier, hug a little longer, and cherish moments more deeply.

Kathleen Fennig was a patient speaker at the ATS 2017 International Conference in Washington, D.C.

Katherine Anne Lewis

PULMONARY ARTERIAL HYPERTENSION



“I feel strong, I continue to take my medications, I eat wisely, exercise frequently, and am not afraid to take on life’s challenges. In the past three years I have traveled internationally, my portable oxygen concentrator in tow.”

Katherine Anne Lewis...

In 2009 I weighed 293 pounds, did not exercise, thought six hours of sleep was a good night's rest, and shouldered the stress of being the director of student services for a large school system. For most of my adult life I struggled with “bronchial problems,” but the frequency of my breathing difficulties and shortness of breath increased. I could not walk from my office to the opposite end of the building without stopping to catch my breath, and climbing stairs was virtually impossible. Then my ankles started swelling, and I was constantly fatigued. My son and my sister, two people who know me best, pressed me to see my physician.

I knew that my primary care physician would once again say that I needed to lose weight, exercise, and sleep more. But that was not the case this time. She ordered tests. I still believed that nothing much was wrong.

Many tests, appointments, and doctors later I was diagnosed with pulmonary arterial hypertension, prescribed one medication, and told to lose weight. I returned home from that appointment and read everything I could find about PAH. Articles suggested that I should adjust to my “new normal,” would continue to worsen, and had only two to four years to live.

Subsequent appointments taught me that most of what I had read was outdated. I don't give up easily, and I began to see myself as a partner in my health care, willing to do whatever I could to maintain quality of life—and maintain life itself.

The nurse coordinator and pulmonologist specializing in PH recommended a pulmonary rehab study through the NIH. For 10 weeks I drove to the NIH during rush hour and worked with a physical therapist and exercise specialist, walking on a treadmill and participating in educational sessions. Before the study ended I joined a local gym; I was not going to sacrifice the progress I had made.

I have exercised at the gym regularly, and I now also work with a fitness coach who specializes in clients with lung diseases.

PULMONARY ARTERIAL HYPERTENSION



The pressure that the right side of your heart is pumping against is called your pulmonary pressure. When this pressure is too high, it is called pulmonary hypertension (PH).

Pulmonary Arterial Hypertension (PAH) used to be called “primary pulmonary hypertension”. PAH occurs when the blood vessels in the lung are directly diseased (unlike the other forms of PH where the increased pressure is due to another reason like chronic lung or heart disease) and become thick and narrow. The pressure on the right side of your heart increases as it tries to pump blood through these narrow blood vessels. In PAH the pressure that the right side of your heart is pumping against is usually a much higher pressure than in patients who have PH from other causes.

*Learn more: ATS Patient Education Series.
“Pulmonary Arterial Hypertension” New York, NY. www.thoracic.org/patients/patient-resources/resources/pulmonary-hypertension.pdf*

Katherine Anne Lewis...

When I started having GI difficulties, I learned of a rheumatologist, who understood PH and might be able to help. She explained that I also had limited systemic scleroderma, helped to control my esophageal and GI issues, and continues to monitor my condition.

I'm participating in an NIH natural history study that collects data about individuals with PH. I'm hopeful it may lead to the further development of therapies, or even a cure.

Currently, I weigh 136 pounds. I feel strong, I continue to take my medications, I eat wisely, exercise frequently, and am not afraid to take on life's challenges. In the past three years I have traveled internationally, my portable oxygen concentrator in tow.

PH medicines have changed along the way. I am grateful for the work that has resulted in my new medications, and for my health care team who stays current and helps design solutions that work best for my body.

Katherine Anne Lewis was a patient speaker at the ATS 2017 International Conference in Washington, D.C.

Mary Stojic

LYMPHANGIOLEIOMYOMATOSIS (LAM)



“I am active in advocacy, participate in regular visits to the NIH, and I volunteer... I care about giving other LAM patients hope, especially the young women starting their families.”

In 1985, at age 21, I suffered a spontaneous pneumothorax of my right lung, which required pleurodesis. I remember the thoracic surgeon saying that he performed aggressive mechanical pleurodesis and covered everything he could reach, removing cysts from the edge of my lung to prevent future problems. Many years and much research later, it is now known that cysts or blebs should not be removed for patients with LAM because we need the good lung surrounding the cysts for as long as possible.

This aside, even without a LAM diagnosis, the aggressive treatment I received granted me an incredible quality of life. I studied and traveled in Europe, married and had three children. Other than a small “nuisance” pneumothorax of only 10 percent during my second pregnancy and chronic bronchitis, I did well, until 1998. The flu vaccine was not effective that year, and six weeks after a minor flu, my other lung collapsed.

