



# *ATS Patient Voices*

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, 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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**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. To this end, the ATS Public Advisory Roundtable (PAR)—which represents the patient voice of the Society—has for the past ten-plus years 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 **Breathing Better with the ATS** patient and family forum, the **Meet-the-Expert** public forum, the **PAR Symposium** and the many patient speakers integrated throughout the scientific session curriculum.

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

A major thrust of Dr. Hill's presidency was to explore ways of enhancing what the ATS does for patients and their families. That's why the ATS has redoubled its efforts to forge new alliances with patients and patient advocacy organizations at the national and grassroots levels on the issues of disease awareness, public education, and advocacy. That's also why the ATS has opened up its membership criteria—now

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 these efforts to strengthen the relationship between patients, their families, and the ATS.

We salute 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.



*N S Hill*  
**Nicholas S. Hill, MD**  
ATS President 2011-12



*Stephen C. Crane*  
**Stephen C. Crane, PhD, MPH**  
ATS Executive Director

It started out as a realization that though patients are central to what pulmonologists and other medical professionals do, there needed to be a way in which patients and their advocates could interact directly with the Society. There needed to be an effective way to communicate patient needs and a way for physicians to understand their perspective, thus American Thoracic Society Public Advisory Roundtable (ATS PAR) was born.

Many of the founding members of ATS PAR were patients, family members of patients, or advocates who understood the real needs of patients as well as the lung diseases from which they suffered. They articulated those needs and communicated them to the ATS, and they bridged the gap between patients and physicians. They not only created opportunities to strengthen medical care, but also opened the door to collaboration and partnership to increase understanding of lung diseases and to lead efforts to fund treatments and cures.

Now, more than ten years later, ATS PAR is still one of the only patient-centered groups in the United States that is a direct part of a medical membership association. Today, ATS PAR remains a vital part of the ATS and holds high esteem within the organization. ATS PAR is known for its unique ability to respond to patient needs and mobilize efforts to improve patient care, increase research efforts in lung disease, and build advocacy and awareness of lung disease and lung health on a national level.

Additionally, to date, PAR-affiliated member organizations have supported the ATS Foundation research grant program to the tune of more than \$6 million in funding for innovative medical research in lung disease. ATS PAR also holds a seat at the ATS Board of Directors table and has a direct line of communication with ATS leadership.

For the past several years, ATS PAR has had the privilege of assigning patient speakers to medical sessions at the ATS International Conference, a scientific meeting of respiratory professionals including physicians, clinicians, scientists, and researchers. The patients share their personal stories with ATS members, giving them an up close and personal look into the lives and experiences of patients with lung disease. These compelling patient stories provide the important and central “patient voice” for the conference attendees and allow research and innovation to move forward with passion while never losing sight of patients. Never before has a medical association elevated patients to such a visible position within its organization. ATS PAR is truly “the patient voice of the ATS.”



**Teresa Barnes**  
Chair, ATS PAR



*Jennifer Ludwin*

SEPSIS

*“On my first day with my prostheses, I only walked 10 feet. However, the next day I walked 168 feet, then 468 feet and I continued to walk farther each day.”*

It all started with what seemed like a bad sore throat. Little did I know that this sore throat would completely change everything about my life.

On October 17, 2009, I went to the emergency room with flu-like symptoms and dusky colored fingers and toes. I was admitted and intubated that evening. When I arrived in the ER, I was already in septic shock and was diagnosed with H1N1 influenza A.

Because of the combination, I experienced a series of complications which included multiple organ failure, disseminated intravascular coagulation, acute respiratory distress syndrome (ARDS), gangrene, a neck abscess, and gastrointestinal bleeding. I have had more than 20 major surgeries that include a thoracotomy, an emergency exploratory abdominal surgery, and amputations of both my legs below the knee, the fingers on my left hand, and part of the fingers on my right hand. At an inpatient rehabilitation hospital, I underwent intense physical, speech and occupational therapy daily. I had to relearn how to swallow, walk, dress myself, bathe and perform other daily living skills. When I first started rehab, I could not sit up for longer than 15 minutes and I required assistance. Soon, I was sitting up without assistance for longer time periods. On my first day with my prostheses, I only walked 10 feet. However, the next day I walked 168 feet, then 468 feet and I continued to walk farther each day.

After spending five months in the hospital and rehab, I returned to my parents' home and continued with outpatient rehab. I use prostheses for walking, and with modifications and creativity, I can perform everyday tasks. In autumn 2010, I returned to graduate school, and I'll graduate with two master's degrees in August 2012.

## SEPSIS

- Septic shock occurs when sepsis is complicated by low blood pressure that does not respond to standard treatment (fluid administration) and leads to problems in one or more of the vital organs.
- The condition means that the body does not receive enough oxygen to properly function, and drugs called vasopressors are used to raise the blood pressure.
- Hospitalizations for sepsis, or blood poisoning, more than doubled in the last decade.
- Despite active treatment in the ICU, the death rate is around 50 percent.

Source: Sepsis Alliance—  
[www.sepsisalliance.org](http://www.sepsisalliance.org)

I've resumed a sense of normalcy but I still experience lingering effects from my illness. I had a thoracotomy on my left lung to clear out an infection and scar tissue from ARDS and H1N1 influenza A. Because of this, the left side of my ribcage experiences heightened sensitivity—the slightest touch can cause discomfort. Since numerous nerves were severed during the thoracotomy, this discomfort is due to nerve regeneration.

Scar tissue in my lungs has caused me to not be able to take deep breaths. When I engage in strenuous activities, I often have shortness of breath and take longer to regain my breath. To help break up the remaining scar tissue in my lungs and increase my lung capacity I don't smoke, avoid smokers or smoky places, take the stairs instead of the elevator, and exercise regularly, especially cardio exercise.

I also have a chronic cough and have to clear my throat constantly. My cough is aggravated by smoke, dust, and other airborne particles. Since I have a decreased lung capacity, I run out of breath quicker when speaking and cannot project my voice as well as before I became ill. If I speak for too long, I find that my voice becomes weaker and my cough becomes aggravated. I have to be careful to not strain it, especially in loud environments such as sporting events, bars, and restaurants.

All of these lingering effects interfere with my daily life but have slowly gotten better as the years have passed.

*Jennifer Ludwin's story was featured in ATS PAR News, July-August 2010, Vol. 3, Issue 7.*



*Rodney K. Reese*

SARCOIDOSIS

*“My pulmonologist is very active in our support group. It has opened his eyes and changed the way he handles his patients.”*

In 1997, we experienced a massive explosion at a chemical plant where I worked as a process operator in Baton Rouge, La. The ceiling collapsed in the control room and pushed a huge dust cloud of ceiling tile, fiberglass insulation, and aluminum sheeting through the building. Outside, we discovered a sump overflowing and emitting toxic vapors of formaldehyde, methanol, propanol, butanol, propargyl, sodium hydroxide (caustic soda), acetylene gas, hydrogen gas, copper acetylide catalyst, and nickel catalyst.

Two hours later, my symptoms started with a dry cough. When I went to bed, I couldn't breathe while lying flat on my back. My cough continued with dyspnea and fatigue.

The next day, I reported to the plant doctor. After chest x-rays and a breathing test, I was diagnosed with an irritated airway and given two inhalers. I was told I would be fine in a couple of weeks. This did not happen.

I went to my pulmonologist. After chest x-rays and pulmonary function tests, I was diagnosed with early stages of pneumonia. I was given meds and told it would clear up in a couple of weeks. This did not happen.

About six months later, I returned to my pulmonologist and received the same diagnosis, but I started having frequent and severe nosebleeds.

