



ATS Patient Voices 9

From Disparities to Hope

A PUBLICATION FROM THE ATS PUBLIC ADVISORY ROUNDTABLE.

ATS Patient Voices is published by the American Thoracic Society Public Advisory Roundtable (ATS PAR). Since 2001, ATS PAR has been a core component of the Society and a mutually beneficial partnership wherein organizations that represent persons affected by respiratory diseases, illnesses requiring critical care, and sleep-related disorders collaborate with the ATS to advance their shared educational, research, patient care, and advocacy goals.

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



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PULMONARY • CRITICAL CARE • SLEEP

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Foreword

Since 2001, the ATS Public Advisory Roundtable (PAR) has helped to highlight the patient experience and to weave patients into the fabric of the American Thoracic Society. Along with PAR partners, comprised of various patient advocacy groups, PAR has opened up the Society to include those most personally affected by the diseases we research and treat: patients and their caregivers.

Throughout the year, PAR and PAR partners promote awareness, public education, advocacy, and research. The outcomes of those presentations are expansive and stretch from inspiring investigators to shaping ATS advocacy programs.

Patient Voices is a particularly important part of this effort. In this edition, you'll hear from patients and caregivers in their own words, not just about the disease and its treatment, but about their reactions to diagnoses, their fears, and in some cases, their recoveries. This special edition takes on another element of the fight against respiratory disease – health care access inequalities and disparities in care.

In 2014, the ATS defined respiratory health disparities as “significant differences in respiratory health that are closely linked to racial ancestry, social, economic, and/or environmental differences.” Such disparities adversely affect groups of people who have experienced greater obstacles to health based on characteristics historically linked to discrimination or exclusion, such as race or ethnicity, geographic location, and socioeconomic status. Patient stories are always sobering to read, and this year, the added element of disparities may be particularly disturbing to some readers, as the stories contain descriptions of discriminatory treatment and lack of access to life-saving care, as well as suicide.

The stories, while challenging to read, are even more so to tell, and we're grateful to the contributors for sharing their experiences. We also share in their hope that this edition will raise awareness about lung disease, as well as serving as a step toward respiratory health equality, an ideal strongly supported by the American Thoracic Society.

Thank you for making Patient Voices possible as we work together toward ever more treatments, therapies, and ultimately, cures. ■



Juan C. Celedón, MD, DrPH, ATSF
President, ATS
(2020-2021)



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

Chair's Message

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

Each year, ATS PAR identifies patients to participate in an edition of Patient Voices, with the goal of sharing their journey – to put a “face” to their diagnosis and challenges. As a result, respiratory professionals including physicians, clinicians, scientists, and researchers receive an intimate look into disease impact on patients’ lives.

Understanding the patient perspective is essential for Society members to innovate and to advance scientific research toward better patient outcomes.

This edition, ATS Patient Voices 9, was created to highlight the voices of BIPOC (black, indigenous, and people of color) patients who have experienced disparities on their journey to diagnosis and treatment for their diseases. These stories are vital to understanding that inequities still exist in treatment and access to care within the healthcare system, and only through knowing and understanding struggles such as these can we begin to address how to change them.

Today, we continue to align our work with the unique and urgent needs of individuals living with sleep disorders, critical illness, and respiratory diseases. Together, we’re creating a more unified and powerful research and advocacy community. As our patients gain more knowledge and insight about their diseases and how it affects their quality of life, they remain invaluable resources to us all.

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



Kari Rosbeck
Chair, ATS-PAR

Terry Wright

Terry Wright is a 57-year old African American cystic fibrosis patient who was misdiagnosed for 54 years.



I have Cystic Fibrosis (CF). I was diagnosed three years ago when I was 54 years old, and all these years, I knew something was going on with my body. I was experiencing all these different things: chronic pneumonia, sinusitis, very bad stomach pains, chronic headaches.

I used to wonder as a child why I was sick all the time. I would eat certain foods, and it seemed like it would trigger me to get sick. My stomach would just protrude at the top, and I would have excruciating pain.

I just used to cry, miss school a lot, home sick for weeks at a time. I used to hear my parents talk about how I must be sick, because I would get really quiet and just go in my room and cut the light out and just be balled up.

My mom started taking me to the hospital. They told me I had a virus, I had ulcers, and then just shot me with pain medication. That would just dull the pain, just to get me home,

and then it would get to throbbing back. I was getting to a point, seriously - I just wanted to die.

It also was in my lungs, but at that time it was in the form of a really bad seasonal asthma. I remember playing sports and I'd be breathing rapidly while the other children had already recovered. And no one knew, they just thought I was tired. I kept that part away from my parents. They never knew I had some breathing issues. It was kind of embarrassing, you know, to have different things going on with your body, and have no answers. Emotionally, these are things that come with CF. It was just devastating.