After a month of waiting for it to inflate, I returned to the doctor ready to demand surgery so that I could recover and resume my life. I was surprised to learn that my lung was fully collapsed. After the pleurodesis on the left lung, I anticipated I would resume my normal activities with no further problems. After two more bouts of bronchitis in the next six months, the pulmonologist requested a CT in October 1998.

While awaiting the results, I went to the library to do research online, read about LAM in the Rare Disease and Disorder Book and found the contact information for the LAM Foundation, which led to a doctor at the NIH and the beginning of my quest for a cure.

With the diagnosis came overwhelming fears for my three daughters, ages seven, six, and four. Although it seemed apparent I did not have the extremely fast type, as I had managed symptoms for a minimum of 13 years, my fear was that things would change. I could stumble upon a trigger, and my children would not have their mother. Since LAM seemed to affect only women, I was concerned that my daughters would inherit the disease. Later when we learned about tuberous sclerosis complex, more fears emerged.



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

Mary Stojic...

I am now 53. My daughters have all graduated from college. My desire is to be here for their weddings and to hold their children.

Trying to stay well while raising active young children, with the endless ups and down of my health, was a challenge! In an effort to slow LAM, I took medroxyprogesterone for a year before the research clearly showed it was not effective. My husband deserves an award for seeing me through this trying phase.

I constantly fear lung collapse, and with every chest discomfort I ask myself, “Is it a pneumo or just a chest twinge? Is it necessary to visit the doctor or go to the hospital?”

I have some assurance that the pleurodesis will not allow a tension pneumo. Yet repeated “nuisance” pneumos (those I define as causing disruption to the family routine and requiring rest, but do not require medical intervention) have occurred on each side. In 2009 and 2010, after many disrupted family plans due to pneumos, both lungs had to be repleurodesised. As a consequence, I am a strong proponent of aggressive pleurodesis for a better quality of life, with longer periods of time between events.

Fatigue afflicts many LAM patients. It saps our energy, which can impact our career choices and finances. As a college graduate, I did not work outside the home other than the occasional mornings at the local nursery school to reserve my energy to be able participate in my children’s lives after school. I continue to plan my schedule daily, weekly and monthly, so as not to have too many activities which would exhaust me and lead to bronchitis or a lung collapse.

Routine activities, like grocery shopping, have become events that need to be planned. What appears simple requires a lot of energy. Beyond the shopping, there’s the loading and unloading of the car, sorting and storing food, and finally preparing the meals. Bronchodilators helped liberate me. Previously, I would have to nap most afternoons.

Mary Stojic...

With my daughters grown, I decided to return to work. I needed a position with limited exposure to germs, so nothing in retail or working with children. Although my former career path was not an option as it would be too physically demanding, I found a sedentary job that allowed me to reserve some energy for my husband and our life together.

I have been taking an immunosuppressant for over five years to help slow the disease. I wonder about side-effects as I will likely be taking it for the rest of my life. My lungs have not collapsed since 2010. Yet I worry as I plan vacations, if I'll have to postpone or cancel trips, and I feel generally uneasy about being away from home and my doctors. My function has declined, and I am short of breath on exertion.

I am grateful to my pulmonologists. I am active in advocacy, participate in regular visits to the NIH, and I volunteer as a liaison for the LAM Foundation. I care about giving other LAM patients hope, especially the young women starting their families. Young women are given this diagnosis with too many unknowns, but this can change.

Where there's research, there is hope.

Mary Stojic was a patient speaker at the ATS 2017 International Conference in Washington, D.C.

Susan East

ACUTE RESPIRATORY
DISTRESS SYNDROME



“I pulled through, thanks to a change in environment and support of my family.”

Susan East...

My ARDS journey began in 2008. I had never had a serious illness before. It felt like I had a sinus infection. I saw my primary doctor on June 30, and he said I had a slight case of pneumonia, gave me a shot and medicine, and sent me home. On July 3, my daughter found me in respiratory distress.

Once I arrived at the hospital I was immediately taken to the ICU and placed on BiPAP. My oxygen saturation was around 42, and they tried using BiPAP for 12 hours but it did not work. They put me in a medicated vented state for seven days. When they took me off, it took two days for me to wake up. I began to crash again.

It was very difficult for my family because they could only see me for 15 minutes, four times a day. At the end of nine days I was re-vented and transferred to LSU Medical, which is a Trauma I medical facility.

Once there, they woke me up but kept me vented. At LSU, my family was allowed to visit more often. This helped with my anxiety. They allowed my hairdresser to come and wash my hair. My massage therapist would come and work my arms and legs. One of the nurses would even bring me her laptop when I was strong enough to sit up and use it.