Eventually, my primary care physician referred me to an ear, nose, and throat specialist. A CT scan revealed that I didn't have a normal sinus, and surgery was performed. An allergist who read the biopsy report found non-caseating granulomas and told the physician and specialist that I possibly had sarcoidosis.

## SARCOIDOSIS

- Sarcoidosis is a potentially fatal inflammatory disease that can appear in almost any organ in the body. Although the lungs are affected in more than 90 percent of patients, the disease often attacks the heart, eyes, central nervous system, liver and kidneys.
- In the United States, Sarcoidosis is most common in African Americans and people of European—particularly Scandinavian—descent.
- In the United States, Sarcoidosis frequently occurs more often and more severely among African Americans than among Caucasians.
- Among African Americans, the estimated lifetime risk of developing Sarcoidosis might be as high as 3 percent.

Source: Foundation for Sarcoidosis Research—<http://www.stopsarcoidosis.org>

After tests for TB and Wegners Granuloma came back negative, I was diagnosed with sarcoidosis. By that time, I had lost about 40 percent of my lung capacity.

I was given two inhalers and placed on 80 milligrams of prednisone per day, which continued for three-and-a-half years. The side effects of these high dosages wreaked havoc on my body. Along with being diagnosed with glaucoma and severe muscle and bone pain, I had to have both hips replaced by the age of 48.

The effects of sarcoidosis on my work and family life have been devastating. I had to retire at the age of 49 because I could no longer perform the duties of my job. Because of my breathing difficulties, fatigue, and orthopedic problems, I can't be as active in my son's and daughter's personal, academic, and athletic lives.

After trying just about every drug listed to use for sarcoidosis, the drug Remicade been a godsend. I feel better than I've felt since being diagnosed. I'm not as fatigued, my breathing tests are significantly better, and the aches and pains are not as severe.

I urge doctors to listen to their sarcoid patients' complaints and to become involved in support groups. My pulmonologist is very active in our support group. It has opened his eyes and changed the way he handles his patients.

*Rodney Reese was a patient speaker at the ATS 2010 International Conference in New Orleans, La.*



## *Nicole Seefeldt*

LAM AND TUBEROUS  
SCLEROSIS COMPLEX

*“It’s been hard for me to accept. Yet, I have reason to hope. The puzzle pieces for my diseases are coming together.”*

I liken most of my days to boxing. If I get knocked down, I might have lost the round but not the match. As soon as I can, I'm up for the next go and ready to score the knockout.

When I was just 7 months old, I started having seizures. They arrested early, but at age 3, I was diagnosed with tuberous sclerosis complex (TSC). TSC affects me genetically by causing benign (but large) tumors on many of my organs.

Though my parents did their best, I knew I was different at a very early age. Outside of what looked like oversized freckles on my face and body, hardly anyone could tell.

In 1999, I graduated with a bachelor's degree in journalism and moved to New York. On New Year's Day 2002, I rung in the holiday with my first lung collapse. It was then that I learned of another disease, lymphangioleiomyomatosis (LAM), and in 2003 I received the diagnosis.

LAM is an insidious, savage illness that acts like asthma but also secretes proteins to break down the healthy tissue around my lungs.

It acts as unpredictably as multiple sclerosis (MS)—I have periods when I'm fine and you'd never know that anything is wrong outside of my being a little short of breath. But when something goes wrong, it goes painfully wrong.

I've had multiple hospitalizations, surgeries, and even two brushes with death because of the war both diseases have waged on my kidneys and lungs. It's as though they take turns acting up.

I have remissions, plateaus, and exacerbations at any given point (much like MS or cancer). It's a particularly ugly combination and, in the case of LAM, it can be lethal. Sometimes, I have obvious warning signs something is wrong, like lung

## LAM

- 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, and/or fatigue. As many as 40 percent of women with LAM have a benign kidney tumor called angiomyolipoma.
- 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 progressively declines, sometimes resulting in the need for supplemental oxygen.
- Women often go undiagnosed for years, and are frequently misdiagnosed with asthma, bronchitis, or emphysema.

Source: The LAM Foundation—  
[www.thelamfoundation.org](http://www.thelamfoundation.org)

collapses. Other times, checkups with my doctors or periodic tests catch problems, so it's important to regularly seek medical care even if I'm feeling good.

I've had a progression that has been slower than some and faster than others—a blessing and curse with no predictable course or control.

It's been hard for me to accept. Most people in their 30s don't have to deal with the gravity of issues that results from this “double whammy.” It's cheated me out of some very important things.

Yet, I have reason to hope. Understanding and advances in both diseases has come leaps and bounds, and there are drug trials that seem promising. The puzzle pieces for my diseases are coming together.

That keeps me hopeful that one day I'll have the chance to win the match. I have won a few rounds since 2009. I started a medication that has stopped the roller coaster of constant hospitalizations and checkups, and it allows me to focus on my job and hobbies.

Even if I lose in the end, I can rest assured knowing that I did not go down without a fight, that I gave it my best effort, and that by sharing my story I might have inspired another brave soul to stay in the fight and win.

*Nicole Seefeldt's story was featured in ATS PAR News, October 2008, Vol. 1, Issue 11.*



*Len Geiger*

CHRONIC OBSTRUCTIVE  
PULMONARY DISEASE

*“I cherish my life now more than ever before, and I wouldn’t trade it in for a ‘normal’ life for all the money in the world.”*

I had just turned 35 and still thought I was going to live forever, but then I was given the worst news I thought I'd ever receive. After several years of being told that asthma was causing my increasing breathing troubles, my physician told me that I had Alpha-1 antitrypsin deficiency, a genetic protein deficiency that caused me to develop a form of severe, progressive, and irreversible chronic obstructive pulmonary disease (COPD).

With one phone call, I was suddenly forced to recognize my own swiftly approaching mortality for the very first time.

I had lost over 60 percent of my lung function and needed IV infusions every week. Within two years I had become so ill that I could no longer work. Eventually, my wife and I divorced. I had lost everything by which I had defined myself. I was evaluated and placed on the list for a double lung transplant.

During this difficult time, I recognized two unalterable facts. First, I could only survive with a positive attitude—negativity would kill me. Second, my breathing was only going to get worse, so I needed to get in the best shape possible to prepare for whatever the future would bring.

I took steroids to help my breathing, but they kept blood from reaching my hips, which eventually had to be replaced with titanium. The surgeries made exercise even tougher and my lungs continued to deteriorate, but I kept a positive attitude.

In 2002, the University of Virginia's transplant center had lungs for me. In a flurry of activity I underwent the eight-and-a-half-hour, double lung transplant procedure. Korinne Shroyer, 14, saved my life, and I would later meet her family and run an 8K-and-half marathon with her father, Kevin.

*Len Geiger*

## CHRONIC OBSTRUCTIVE PULMONARY DISEASE

- COPD is an umbrella term used to describe progressive lung diseases including emphysema, chronic bronchitis, refractory (non-reversible) asthma, and some forms of bronchiectasis. This disease is characterized by increasing breathlessness.
- COPD is the third leading cause of death in the U.S. — 12 years earlier than predicted.
- Every four minutes an individual dies of COPD.
- COPD kills more women than men each year. In 2006, COPD killed more American women than breast cancer, Alzheimer's disease, and diabetes.
- The National Heart, Lung, and Blood Institute estimates that 12 million adults have COPD and another 12 million are undiagnosed or developing COPD.