I was so glad, in 2001, when my wife pushed me to have surgery. They removed a piece of my pancreas and one of my ducts. That solved the problem with intense pain in my GI. I wouldn't be alive right now without that. I also started taking enzymes which really helps break down my food. It makes a difference.

After the surgery, the mucus moved into my lungs and sinuses, where it wreaks a lot of bad havoc. It's a thick mucus, like snails. I use irrigation and antibiotic ear drops to break it up. My joints ache in certain areas because that mucus just clogs up everything.

I push so hard on taking care of yourself, even just drinking water, staying active, or going and doing something for someone else. It's a horrible feeling when you can't breathe. You can go into all types of places with your mind, especially if you don't have information about why you feel this way. This is something you have to live with all your life, so you might as well keep a positive mind and do fewer things that can harm you. There are so many things CF patients can do to harm ourselves, like not doing our treatments. It can get us to a point where we can't get help because it's gotten too severe. It's also important to have someone to advocate for you.

I believe that each patient deals with CF differently. I'm just so happy that I feel like it's getting a breakthrough, and we can get a word out. Someone needs to hear my story. Emotionally, I have many scars, but I've learned to live with it and try to keep a positive attitude and just go forward and not be stopped. You have to develop mental stamina in addition to physical stamina when you're dealing with CF.

► *Continued on next page*





When I met my husband, Terry, I saw death. I felt love but I saw death. He was going to the hospital two to four times a week. I didn't know what was going on, but I knew when he would eat something, he would throw it right back up, violently. I knew something was wrong.

Fortunately, because of my pharma background, in 2000 he told me his chest hurt, and I told him he had to go to the clinic. I believed he had pneumonia. You don't play with pneumonia. Terry was diagnosed with double pneumonia, but interestingly the young doctor said, "You know, if you were not African American, I would say you have cystic fibrosis." That was the first time we heard the words "cystic fibrosis."

Terry continued to get so sick that I knew that if we didn't do something, he wasn't going to make it. I started reaching out to everyone I could. I finally found this doctor who worked on the pancreas. He said that in his entire career, he had never seen a pancreas that bad. He didn't know how Terry

was walking, or doing anything, and Terry had just run a marathon! That's when the discussion of the pancreas surgery came up. I was still new in his life, and I was pushing for surgery, but his family was worried about the risk. I don't think anybody realized he wasn't really living; he was barely surviving.

He had the surgery but still by the end of 2016, Terry was hospitalized back-to-back for four to five weeks at a time with pneumonia. He was on several antibiotics but getting worse. I was worried he wasn't going to make it to 2017, and when your advocate starts to give up hope, that's a bad story. At that point he'd seen every top specialist, and it was not looking good.

I tried to think of what we were missing. I thought back to when I used to work with infectious disease doctors. When no one else could find the issue, they could. We needed a fresh set of eyes because doctors had been missing something for 54 years.

I found an infectious disease doctor, and when they asked me what was wrong, I said "EVERYTHING!" I am not exaggerating, within 30 minutes, the doctor said that had Terry not been African American, he would have diagnosed him with CF, but he still wanted to rule it out.

We looked at each other, and said 'Wait a minute, that came up 17 years ago!'

They wanted to send him back to the children's hospital for tests, and we decided we didn't want to go. Finally, I told Terry that

Cystic Fibrosis (CF)

he should just get that check in the box so they can really find out what's really wrong, even though it was wasting our time. We still believed the doctor from way back in 2000, and had ruled out CF. We had the tests done, and I got a phone call a few days later asking that he come back to repeat it. I asked what happened, if there had been a mistake, and the person I spoke to told me to ask the doctor. I thought they found cancer or something. We went back to repeat the test, and they asked if they could send the results to another hospital to confirm. Terry had CF.

Nobody knows the pain patients go through like the people closest to them. To see what he's gone through is just remarkable. This is a person who will do 100 miles on a bike, and then he's done, he's beaten everybody else, he's drenched in salt, he's dehydrated to the point of maybe having to go to the hospital, but he keeps going. He is also a certified Master Gardener and Master Naturalist, and he was Master Gardener of the year. His dream was always to be a Master Gardener, and when they selected him, he had to do the interview in his hospital bed. Ever since then he's been on the top garden projects, like maintaining the Governor's Mansion. We've been married 20 years, and if he's not hospitalized, he's at his mother's house every week, doing her yard.