I spent a total of six weeks in the ICU and 28 days on a ventilator. The whole time I was on a tight, day-to-night schedule. Everything I needed that could be done was done during the day, and I slept at night. There were no more interruptions, like at the other hospital. I pulled through, thanks to a change in environment and support of my family.

In July 2014 I had to have neck surgery. Unfortunately, three days into it, I went back into ARDS. I spent nine days in the ICU and only had to be on BiPAP and not vented. It was very hard on me. After my release I did lung testing and found out I have pulmonary fibrosis and 55 percent lung capacity. It was at that point that I felt I had all of the ARDS my body could take.

ACUTE RESPIRATORY DISTRESS SYNDROME



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

Susan East...

In May 2017 I was honored to be a patient speaker at the American Thoracic Society International Conference in Washington, D.C. I followed the conference with a visit to my daughter at Dauphin Island, Alabama. It was meant to be a relaxing beach vacation. I was not there six hours when—getting ready for bed—I passed out and aspirated. When my daughter found me I was unresponsive. I was airlifted to Providence Hospital in Mobile. I was in a coma. It took three days to be diagnosed with viral meningitis, pneumonia, and ARDS. I fully woke from my coma on the sixth day and stayed in the ICU for 17 days (vented for a total of 14 days). This was an ordeal because I had so little strength.

Yet I know I will fully recover—because my goal is to one day serve on the ATS Public Advisory Board. My passion is helping others with ARDS, and this passion drives me.

Susan East was a patient speaker at the ATS 2017 International Conference in Washington, D.C.

The Dance for Balance

I work with our patients and family members every day. As much as half of our members—clinicians or clinician-hybrids in academia also work with patients and families every day.

Member researchers and scientists, however, have less face time with patients. Some days, they may not interact with patients at all.

There are some things the patient will always know better than us. There are some things only a patient and family members will know.

We need patients to remind us—to help us know what it's like to live with asthma, COPD, or a sleep disorder. Or understand what life's like after sepsis, lung cancer, or a lung transplant.

The ATS Public Advisory Roundtable (PAR) has made patient understanding possible since the earliest stages of our organization.

Our doors remain open. From the advocacy groups who are members of the roundtable, and also to the patients and advocacy groups beyond our walls. Beyond our conference symposia, or board meetings, or congressional visits, where patients accompany ATS members to lobby for increased medical research funding.

In PAR's annual Lung Disease Week series, for instance, we recognize many rare lung disorders and spotlight patient issues. In collaboration with PAR partners and experts, the ATS develops resources and hosts live webinars with disease-specific content. The broader public is most welcome in this ongoing discourse concerning patient needs.

We look to the patient, the family, and community for their perspectives and guidance. For it is not in a select few, but a symphony of voices, in which we place our hopes.



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

New Patient Resource: Asthma Today

Download Now!

Available at thoracic.org
Featuring highlights from ATS 2017

Asthma Today
PATIENT INFORMATION SERIES | CONFERENCE EDITION
ATS 2017
Where today's science meets tomorrow's care™

Asthma affects more than 24 million people in the United States, both children (about 6 million) and adults (18 million), according to the latest data from the U.S. Centers for Disease Control and Prevention (CDC). Between 2001 and 2011, the number of people with asthma in the United States increased by 28 percent.

The government estimates that asthma costs the U.S. economy \$56 billion each year in medical bills, lost school and workdays, and premature deaths. Nearly three in five people with asthma say it interferes with their daily lives, causing them to limit their activities.

There is currently no cure for asthma, but it can be controlled with medicine and lifestyle changes. You should work with your health care provider to develop a personalized asthma management plan. Tell your health care provider about your symptoms and how they affect your life, as well as what triggers your asthma. Triggers are those things that lead to asthma symptoms and make your asthma worse.

Increase of people with asthma in the United States
2001 to 2011: **28%**

8.9 million asthma-related doctor visits annually

1.9 million asthma-related emergency department visits annually

479,000 asthma-related hospitalizations annually

Supported by an educational grant from GlaxoSmithKline.

Source: U.S. Centers for Disease Control and Prevention

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 thoracic.org/patients.



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.



We help the world breathe
PULMONARY • CRITICAL CARE • SLEEP

ATS Annual International Conference each May

Previous Voices



*View all past editions
and many more
patient resources at:
thoracic.org/patients.*

“It’s heartbreaking when you’re a parent and the hurt that your child suffers from asthma is out of your control.” — CHARDAY EURY

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A publication from the ATS Public Advisory Roundtable.



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