Source: COPD Foundation—  
[www.copdfoundation.org](http://www.copdfoundation.org)

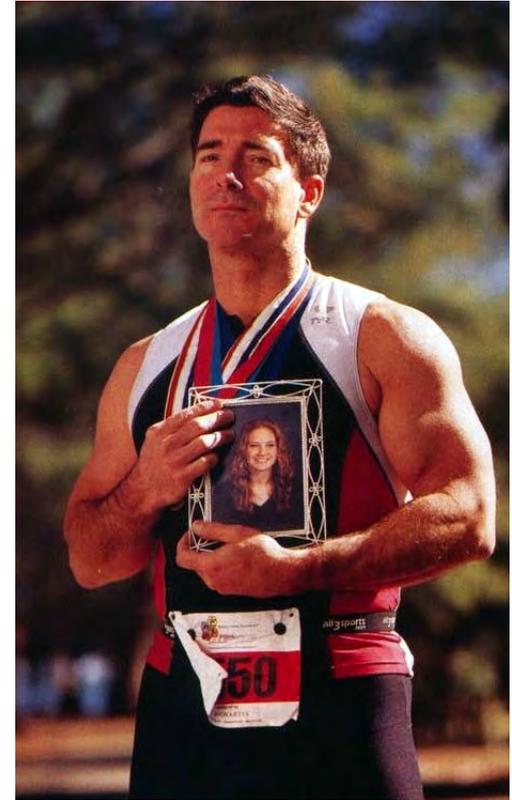
Just a few days after surgery, I was walking again on a treadmill, faster than I had in years. Since I could breathe again, I wanted to elevate my exercise regimen, but I was unable to run because of my hip replacements. So, I took up mountain biking. My lung transplant was less than three months old when I wrecked my mountain bike. After surgery on my left femur, my new lungs stopped working. I was put on life support and placed into a drug-induced coma. Almost three weeks passed before I could breathe on my own.

Even with extensive physical rehabilitation, it was weeks before my knee would bend and several months before I could put any weight on my repaired leg. Still, I focused on my attitude and goals, and I emerged ten months later in the best shape of my entire life.

I cherish my life now more than ever before, and I wouldn't trade it in for a "normal" life for all the money in the world. I am enjoying my new opportunity for life and love with my wife, Christina, and our daughter, Ava Corinne.

As an Alpha-1 patient advocate, I actively promote awareness, early detection, and treatment. I also provide support to individuals diagnosed with the disease. One of the first things I tell a newly diagnosed patient is that they have a long road in front of them. The decision they must make is what attitude they will carry on their journey.

*Len Geiger was a patient speaker at the ATS 2008 International Conference in Toronto, Ontario.*





# *Isabel Stenzel Byrnes*

CYSTIC FIBROSIS

*“I was very fortunate to travel through life with a twin, and we are tremendously grateful to be alive and have never-ending gratitude to our organ donors.”*

My identical twin sister, Ana, and I were both diagnosed with cystic fibrosis (CF) shortly after birth in 1972. Ana had meconium ileus, a condition that is often one of the first signs of the disease. The doctors told my parents that we'd be lucky to reach our 10th birthday. This dismal diagnosis thrust my mother and father into a whole new and intimidating world.

As children, we didn't have access to a care center accredited by the Cystic Fibrosis Foundation (CFF). My treatments involved ultrasonic nebulizer aerosols and chest physical therapy three times a day. We also used powdered enzymes to help digest our food.

When our lungs had cultured staph aureus, we were hospitalized for staph and aspergillus lung infections. Then at age 11, we cultured pseudomonas aeruginosa, which started a relentless spiral of chronic lung infections.

Throughout our junior high school years, we were admitted for triple IV antibiotics for two to three weeks at a time, sometimes as often as every other month. To become more independent from our parents, my sister and I started to do each other's chest physical therapy. The powder enzymes and our chronic infections demanded tremendous energy that prevented us from going through puberty, which was a real challenge as a teenager.

We enrolled at Stanford University and attended our first CFF care center. The team changed almost every medication we were using and taught us about clinical trials, cross infection dangers, and educational and support opportunities. I learned about home IV therapy so that I could minimize absences from college courses. With new treatments, I was able to gain weight, have more energy, and thrive in college.



*Isabel Stenzel Byrnes*

The most dramatic change in my health was a result of participating in the DNase clinical trials at Kaiser, which I joined during my sophomore year at Stanford. After a year-and-a-half, I gained 35 pounds, hit puberty and my lung function increased 13 percent. I was able to live a healthy life that I could not have even imagined before.

About 10 percent of all CF patients have been in a clinical trial, the highest proportion of all disease populations. Desperation was my primary reason. I needed hope that I could plateau or get better. It took a great deal of effort to be part of clinical trials, and I only wanted to be in Phase III trials because I was afraid—and I knew that Phase II trials tested the side effects of medication.

Our dreams for a cure or miracle treatment could not be fulfilled in time, and my sister and I received lung transplants. It was a grueling emotional process to accept that we had done everything we could to fight CF, and that there was nothing else the medical team could do.

I was very fortunate to travel through life with a twin, and we are tremendously grateful to be alive and have never-ending gratitude to our organ donors. We are also extremely grateful to the researchers and physicians who have kept us alive long enough for advances in transplantation technology.

*Isabel Stenzel Byrnes was a patient speaker at the ATS 2007 International Conference in San Francisco, Calif.*

*Isabel Stenzel Byrnes*

## CYSTIC FIBROSIS

- Cystic Fibrosis (CF) is an inherited chronic disease that leads to life-threatening lung infections and digestive problems.
- The rare disease affects about 30,000 children and adults in the United States, and there is no cure.
- More than 10 million Americans are unknowing, symptomless carriers of the defective CF gene.
- The most accurate way to tell if a child has CF is the sweat test, a diagnostic test that measures how much salt is in a baby's sweat.

Source: Cystic Fibrosis Foundation—[www.cff.org](http://www.cff.org)



*Robert Ngo*

PULMONARY HYPERTENSION

*“Thanks to the PH community, I’ve survived a 1.2-mile gauntlet swim, a 56-mile bike ride in 90 degree heat, a 13.1-mile trail jog, and all 70.3 miles in the Orlando, Florida, IronMan contest.”*

August 25, 2006, is my new birthday. That afternoon during my fourth and last year of pharmacy school at Western University of Health Sciences, I was in my cardiology rotation learning about ECG and ECHO at Centinela Hospital in Inglewood, Calif. After I volunteered to get read, the cardiologist said, “You have pulmonary hypertension.”

I chuckled and said, “Viagra, three times a day!”

However, no one was laughing. I have idiopathic pulmonary arterial hypertension.

In retrospect, PH has been a gift in disguise. It directed me to a lifestyle with very different accomplishments. I grew up in the hood. I could have been a gangbanger running with the Blood or Crips, but I couldn’t run. I could’ve mastered five-finger shopping, but I couldn’t run. I could have gratified the whole city, but guess what? I couldn’t run.

Throughout my whole life, I couldn’t run. I couldn’t join the basketball, soccer, football, or cross-country teams at my high school. I was always beating the books. Sometimes, I literally beat my books when I saw others playing in the sun. Not having much luck on land, I tried my luck in the water. I tried out for the high school water polo team. Everyone on the team told me that my lips were blue—I almost drowned in the deep end because I didn’t know how to swim. I wore floaties everyday during practice until I learned how to swim. My perseverance and dedication earned me a spot on the team as the junior varsity goalie. During the two water polo seasons, my teammates occasionally ask me why my lips were blue, but it wasn’t because of my lack of swimming skills.