Disparities happen when assumptions are made – sometimes on demographics, like race. About five percent of CF patients are African American. One misdiagnosed case is too many. There are no excuses. We need to see faces. ■

Cystic Fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. Those with only one CFTR mutation are carriers and do not have it. If both parents are carriers there is a one in four chance their child will have the disease. While there is no cure, life expectancy has steadily improved the median survival exceeding 45 years in the United States. Some other facts about Cystic Fibrosis are:

- There are now more adults than children with CF in the United States.
- Newborn screening for CF done on blood samples can identify most children before one month of age, which allows for early treatment and disease monitoring.
- Older children and adults are usually diagnosed based on symptoms, such as frequent respiratory infections, malnutrition, and/or male infertility.
- CF individuals have abnormally thick mucus, which blocks the airways (obstruction) and leads to repeated infections and damaging inflammation in the lungs. Treatments are directed at trying to prevent and treat these problems.



Learn more

ATS Patient Education Series.
"20 Facts About Cystic Fibrosis."
New York, NY.

<http://www.thoracic.org/patients/patient-resources/resources/cystic-fibrosis-facts.pdf>

Yvonne Lewis-Holt

Yvonne Lewis-Holt is a 27-year survivor of sarcoidosis who advocated for herself to get the right diagnosis and proper treatment.



My name is Yvonne and I'm a 27-year survivor of sarcoidosis and a five-year survivor of breast cancer. My strong faith and strong will to live helped me survive and go through those hard and trying times.

My shortness of breath first started in 1978. One doctor said I had asthma, one said bronchitis, another COPD. I was treated for this for nine and a half years.

Then I met a new doctor. I told him my symptoms, and he immediately started doing tests. I had finally found someone that was going to do something for me. The doctor called me into his office to discuss the results. He said everything was normal, even the x-ray. I knew that couldn't be right, so I asked him what was causing my symptoms. He looked me in my eyes and asked, "Have you ever had psychiatric help?" I will never forget those words. In fact, they still ring in my ears. I left crying and still not knowing what was going on with me.

In 1993, I started a hacking cough. I didn't really pay any attention because I was a smoker. One day, I started coughing up blood. My first thought was, "OH MY GOD! I HAVE CANCER!" I was so scared! I threw the cigarette away, and to this day have never smoked another one. I ran into the house to tell my husband, and he immediately took me to see my doctor, who said I had a bad case of bronchitis, prescribed antibiotics, and sent me on my way.

I was working in a doctor's office at the time and started coughing at work. The doctor said my cough didn't sound good, and she called a pulmonologist, who said I could come right then. I left work and went to his office.

After everything I'd been through in the past, I wasn't looking forward to seeing him and hearing the same thing over again, but I went. After hearing my symptoms, he told me it sounded like I had sarcoidosis, but that to be sure he would have to do a biopsy of

the lungs. I agreed, and we set a date for a couple of days later.

After I woke up in recovery, the doctor came in and told me his suspicions were correct. I had sarcoidosis. He explained that I only had 40 percent of my lung capacity left. Had we found this sooner, we may have been able to prevent the lung loss from being as bad as it was.

He started me on a steroid, and after about two years that stopped working, so he tried several other drugs, before trying a steroid again. I was also on two inhalers. Nothing seemed to be helping me. I kept getting worse. The doctor said my only other option was the sarcoidosis clinic at Johns Hopkins. I agreed and found that when I got to Johns Hopkins, I had an appointment with the head of the department. I felt in my spirit that God had guided me to the right place at the right time.

The doctor talked with me about my history, ran some tests and started me on a new medication, which was a miracle drug for me. My body started feeling better in a week's time. I was really feeling great, breathing better and my spirit was really up.

In 2005, I'd been on that medication for about three years, when I started getting very tired and had trouble breathing. I was admitted to the hospital and into surgery to put in a pacemaker. My doctor said it was a wonder I wasn't found dead somewhere. God is so good!



After the surgery, I found out that sarcoidosis had attacked the electrical system in my body and affected my heart. They put me on oxygen 24 hours a day and diagnosed me with sleep apnea.

In August of 2013, a new doctor took me off my medication because I had been on it so long, and it can cause cancer. In fact, he took me off sarcoidosis medication altogether, because the sarcoidosis burned itself out.

I walked around on a cloud until it floated away from me. During my annual exam, my gynecologist found a knot. He did a biopsy and confirmed I had stage 3 breast cancer.

I opted for a double mastectomy. The surgery was successful and had gotten all the cancer. We were so happy about the news, and I started chemotherapy.

Chemotherapy was the roughest and sickest road I had ever travelled. I had treatments once a week, and always ended up in the hospital. After the fourth of six treatments, I was put in the ICU.

After all those years of believing God was going to heal me, my faith had dwindled. I prayed for God to take me if He wasn't going to completely and immediately heal me. I couldn't take that sickness anymore. It was too much. As soon as I said, "Amen" to my prayer, my pastor knocked on the door. After a short pause, he entered and asked me how I was feeling. I told him how sick I felt. We just looked at each other before he spoke and made me promise to fight physically, while he promised to fight spiritually. With the little mustard seed of faith I had left, I managed to get out, "I promise." He prayed for me and left to come back the next day. I was determined to keep my promise.

The next morning the doctor came in and told me they weren't doing any more chemo, because the amount I had done was enough.

My fights with cancer and sarcoidosis weren't easy ones, but if you don't give up and believe in your heart, trust God, and pray, I know you can beat anything! ■

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells in various organs and tissues of the body. These lumps are called granulomas. Sarcoidosis most often affects the lungs and its hilar lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart. Sarcoidosis varies in how active and how severe it is for each person and over time. Some signs and symptoms of Sarcoidosis are:

- Lungs: Shortness of breath, wheezing or dry cough that may lessen or go away over time in some people, but remain in others.
- Eyes: Burning, itching, tearing, redness, sensitivity to light, dryness, seeing black spots, blurred vision, reduced color vision, and, in rare cases, blindness.
- Skin: Bumps, ulcers, or rarely, flat areas of discolored skin that appear mostly near the nose or eyes or on the back, arms, legs and scalp.
- Heart: Shortness of breath with activity and swelling in the legs. One may have an irregular or fast heart beat at times, or pass out without warning.
- The Nervous System: Headaches, vision problems, numbness, weakness, or loss of movement of arms or legs, drooping of one side of the face, pain or a "pins and needles" feeling.



Learn more

ATS Patient Education Series.
"What is Sarcoidosis?" New York, NY.

<http://www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf>

Laonis Gooden

Laonis Gooden lost her young adult son to severe asthma after he struggled with it for 20 years and aged out of parental insurance coverage.



My son, Anthony, was about 18 months old when he first was diagnosed with asthma. It didn't take too long to diagnose, because he kept having asthma attacks and going to the emergency room. I knew he had it because I have asthma myself, and I'm a nurse, so we went back and forth, between emergency rooms and doctors' offices before they said, "Yes, he has asthma."

He was immediately referred to a pulmonologist/allergist, and they put him on a nebulizer, and he also had inhalers. He was on prednisone a lot, but he still had asthma attack after asthma attack, leading to hospitalizations. He was there so much that he had the same room, the same nurses. They all knew Tony.

It was disheartening because when Tony was ready to start school, the public schools would not accept him because of his nebulizer, and they were not familiar

with nebulizers. So, I had to send him to a private school where I had to pay. One school he went to accepted his nebulizer and his inhalers, but they had to be kept in the office. Whenever he needed to take his medication he would have to go to the office, and by the time he'd get there the attack would be full blown, so we would have to pick him up from school and he'd have another hospitalization. This was Tony's life. He had more days out of school than he had in school.

It was just one thing after another. We went to Canada to find an allergist, we went to sleep studies, we did everything. Tony had allergy shots. They changed his medication. It was exasperating for all of us, including him, but Tony never ever complained. His whole life was on the sidelines because he couldn't do a whole lot of stuff. Depression set in as he got older because he loved football, but he couldn't play football. But Tony had great

friends. In our neighborhood everybody knew Tony had asthma, and they'd all look out for him. I'd hear a knock on the door, and one of the kids would tell me, "Tony's having an asthma attack," or "I don't think Tony's feeling well," and I'd go right down the street and he'd be hunched over. It was just nonstop, really. It was nonstop.

// *Even the pulmonologist, and the people who deal with asthma, they would always say they'd never seen a case like his. But yet even still, they didn't want to take care of him anymore.*

When he turned 21, it was company policy that adult children could no longer be covered under their parent's insurance plan, so therefore the pulmonologist that he had been seeing since he was 18 months old told us Tony could no longer go there. I literally begged them, "Please, please don't do this," because I knew he would have to go to a free clinic. I said I would pay, but the doctor said I couldn't because the fee was too high, and they kicked us out. I had to find a free clinic, which was horrible. It was literally heartbreaking. He saw that physician one time and then we just went and picked up his medications. He didn't have to go back. They never saw him again. I tried to get Medicaid coverage so that he could

see a pulmonologist, but we were denied at least six times. I said, "He is disabled. He can't work. He can't do anything." I think Tony knew things were not going well with the insurance and he began to get more and more depressed. I took him to a psychologist and they put him on medication, but he would not take it because he said it made him sleepy.