*Robert Ngo*

## PULMONARY HYPERTENSION

- Pulmonary hypertension is high blood pressure in the arteries of the lungs that can lead to heart failure.
- PH patients experience symptoms such as shortness of breath, dizziness, and fatigue. The severity of symptoms usually correlates with the progression of the disease.
- The average time between symptom onset and diagnosis is 2.8 years. This time has barely changed in the past 20 years.
- Most patients are not diagnosed until they are in the late stages of the disease and are experiencing significant limitations of ordinary physical activity.

Source: Pulmonary Hypertension Association—[www.phassociation.org](http://www.phassociation.org)

In college, I signed up to represent my school as an Army cadet, and during the summer of my junior year, I was shipped to Fort Knox, Ky. When the bus stopped at the barracks, two drill sergeants rushed toward us screaming bloody murder. I didn't have to deal with their anger management issues the first week because I passed out. But soon after, the military physicians cleared me for training.

During two months of basic training, I rappelled out of a Black Hawk helicopter and mastered my M16 rifle. I sounded off my name, rank, and platoon while my eyes, lungs, and skin burned. With 50 pounds of gear weighing down on me, I navigated through a forest with basketball-size spiders hanging from the trees. While others dropped, I graduated and was offered \$17,000 school scholarship. I just had to pass the run test. I trained and trained, but I couldn't run.

September 11, 2001, to August 25, 2006, was a period of failing health, several appointments with doctors, and misdiagnoses. I was prescribed an Albuterol inhaler and an exercise regimen, which worsened the PH to the point where I couldn't even button my shirt without becoming short of breath.

I was fortunate to be diagnosed during my rotation. I've been prescribed 100 mg of Viagra three times a day, and I feel like three times the man I used to be.

After my birthday, I've tried everything—from skydiving to scuba diving. Thanks to the PH community, I've survived a 1.2-mile gauntlet swim, a 56-mile bike ride in 90 degree heat, a 13.1-mile trail jog, and all 70.3 miles in the Orlando, Fla., IronMan contest.

*Robert Ngo was a patient speaker at the ATS 2012 International Conference in San Francisco, Calif.*



## *Nora McCormack*

PULMONARY HYPERTENSION

*By Claire A. McCormack, Nora's mother*

*"Kids of all ages notice that Nora is wearing oxygen. They pretty quickly realize that they have to watch out for the tube, and often the older kids will try to keep it from getting stuck on anything."*

Our daughter, Nora, was diagnosed with pulmonary arterial hypertension when she was three months old.

Nora's journey started well before that diagnosis. Despite being a healthy woman with no risk factors for having a premature baby, my pregnancy was complicated by a placenta previa. My water broke at about 22 weeks gestation. Nora was born at 25 weeks, weighing only 575 grams. She had an APGAR score of 1 at birth and she was immediately intubated. Initially, she was on a conventional ventilator, but within a few days, she graduated to an oscillator.

She battled daily for survival, underwent multiple surgeries, and struggled to gain enough weight to be released from the hospital. Somehow, she pulled through. One day at home, she turned blue. We went to the ER, and the radiology technician discovered she had PH. We were discharged with an oxygen concentrator, a nebulizer and a follow-up appointment with a pulmonologist.

Specialists in PH at University of California, San Francisco, prescribed sildenafil, bosentan, and oxygen. This treatment plan made a big difference with Nora. She seemed more energetic and alert than she had in months.

While Nora was an infant, having her on oxygen was not that big of an inconvenience. We have a 50-foot tube connected to the concentrator and we live in a flat. So we could drag the tube to wherever she was playing pretty easily or we could pack a portable tank of oxygen under the stroller for a walk. Once Nora started crawling and walking, oxygen management became more challenging.

## PULMONARY HYPERTENSION

- While women are four times more likely than men to be diagnosed with pulmonary hypertension, PH affects people of all ages, races, and ethnic backgrounds.
- Many patients will see three or more different physicians over a three year period before they are properly diagnosed with pulmonary arterial hypertension.
- Confirmation of diagnosis is made by a right heart catheterization.
- Research and treatments for this complex disease are developing rapidly. Therefore, pulmonary hypertension patients are encouraged to seek treatment from a PH specialist.

Source: Pulmonary Hypertension Association—[www.phassociation.org](http://www.phassociation.org)

We see other parents sitting on the periphery at the playground while their toddlers play. We can never do that—we have to carry the oxygen and follow her everywhere, whether it's down a slide or through a tunnel.

We also see other parents at play dates sitting and talking to each other. We also can't do that. As you probably know, toddlers don't move in a straight line. We always have to keep one eye on her to make sure we are moving at the same time and in the same direction that she is.

In the house, we can't leave Nora in her bedroom alone while we go into the kitchen. The tube can get stuck under a heavy book or catch on the doorway and pull Nora down. There is nothing worse than seeing Nora gleefully running down the hallway only to get yanked backwards and fall down because the tube got stuck on something.

Kids of all ages notice that Nora is wearing oxygen—little kids often want to play with the tube and older kids are fascinated by the portable tanks and the concentrator. But they don't seem to treat her differently. They pretty quickly realize that they have to watch out for the tube, and often the older kids will try to keep it from getting stuck on anything.

Despite all of these challenges, Nora is doing well developmentally. She has done everything late—crawling, walking, and talking. But she has eventually caught up on everything. She has good balance, likes kicking and throwing a ball, enjoys painting and drawing, and has started talking in full sentences in both Swedish and English.

*Claire McCormack spoke at the 2012 ATS International Conference in San Francisco, Calif.*



*Ashley Holley*

SICKLE CELL

*“It’s not just about the cure—it’s about improving the quality of life for patients until there is a cure.”*

I'm an adult living with sickle cell disease, and I've spent the majority of my professional career studying it, first as a research assistant in a biochemistry lab and now both as a clinical research coordinator and hematology oncology medical practice administrator.

I was diagnosed shortly after birth, and it was always clear to me that I was different. As the daughter of two diligent parents, I was prepared for anything. Every morning, I would sit down to breakfast with penicillin, folic acid, and vitamin C. I hated those pills, but I knew that I would be very sick without them. My parents convinced the school principal to set aside one hour during the day for me to use her office to rest as well as enforce mandatory water breaks for me during recess.

I made it through my first pain episode when I was about eight years old. The pain was excruciating and the speed of onset was terrifying. I recovered quickly and moved on with my life, still without a full understanding of the magnitude of my illness. When I was 14 years old, all of that changed. I went to the emergency room one evening with a fever and pain. After a second round of x-rays, they noted lower lobe infiltrate. The doctor told me I was suffering from acute chest syndrome, something like pneumonia, but not really.

Over the next couple of days, my condition worsened. My ACS progressed and eventually my left lung collapsed. My hemoglobin levels dropped as a result of aplastic anemia induced by what was thought to be parvovirus at the time. I also developed an infarct in my spleen which caused my spleen to collect my circulating blood.

I almost lost my life during those two weeks, which shifted the way that I viewed and coped with my disease. Every day, I was tortured with the uncertainty of what was turning into a very life-threatening and unpredictable disease.

*Ashley Holley*

## SICKLE CELL

- Sickle cell disease is an inherited blood disorder that affects red blood cells.
- When sickle-shaped cells block small blood vessels, less blood can reach that part of the body. Tissue that does not receive a normal blood flow eventually becomes damaged.
- The sickle cells also block the flow of blood through vessels resulting in lung tissue damage (acute chest syndrome), pain episodes (arms, legs, chest and abdomen), stroke and priapism (painful prolonged erection).
- Health maintenance for patients with sickle cell disease starts with early diagnosis, preferably in the newborn period and includes penicillin prophylaxis, vaccination against pneumococcus bacteria and folic acid supplementation.