On that morning as I was leaving work my younger son called me screaming, I knew something had happened to Tony. He kept saying "He's gone, he's gone, he's gone." Tony passed away in my husband's arms. My husband never got passed it. Six months later, he also passed away.

The disparities, for me, came from not having proper insurance coverage. Even the physician he had been going to his whole life, who knew Tony like the back of his hand, knew how sick he was, just refused to see Tony. And the free clinic we went to -they didn't know him. They saw him that one time, they knew he had asthma and that was it.

My youngest son has asthma. I have asthma, my niece and nephew, just about my whole family, but no one had it like Tony. No one. He was the sole case that had it like that. Even the pulmonologist, and the people who deal with asthma, they would always say they'd never seen a case like his. But yet even still, they didn't want to take care of him anymore.

I'm still heartbroken and probably will be for the rest of my life. I started the Breathe Anthony J. Chapman Asthma Foundation because there are so many other families out there that are like mine. Medications cost a lot of money. I know there are other families that may not be able to afford the medications. The Foundation is going to help out with that. It's all because of Tony. Tony was a helper. He loved the Lord, was a Christian, and was just a caring and very humble person. I have come to think this is God's way of still allowing Tony to be that person. He has inspired me to do something, to help someone else. Tony was always like that. The thing to honor him the most is to help someone else. ■

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 betablockers (heart or blood pressure medicine)
- Sulfites in foods such as dried fruits, wine and beer



Learn more

ATS Patient Education Series.
"What is Asthma?" New York, NY.

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

Drushane Teehee

Drushane Teehee lost her teenage son to suicide after struggling with severe asthma for most of his life and having many challenges getting treatment from the local healthcare system.



My son, Izaiah, was nine years old when he was first diagnosed with asthma. I didn't really know much about it. The doctors just said, "Oh, he has asthma" and gave him an albuterol inhaler. They gave him medication to take, too. He took it every now and then, but it was usually just the inhaler. That worked fine for a few years.

His asthma progressed when he became more active and involved with running and sports. It seemed like that's when it became harder for him to breathe. He also had allergies - our weather is crazy - nice one day, cold the next or hot and humid, or rainy, and it messed with his asthma. Then they thought he was allergic to cats, so we kept the cats away from him. They changed the inhaler to a different brand of albuterol and then added another inhaler.

He wasn't recommended to a specialist until he was 16, about a year before he passed away - we didn't even know what

a spirometer was until then. From the ages of 9 to 16 we had no knowledge about how he should be breathing or what his lungs should be doing. We use the Indian healthcare system, and in our health facility we are not given one specific doctor to see, just whoever is available or has an opening in the follow-up time frame. I remember a time when one doctor did tell my son to return in a week or two for a follow-up. We returned in that exact time, requested the same doctor, and then waited about six hours to see her. She was actually upset with us, because we had waited and hadn't just seen whoever was available. The treatment we received from some doctors made us feel that they just wanted to get us in and out without actually listening to the patient. From my experience, they would do an x-ray and if that was fine, that was it. It's as though they didn't want to do more testing. Izaiah was having more and more problems with his asthma that sent him to the emergency room several times within a couple weeks' time. The Indian hospital

Emergency Department has a policy, if you check in after 5 p.m., they determine whether it's an actual emergency. If it's not life or death, then they send you to urgent care. We didn't have any real care for the asthma - it was basically, "Here's an inhaler. Good luck."

Eventually he couldn't even go outside without having an attack, so he always had to have his inhalers. That's when they put him back on daily medication. And it seemed like it got worse after that, because that's when his lungs started swelling. I had him in the emergency room several times, and the doctor said his lungs were so swollen they were pushing up against his ribs.

His breathing was getting to him. He would get frustrated because he loved to run. He was pretty fast. He loved to do that. But then he started having attacks in the middle of races. He'd have to stop, try to regain his breath, and then he'd still push himself and finish. Afterwards, I'd have to take him to the emergency room because he couldn't breathe. He started running less and started staying inside more. He also led praise and worship at our church, but when he was singing, he would get short of breath, so he'd have to stop and play his bass. He was starting to play the keyboard, but he didn't have that mastered yet. Overall, Izaiah was very active in our community. He always helped with food banks, soup kitchens, always volunteered to help do stuff for other people.