Source: Sickle Cell Disease Association of America — [www.sicklecelldisease.org](http://www.sicklecelldisease.org)

As I grew older, my disease impacted every part of my life. I developed avascular necrosis of my left hip and it quickly advanced to stage four. It relegated me to crutches and a wheelchair for two years, and I had to discontinue sports and dancing. I'm still waiting for it to give out so that I can replace it.

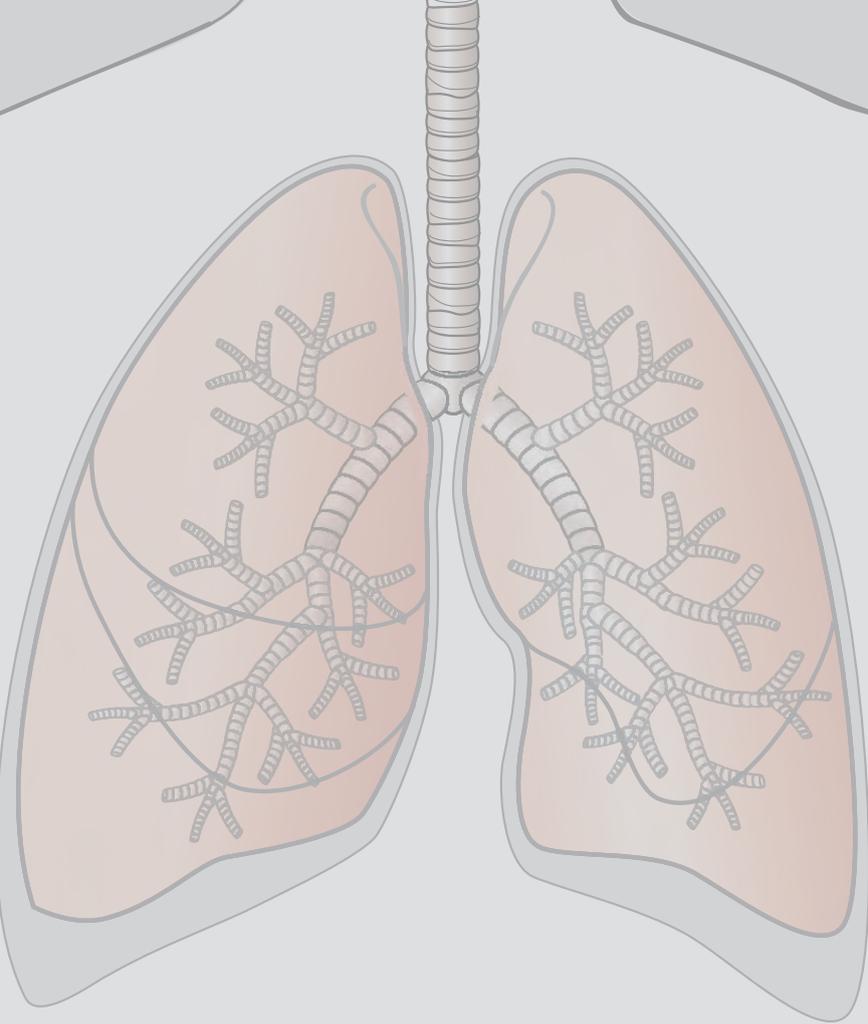
In college, my roommate and I studied for many mid-terms and finals in my hospital room when I was lucid enough. I managed to finish in five years, despite withdrawing for a quarter for health reasons. I've had about six additional run-ins with acute chest syndrome, and there's growing concern about whether I'll develop pulmonary hypertension or a chronic lung disease.

My echocardiogram seems to indicate that I'm at risk, but no definitive diagnosis has been made and no plans or options for treatment have been presented.

Drs. Clarice Reid, Marilyn Gaston, and Roland Scott changed the medical landscape, and greatly improved sickle cell patients' survival with their work on prophylactic penicillin, newborn screening, and the establishment of comprehensive sickle cell centers and a national sickle cell disease organization. Unfortunately, advocacy has waned and clinical advances are slowing. Medicine has managed to keep us alive, but our quality of life is compromised by the accumulation of co-morbid conditions such as pulmonary hypertension, avascular necrosis, and other degenerative organ diseases.

I'm hopeful we can finish the work that has been started. It's not just about the cure—it's about improving the quality of life for patients until there is a cure.

*Ashley Holley was a patient speaker at the ATS 2012 International Conference in San Francisco, Calif.*



*Beth Mittelstadt*

PULMONARY FIBROSIS

*“As my disease progressed, requirements increased as did the complications.”*

I noticed that I had difficulty breathing after jogging or biking, but I assumed it was just because I was out of shape. When I was pregnant with my first daughter a few years later, I mentioned it to my obstetrician, who said it was exercised induced asthma. After my daughter was born, I saw an allergist who prescribed an inhaler to use when I exercised, but I didn't really see any difference.

Several years later, my husband and I attended a Christmas party in a restaurant where there were several smokers in a small space (this was 1997). I had difficulty breathing throughout the night, and I saw my allergist the next morning. He told me that my condition had progressed to full blown asthma.

We spent the next 12 months trying different medications and dosages to get the breathing under control but nothing worked. After some time, I visited a pulmonologist who listened to my chest and looked at x-rays and said I probably had interstitial lung disease. The pulmonary function tests were completed and showed an FVC of 70 percent, an FEV1 of 65 percent, and DLCO of 55 percent. I was pregnant with my second son, so the high resolution CT scan was postponed until the second trimester. Months later, I had an acute episode of shortness of breath and ended up in the ER. After this I had to use oxygen when active. A CT scan revealed mild interstitial lung disease.

I chose to go ahead with a video assisted thoroscopic lung biopsy at Porter Hospital in Denver. Reports showed usual interstitial pneumonia, and I took prednisone, Cytoxan, N-Acetyl Cysteine, and prophylactic antibiotics. The disease continued to progress, and I was listed for a transplant at the University of Colorado Hospital.

## PULMONARY FIBROSIS

- Pulmonary Fibrosis is a debilitating disease-marked by progressive scarring of the lungs that gradually interferes with a person's ability to breathe.
- Every day in the United States 128,000 people are suffering from pulmonary fibrosis.
- Every day in the United States 130 people will be diagnosed with pulmonary fibrosis.
- Every day in the United States 110 people will die from pulmonary fibrosis.

Source: Coalition for Pulmonary Fibrosis—  
[www.coalitionforpf.org](http://www.coalitionforpf.org)

I have a high level of PRA in my blood and all attempts to reduce it in order to facilitate transplant have failed, so I placed myself on inactive status with the transplant team. I haven't participated in any drug trials as I have lost too much lung function to take a chance. Cytoxan and prednisone put the disease in a holding pattern, and I can't ask for more than that.

Since March 2000 my disease has remained stable with normal variables for weather, season and overall sense of well-being. Temperatures above 90 or below 20 increase the difficulty breathing. High humidity makes breathing harder as does a drop in barometric pressure. Breathing is easier at sea level and requires more oxygen at this altitude.

When I first started using oxygen, it was only with activity and one liter per minute. As my disease progressed, requirements increased as did the complications. Using 6-10 liters per minute has a detrimental effect on the sinuses—increased infections, nose bleeds and hearing difficulty. I had trans tracheal oxygen placed in October 2003 and have never regretted it.

*Beth Mittelstadt was a patient speaker at the ATS 2011 International Conference in Denver, Colo.*



*Maki Inada*

LUNG CANCER

*“During treatment, I kept working. I was teaching undergraduates and trying to run as much as possible. I was not going to take this lying down.”*

I swim, bike, run and play a sport called underwater hockey. The summer before I was diagnosed with lung cancer, my husband Jeff and I hiked to the top of Half Dome in Yosemite National Park, Calif.

The winter after we moved to Ithaca, N.Y., from San Francisco, Calif., in 2007, I caught a bad cold and cough that would not go away for two months. The doctors found a large, seven-centimeter mass in my lung. They didn't believe that an active and healthy nonsmoker at age 36 could have a tumor, so they sent me home with antibiotics and asked me to come back in a few weeks. I felt better, but I still had the cough and the x-ray looked the same.

I was diagnosed with non small cell lung adenocarcinoma in March 2008. Research on Wikipedia showed that 90 percent of people with lung cancer are smokers (which I'm not), only 15 percent of lung cancer patients survive 5 years (what?!), and new targeted therapies were being developed and worked well for nonsmoking Asian women (I'm all three).

My best friend from graduate school, a pediatric oncologist at Dana-Farber, walked upstairs and was able to get me an appointment with Dr. Pasi Janne at the Dana-Farber Cancer Institute, who is a specialist in EGFR mutations in lung cancers and targeted therapies.

We had a surgical biopsy to have genetic testing done on the mutational status of my tumor, but the surgeon sent me away because she found tumor studs on the inside lining of my lungs and didn't operate on stage IV. Totally devastated, I returned to Ithaca to begin chemotherapy and daily Tarceva, which was only approved as a second- or third-line therapy.

*Maki Inada*

## LUNG CANCER

- Lung cancer takes more lives than breast, prostate and colon cancers combined—it accounts for nearly 30 percent of all cancer deaths.
- Smoking is a major risk factor for lung cancer, but between 20,000 and 30,000 nonsmokers are diagnosed with lung cancer each year in the United States.
- African-American males have the highest incidence of lung cancer and the highest death rate.
- Only 16 percent of lung cancer cases are diagnosed before they have spread, which makes treatment challenging. Median predicted survival is in the late 30s and rising.

Source: National Lung Cancer Partnership—[www.nationallungcancerpartnership.org](http://www.nationallungcancerpartnership.org)

During treatment, I kept working. I was teaching undergraduates at Cornell University at the time and trying to run as much as possible. I was not going to take this lying down.

After three long weeks, I learned that I had an EGFR exon 19 deletion. After three months and four rounds of chemotherapy, my tumor was down to less than two centimeters. I was scheduled for surgery two weeks later. I started training to be in the best shape possible for surgery. I ran all over Ithaca.

On July 2, 2008, I had an upper left lobectomy. The surgery was a success. There was no sign of disease in the tumor studs, and the margins were an inch. Being in good shape, I walked a mile the day after surgery. I was ready to leave the hospital in just three days. In August 2009, I trained and competed in the Cayuga Lake Triathlon with my husband.

Today, we have a beautiful little girl, Mariko! I took daily Tarceva for two years post surgery and then went off to start a family. We feel very, very lucky!

*Maki Inada was a patient speaker at the ATS 2010 International Conference in New Orleans, La.*





## *Heather Kirkwood*

HERMANSKY-PUDLAK  
SYNDROME

*“I made the nurse take a picture of me taking my first pill. For me, it was a grand moment. It was the moment I went from a gloomy certainty about what my future held, to a blissful land of the unknown.”*

I wear a lot of hats. I'm a daughter, sister, editor, patient advocate, and participant in the phase III clinical trial of Pirfenidone to treat pulmonary fibrosis of Hermansky-Pudlak Syndrome (HPS).

HPS is a rare type of albinism that causes vision impairment, bleeding disorder, and, in some mutations, digestive problems and ultimately pulmonary fibrosis. Although my lungs were relatively healthy, the road to becoming a clinical trial patient was a long one of misdiagnosis, misinformation, and the realization that I was not invincible—a shocker for a 29-year-old.

My background as a journalist compelled me to gather every piece of information I could, but none of it seemed good. I read abstract after abstract that stated, “usually fatal in the third to fourth decade.” If they were really generous, they said fifth decade. Even worse than my diagnosis was having to tell my 25-year-old brother that we shared this diagnosis. I couldn't bear the idea of one of us watching the other die.

I became involved in the Hermansky-Pudlak Syndrome Network and contributed however I could, whether it was producing the newsletter, holding a fundraiser, or managing the online support communities.

And one day, fortune smiled on us. The National Institutes of Health was able to follow up their phase II Pirfenidone trial with a phase III trial. As a community we were beyond thrilled. But when I was screened, I was deemed too healthy to be admitted.

A year later I felt as though my asthma was getting worse. I just didn't seem to have the endurance I normally had walking around the neighborhood and running errands. I did my yearly pulmonary function tests at home and I was nervous.

## HERMANSKY-PUDLAK SYNDROME

- Hermansky-Pudlak Syndrome is a genetic disorder that causes pulmonary fibrosis in certain subtypes.
- Pulmonary fibrosis occurs nearly 100 percent of the time in HPS gene types 1 and 4, although the age of onset varies.
- HPS is characterized by albinism, decreased visual acuity, nystagmus, a bleeding tendency, and, in some, a digestive problem similar to Crohn's disease.
- Genetic testing for HPS can result in false negatives because not all HPS genes have been identified.

Source: Hermansky-Pudlak Syndrome Network—[www.HPSNetwork.org](http://www.HPSNetwork.org)

I discovered that my FVC had fallen from 94 to 69 and my DLCO had fallen from 70 to 53. I reapplied to be included in the trial and was accepted.

I remember picking up my pills for the first time at the pharmacy at NIH. I looked at the bottle with my name, my patient number, and the words “Pirfenidone or placebo.” I don’t know which I’m receiving. My doctors don’t know. Only some bureaucrat statistician in the depths of the NIH knows what’s really in those bottles.

I made the nurse take a picture of me taking my first pill. It’s a horrible picture of me and she seemed to think I was a little strange. But for me, it was a grand moment. It was the moment I went from a gloomy certainty about what my future held, to a blissful land of the unknown.

It was the day I got my hope back.

I know Pirfenidone isn’t a cure. I know this is a trial. And I know I might be on a placebo. But it’s something—it’s a step forward.

It means that just maybe those horrible paper abstracts won’t apply to me.

*Heather Kirkwood was a patient speaker at the ATS 2009 International Conference in San Diego, Calif.*



## *Eileen Rubin*

ACUTE RESPIRATORY  
DISTRESS SYNDROME

*“Doctors urged my family to consider removing me from the ventilator. It was a ‘quality of life issue’ since I would likely ‘never breathe on my own again’ if I lived.”*

When I was 33 years old, I moved from criminal prosecutor to private practice. I was healthy and active. So, when my lower back started to hurt, I just applied heat and continued talking to clients and going to court.

When the pain increased, I went to my internist, who examined me and sent me home with muscle relaxants. As five days passed, I had extreme difficulty breathing. Another visit to my internist produced the same medications but not blood work or chest x-rays.

Over the next 24 hours, I deteriorated quickly. After my internist refused to see me, I found another doctor who discovered my blood pressure was only 70/50. After blood work and a chest x-ray was performed, I was ordered immediately to the emergency room; my white count was three times higher than normal.

I was placed on oxygen and admitted directly into the Medical Intensive Care Unit. That evening, my kidneys failed. Only 24 hours later, I went into respiratory arrest and was intubated. I was soon diagnosed with both Sepsis and Acute Respiratory Distress Syndrome. My family was told the prognosis: ARDS. My chances of survival were, at best, 50 percent.