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We had noticed he'd been short with people and we just thought he was aggravated with his asthma, or just being a teenager. He was a junior in high school, had straight A's, was class president, so there were really no signs we saw that we would associate with suicide. He was planning a mission trip to Costa Rica, raising money, and trying to sell shirts he designed for his trip, so he was still looking at the future. He had names picked out for his future kids, knew where he wanted to go to college. He was goal oriented. The morning that he died, he had been supposed to leave for Texas to lead praise and worship there. He had been out the night before with his friends, and when he came home, he just came in like he always did, said goodnight, and went up to his room. The next morning, we found him. It just didn't make sense at all. Because here's this kid that's going to Texas to lead praise and worship, he's going to Costa Rica, it's the end of his junior year,

he'd just been elected class president for his senior year. He had all these things going for him, and then he was just gone. We had never been told about the mental health elements that can come with asthma or told about the possible side-effects of his medications, and I just kept thinking, "Why my boy? Why my son?"

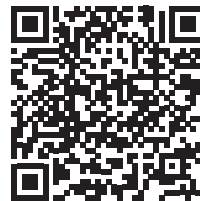
It's the hardest thing in the world to get up every day and continue, so that his life, his death is not in vain. This hurt my child so I'm going to fight against it to help another family, so they don't have to go through what I've gone through. The good thing is, since we have a tribe clinic, I have my tribal council members helping me to make sure doctors know about this aspect of asthma and its treatment. I work with an advocacy group that recently got an FDA black box warning for serious mental health side effects added to one of his medications. I'm just hoping that people's lives will be saved, and that other families won't have to bury their child. It changes you. You'll never be the same again.

Izaiah is still helping other people. He wanted to be a missionary, he wanted to be a doctor, he wanted to be president. I always knew he was going to change the world somehow; I just thought he would be here to do it. I thought he would be able to see it himself, instead of going through me to get it done for him, but anything for that boy. ■

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:

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- Strong odors from paint, perfumes, colognes, hair spray, deodorants, and cleaning products
- Tobacco smoke from cigarettes, pipes, or cigars
- Temperature or weather changes
- Stress or exercise
- Medications, including aspirin and betablockers (heart or blood pressure medicine)
- Sulfites in foods such as dried fruits, wine and beer



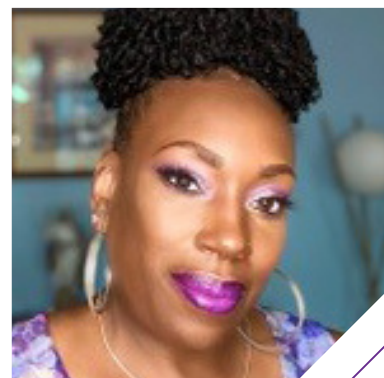
Learn more

ATS Patient Education Series.
"What is Asthma?" New York, NY.

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

Cheryl Bradford

Cheryl Bradford is a sarcoidosis patient who struggled for years to find a healthcare provider who would take her and her illness seriously.



I grew up in Queens, the youngest of six. My block was the coolest in the neighborhood. On Saturday mornings, I would wake up to the sound of jazz music, my father's favorite, playing throughout the house.

My mom was the Big Momma of the neighborhood. She was from Bermuda, believed in the power of prayer, and always trusted in God. One of our traditions is "putting the kettle on," meaning that we never needed an excuse to make tea. In my family, tea would solve anything: whether you were sick, hurt, or sad, mommy would pray for you and give you tea and everything would be okay.

I wish life was still that easy.

I was getting ready for church one morning, and started feeling sick, like someone had peeled the skin off my entire body and was poking me with pins. I went to church anyway,

but afterward, I went to my parents' house. I always felt like that was the best place to be if you're sick, so I crawled into my mom's bed. We called the doctor, who told us to go to the hospital. I had a fever of 104 degrees and felt like I was in a daze. I was having a difficult time breathing, so the doctors took a lung biopsy, and there it was. At 30 years old, I was diagnosed with sarcoidosis. Looking back, I feel sort of lucky to have been diagnosed so quickly, because I know that sarcoidosis can be difficult to diagnose.

The doctors didn't really explain my condition to me. I had to do a lot of my own research, but it still wasn't the kind of information I know now. At the time, I was able to understand that sarcoidosis was a rare inflammatory disease. I learned that it is more common in African Americans, especially women, and that most sarcoidosis patients experience serious lung involvement. There is no cure. It really didn't hit me how sick I was,

because at first, I just had that one episode. Within a month or two, I recovered, so in my mind, I was better. I went back to work and I got on with my life.

Ten years later, I started having a chronic cough and chest pain, but had trouble getting a pulmonologist to take it seriously. I was told by one that the pain was in my head. Another asked if I thought it could be a sinus drip; he could not explain the chest pain, nor did he even check for a cause. When I could not get a specialist to help me, I tried on my own, with over-the-counter medicines. My condition was getting worse, but I had no clue. The pain eventually went away, but the chronic cough persisted.

Eventually, I found a pulmonologist to look into this further. He sent me for a chest x-ray, and asked me to come in to discuss the results. I thought I had finally found a pulmonologist who could help me. Boy, was I wrong. He showed me the x-ray of my lungs and explained to me in medical terms what was going on. I was so confused – I didn't understand anything he said. When I told him I didn't understand, he didn't clarify anything. He just asked if I was still in pain. I told him no, and he said he would not do anything if I wasn't in pain. I had no idea that I needed immediate medical attention. I had no idea that the sarcoidosis had taken over my lungs.

My life went on. I was so disappointed, I never went back to see him again. I decided to just deal with the cough, but that wasn't

as easy as I thought. Later that year, I went to North Carolina to spend Christmas with my daughter, and coughed up blood for the first time. My mother and my sister were there, and they tried to get me to go to the emergency room. I refused to go to the hospital there, so instead the three of us drove all the way back to New York. By the time I got home, the bleeding had stopped. I had already seen so many pulmonologists who didn't do anything to address my cough, I thought I was ok and went on with my life.

A few months later, I was back in the ICU after coughing up blood again. The doctors did not tell me much, or answer the questions that my family and I had asked. A surgeon told me that I might need lung surgery, but he did not explain why; that was the first and last time I saw him. I was released a week later and told to follow up with the hospital's pulmonologist.

In January of 2013, I coughed until I passed out. I woke up in a pool of blood with a split lip and a missing tooth! I looked in the mirror and it almost didn't register. I kept thinking, "I can't go to work like this. My tooth is missing!" My sister Vera rushed me to the hospital.

My condition was grave, and doctors told my family I wasn't going to make it. Through determination, prayer, support of my family and friends, I pulled through. The surgeons started suggesting a double lung transplant, as both lungs had such severe damage: there were holes throughout my lungs, as well as several fungal balls inside them. I was also

diagnosed with Interstitial Lung Disease (ILD) and scarring of the lungs, all on top of the sarcoidosis. After 45 days in the hospital, I was released.

I went to see a new pulmonologist, and he wanted to do his own biopsy. An EKG and an angiogram confirmed that sarcoidosis had also affected my heart, and the doctor diagnosed me with pulmonary hypertension, too. He addressed me very seriously, "You should have come to me a long time ago – you were not getting the right treatment and now you are in grave condition." It took us awhile, but we eventually settled on a treatment plan that was a good fit for me, and he is still my doctor today.

Applying for Disability was an emotionally difficult step for me to take, because I had always planned to work until later in my life, but in the end, I know it was the right choice for me. Now, I spend my days with my family and friends, volunteering and exercising, just caring for my body and never pushing it. I always find time to spread awareness and advocate for sarcoidosis. I am a Patient Ambassador for the Foundation for Sarcoidosis Research and a Mentor for ILD at Snow Companies. Most recently, three members of my sarcoidosis family and I started an organization called Stronger Than Sarcoidosis (STS). I'm so grateful for my life and my family, and always look forward to spending time with my biggest fans, my daughter Lynette and grandson Samir, who live in Charlotte, North Carolina. And I think my mom and dad would be proud of me. ■

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells in various organs and tissues of the body. These lumps are called granulomas. Sarcoidosis most often affects the lungs and its hilar lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart. Sarcoidosis varies in how active and how severe it is for each person and over time. Some signs and symptoms of Sarcoidosis are:

- Lungs: Shortness of breath, wheezing or dry cough that may lessen or go away over time in some people, but remain in others.
- Eyes: Burning, itching, tearing, redness, sensitivity to light, dryness, seeing black spots, blurred vision, reduced color vision, and, in rare cases, blindness.
- Skin: Bumps, ulcers, or rarely, flat areas of discolored skin that appear mostly near the nose or eyes or on the back, arms, legs and scalp.
- Heart: Shortness of breath with activity and swelling in the legs. One may have an irregular or fast heart beat at times, or pass out without warning.
- The Nervous System: Headaches, vision problems, numbness, weakness, or loss of movement of arms or legs, drooping of one side of the face, pain or a "pins and needles" feeling.



Learn more

ATS Patient Education Series.
"What is Sarcoidosis?" New York, NY.

<http://www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf>

Leslie Rojas

Leslie Rojas of Puerto Rico, has Hermansky-Pudlak syndrome and needs to move away from her home, friends, and family to have a chance to enter a transplant program on the mainland.