I was forced into a drug-induced coma, insulted with tubes, and assaulted with machines. As days turned into weeks, the grim reality of my illness was evident. Doctors urged my family to consider removing me from the ventilator. It was a “quality of life issue” since I would likely “never breathe on my own again” if I lived. A tracheotomy was performed after about two weeks.

After four weeks, I was given steroids, and I showed minimal improvement. Medications were reduced and I emerged from my coma. Almost immediately, I

## ACUTE RESPIRATORY DISTRESS SYNDROME

- Acute respiratory distress syndrome (ARDS) is defined as an acute process, which results in moderate to severe loss of lung function.
- Between 150,000 and 200,000 Americans will be diagnosed with ARDS each year. Worldwide, that number is about 2.2 million.
- There is no known prevention or cure for ARDS, and patients are treated with supportive care in the Intensive Care Unit.
- Although ARDS is always a critical syndrome, more than half of the patients who are diagnosed with ARDS survive.

Source: ARDS Foundation—  
[www.ardsusa.org](http://www.ardsusa.org)

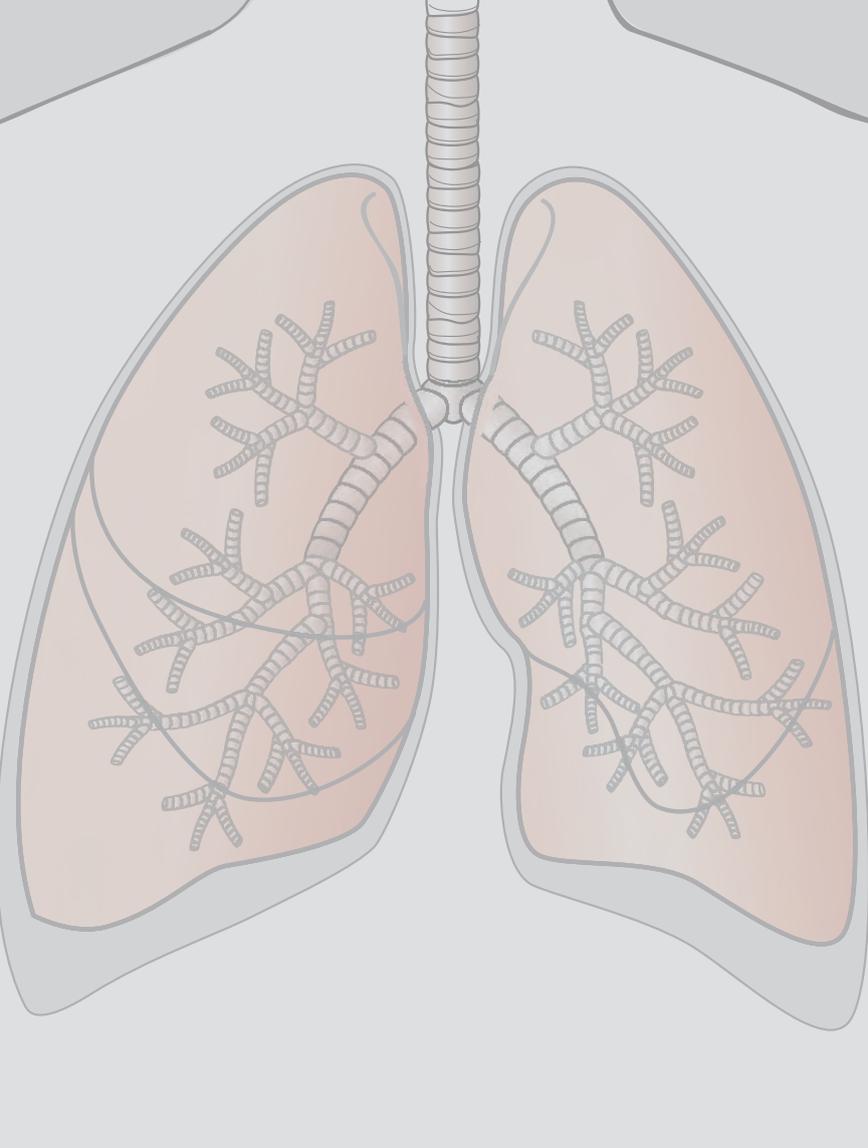
suffered a delirium and both of my lungs collapsed a second time. I was losing blood. Five chest tubes, eight blood transfusions, high fevers, and more infection followed.

After another four weeks on the ventilator, I could breathe on my own. It took an additional week in the hospital and several months of recovery to restore my emaciated and deconditioned body.

I delayed my attorney work for another eight months, but I was able to get pregnant six months following my release from the hospital.

I now have two daughters, Lily and Dana, work part time as a trial attorney, and serve as president of the ARDS Foundation. I feel a passion and desire to support those who are dealing with ARDS as patients or family members every day.

*Eileen Rubin was a patient speaker at the ATS International Conferences in San Francisco (2007) and San Diego (2009), Calif.; and Denver, Colo. (2011).*



*Peter Helm*

OBSTRUCTIVE SLEEP APNEA

*“I began to dread going to bed because I knew I’d have to be strapped up to the CPAP.”*

Hypoglossal nerve stimulation couldn't have come at a better time in my life, given that in the past two years I have also been dealing with increased sleep interruption from my two-year-old daughter.

My diagnosis of obstructive sleep apnea is relatively typical. Unfortunately, I had already spent the majority of my 20s suffering from constant fatigue, mild depression, and other complications of OSA. When I was 29, I participated in a sleep study at the University of California, San Francisco. I learned that I had an apnea-hypopnea index (AHI) of 35 to 40 events per hour, and that my oxygen levels dropped to the mid-80s. Much to my chagrin, I was immediately prescribed a CPAP, a continuous positive airway pressure machine.

During the year between my initial diagnosis and my entry into the Apex HGNS Study, I fought that machine every single night. I tried five different masks and different hose configurations, but I ended up using my CPAP roughly an hour per night, if that. I began to dread going to bed because I knew I'd have to be strapped up to the CPAP. Even my wife complained about it. She was awakened as often by a pressure leak as she would be by my snoring. I was banished to the couch more than a few times.

When I was contacted by UCSF for the Apex HGNS study, I jumped at the chance and only hoped I would qualify. I have to admit, though, in my eagerness to get a good night's sleep without using the CPAP, I didn't realize exactly how significant the surgery to implant the device, stimulator, and sensor would be. With a one-month-old daughter, it was a rough several weeks of recovery, but we worked hard to perfect the appropriate stimulation levels and vectors. I got very familiar with the staff at the sleep center, to the say least.

## OBSTRUCTIVE SLEEP APNEA

- At least 18 million Americans suffer from obstructive sleep apnea (OSA). Of these, at least 75 percent are undiagnosed.
- Although obesity, age, and male gender are among the risk factors for OSA, this common disorder affects many women, children, and people of all sizes.
- Not everyone with untreated sleep apnea falls asleep in the daytime, but people with OSA are six times more likely to have a crash and seven times more likely to have multiple accidents.
- People with OSA tend to have associated conditions including diabetes, obesity, anxiety and depression, sexual dysfunction, and high blood pressure.

Source: American Sleep Apnea Association—[www.sleepapnea.org](http://www.sleepapnea.org)

HGNS feels like I stuck my tongue into an electrical socket. While that is a bit of hyperbole, it is a somewhat uncomfortable. I don't know if I will ever get used to the idea of my muscles moving involuntarily. I don't fall asleep with stimulation active, I have a 30 minute delay from the time I turn on the device, and I have the option to pause the treatment if I wake up in the middle of the night (this happens a lot with a baby).

Discomfort aside, if I'm asleep already, the stimulation is not strong enough to wake me up, and I would definitely consider myself a light sleeper. Even after two years, my wife continues to marvel when my snoring stops as if someone flipped a switch when the stimulation kicks in. Her sleep has improved alongside mine.

The most obvious impact has been the dramatic increase in my energy level. My career, my relationship with my wife and daughter, and my happiness have all improved, due in no small part to the better sleep I enjoy because of HGNS.

*Peter Helm was a patient speaker at the ATS 2012 International Conference in San Francisco, Calif.*



*Geoff Burkhart*

NONTUBERCULOUS  
MYCOBACTERIA

*“Most people breathe these bacteria and fungi in and simply breathe or cough them back out, but they were making a home in my lungs.”*

I started coughing up blood in 2004. I went to a hospital near my home in Chicago, and x-rays showed several cavities in my lungs. The biggest was the size of a quarter. For four days, doctors ran tests, asked questions, and gave frustrated looks.

I went home without a diagnosis. I had been teaching at a community college, and the doctors assumed I had picked up tuberculosis from one of my immigrant students. They didn't want me to spread the disease, so I was quarantined at home for three weeks. But all the TB tests turned up negative.

I went months without a diagnosis. I coughed up blood in the morning, sometimes in the evening, and always after I exercised or did anything close to cardio. The year 2005 was better. I married my wife, Beth, at a park in her hometown—we wrote the ceremony ourselves, served barbecue, hired an Elvis impersonator, and rented a moon-walk. A month later, I started law school. Remarkably, I didn't cough up blood during our wedding or my law school orientation. But most days, I still coughed up blood.

That year I also met Dr. Dean Schraufnagel at the University of Illinois at Chicago. Dr. Schraufnagel, a former ATS president, found that I had chronic necrotizing aspergillosis—fungus growing in my lungs—and mycobacterium lentiflavum. These bacteria and fungi were slowly eating up my lungs, so he started me on an anti-fungal medication and a series of antibiotics.

Most people breathe these bacteria and fungi in and simply breathe or cough them back out, but they were making a home in my lungs. I had pulmonary alveolar proteinosis.

You might have seen pictures of air sacs in a lung diagram. Proteins or surfactant build up in my air sacs and make it difficult for me to breathe. The fungi and bacteria get stuck in the surfactant.

*Geoff Burkhart*

## NONTUBERCULOUS MYCOBACTERIA (NTM)

- NTM infection causes the bronchial tubes to fill with mucus and, over time, may lead to dilation and scarring of the tubes.
- Types of Nontuberculous Mycobacteria include: *mycobacterium avium* complex, *mycobacterium kansasii*, *mycobacterium abscessus*, *mycobacterium chelonae*, *mycobacterium intracellulare*, *mycobacterium fortuitum*.
- Common symptoms of NTM include coughing, night sweats and fever, loss of weight, loss of appetite, and lack of energy.

Source: NTM Info and Research, Inc—  
[www.ntminfo.org](http://www.ntminfo.org)

Dr. Schraufnagel prescribed a medication called GMCSF, Leukine, or Sargramastom. I inhale it through a nebulizer, and it helps my body process the proteins. Although it's nice to have a diagnosis, alveolar proteinosis is rare. There isn't a standard progression. I could recover entirely or I could get much worse.

The diseases wreaked havoc on my life. Sometimes, I couldn't hold my wife as we slept or much less be in the same bed. I had to sleep on inclined pillows on my couch because I would cough up between a tablespoon and a cup of blood. I had to go years without serious exercise because bending, twisting, yoga, and even sitting down too fast could trigger the symptoms.

Because of the inhalers, I would develop thrush and lose my voice, which made practicing law or carrying on a normal conversation difficult. One of the anti-fungal drugs caused so much abdominal pain that doubled over on the couch. Some of the medication I've inhaled through a nebulizer made me cough up more blood.

For now, I've shown improvement. The cavities have mostly closed, and I'm off anti-fungal and antibiotic medications. I still cough up blood, but it's less and less. The years have brought shortness of breath, exhaustion, and worry. But they've also brought marriage, the practice of law, and fatherhood.

Being a dad has been exhausting and exhilarating. But it gives me pause. I worry about my daughter watching me coughing up blood. I worry about not being able to run with her in the park.

I worry that she could develop something like this.

*Geoff Burkhart was a patient speaker at the ATS 2012 International Conference in San Francisco, Calif.*



## *Laura Steves*

WORK-EXACERBATED  
ASTHMA

*“Going back to work that fall was a nightmare. I began to get sick almost at once. The same tightness, wheezing, asthma attacks increased and I wasn’t able to take care of my son’s needs because I was so sick.”*

I'm a clinical psychologist from Fort Worth, Texas, and I've suffered from asthma and allergies for most of my life. My situation worsened about ten years ago when I was overseeing a mental health center for children and adolescents.

Like many nonprofits, we didn't have the luxury of the best in accommodations. Most of the funding we received was governmental and needless to say, as the demand for our services grew, so did the need to grow our offices. We leased a fitness center which we renovated into many offices for children and families to receive outpatient services.

The center was filthy and filled with mold. As much as we tried to make the situation better, aesthetically it look wonderful, but my asthma worsened daily. I had days where I could not breathe; I had tightening in my chest and wheezed throughout clinical meetings.

I thought I was suffering from occupational asthma. My job included home visitations filled with smokers, heavy perfume wearers and the like. I also conducted several assessment and evaluations at juvenile centers which exacerbated my conditions.

My weekends and holidays were the best of my time. My control medications seemed to help, and I was able to enjoy my time off.

I changed offices several times within the same renovated fitness center, but nothing seemed to work. I had several colleagues tell me to seek biofeedback, hypnosis and such because they felt I was having anxiety attacks. But this was not the case.

I was slowly becoming worse while at work, and the flare ups increased in duration and magnitude due to smokers and an increase in cleaning supply use

## WORK-EXACERBATED ASTHMA

- More than 25 million children and adults live with asthma all across the United States.
- Low income and minority children bear the heaviest burden of asthma, including death.
- Early childhood food allergies heighten the risk for developing asthma later in life.
- Each year, 3,000 asthma deaths occur in the United States.

Source: Asthma and Allergy Foundation of America—[www.aafa.org](http://www.aafa.org)

to alleviate my conditions. Green cleaning, an Oreck air machine, and nebulizer treatments were not helping me stay at work.

I took a leave during the last two months of pregnancy and extended my maternity once my son Spencer was born. I was out six months all together. I never felt better. I used my medications, rarely had a flare up and was enjoying all the work of being a first time mother. I could finally breathe.

Going back to work that fall was a nightmare. I began to get sick almost at once. The same tightness, wheezing, asthma attacks increased and I wasn't able to take care of my son's needs because I was so sick. I decided then that I needed to make a drastic change.

I left my role of fifteen years and decided to be a stay-at-home mom. I've contracted with my old employer as well as several other nonprofits to make ends meet. I make less than half of what I made ten years ago, but I have the flexibility of working out of my home and taking care of myself.

My two sons also suffer from allergy and exercise induced asthma. Without the proper care and control drugs, I wouldn't be able to create a future for them.

For two past years, I've served as the executive director of the Asthma and Allergy Foundation of America, Texas Chapter. I hope that as we continue to learn more about work-exacerbated asthma, we continue to research the many socioeconomic, demographic, and infrastructural conditions which make it such a varied disease.

*Laura Steves was a patient speaker at the ATS 2012 International Conference in San Francisco, Calif.*



## *ATS Patient Voices*



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