My name is Leslie, and I was born with a rare genetic disease. I have no pigmentation on my skin. I have lived my whole life in Puerto Rico, where the sun's UV index runs from moderate to extreme all year long. I did not have access to sunscreen. Throughout my childhood my parents tried to keep me indoors to prevent my skin from burning, but I always found a way to go out and play. When I started primary school, I learned I was legally blind.

One afternoon, when I was 14 years old and visiting my aunt in New York, her dog chased me around the apartment and I fell. When I stood up, my face was covered in blood. The bleeding did not stop, so I was rushed to the hospital where I continued losing blood through my nose and mouth for about five hours. I was admitted to the hospital that night, but I didn't understand any English so I could not understand what was happening. I was hospitalized for a week and after multiple tests, doctors diagnosed me with Hermansky Pudlak Syndrome (HPS).

After completing college, I began searching for a job as a chemist. It was almost impossible for a legally blind chemist to find a job. A year passed, and I was offered a position as a laboratory technician at a pharmaceutical company. I had to work with solvents that in some instances could be dangerous to the lungs, so every year they would perform a pulmonary function test (PFT) on the lab analysts. I still did not know about the lung element of HPS. When they found that my lung capacity was declining every year, I was referred to a pulmonologist. I had a Gallium scan and the results of the test indicated that I had an inflammatory process consistent with pulmonary fibrosis (PF). The results were devastating. I had a terminal disease and there was no treatment, no cure, no hope.

I was so scared! For days I could not sleep, nor eat a full meal. I could not think rationally and could not go to work, where I had been relocated out of the lab, and

had started working on computer systems. At nights I just laid down on the sofa crying until I fell asleep, just to wake up an hour later to start crying once again. I remember trembling and shaking, and my teeth chattering uncontrollably. In time, accepted my diagnosis and decided to learn more about my condition. I visited several pulmonologists in Puerto Rico, but none of them could agree on the stage of the pulmonary disease, or on a treatment option. One of them mentioned that the NIH had a protocol on HPS related pulmonary fibrosis, but I would not be accepted because I had HPS Type 1, which he said was “the less severe manifestation of HPS.” I tried to explain to him that Type 1 was the most serious form of the disorder, but he told me I was wrong and did not provide the referral to the NIH. Little did he know that the NIH was only a few clicks away from an educated and persevering patient.

I contacted the NIH directly and I began a drug trial with the NIH in 2006. I was on the medication for three years and was stable up until 2010, when they first started to see some scarring on my lungs. In 2017, we started seeing a major change from my annual CT scans, and that’s when the doctor told me I should move to the mainland U.S. so I could be close to a hospital where I can have a lung transplant. Hospitals in Puerto Rico perform kidney, liver and even heart transplants, but no there is no lung transplant



center on the island, so I would have to leave my job, my home, friends, and family to have a chance to enter a transplant program.

I started researching hospitals recommended by my pulmonologist at the NIH, but then we were hit by Hurricane Maria. I lost the connections I’d made, and so I went to stay with my sister in New Jersey. From there, I traveled to Boston and had my first evaluation for a transplant. It was an interview, not a medical evaluation, but the doctor told me I was not ready to enter into the lung transplant center because I was

too healthy. I returned to Puerto Rico, and I talked to the NIH. They went back to the doctors in Boston and told me I should go back and start on relocation, but since I was already back in Puerto Rico and feeling well, I decided to stay.

I decided to go back for evaluation last year, so in September of 2019, I went to Boston to begin the series of tests to prepare for the transplant. I told them that I had a thyroid nodule, and I brought all my x-rays and ultrasounds. I also scheduled an appointment with a surgeon in Boston who told me that the nodule should normally be removed, but because I have a history of bleeding, I should first ask the transplant program. The



doctor in the transplant program agreed that the nodule should be removed and tested for cancer, because you have to be free of cancer for five years before you can even be considered for a transplant. I decided to return home to coordinate coverage with my insurance and coordinate after care with my endocrinology doctor. I also needed the results from an HLA platelet match test previously performed at the NIH, so my doctors in Boston could find a donor with the same antibodies to avoid rejection after the lung transplant. The thyroid surgery itself has to be performed in Boston, because I saw two experienced surgeons here in Puerto Rico, two of the best on the island, and neither will do the surgery because I am high risk for both bleeding and for the extubation process. I scheduled the removal surgery for March 23, 2020.

The COVID-19 pandemic changed my plans. My procedure was cancelled, and I could not travel. My pulmonologist recommended that I should stay home to prevent exposure to the virus and on March 13, I began to work from home. Since then, I have stayed at home working, ordering groceries with an app, and praying for the end of the pandemic. I have not visited my doctors and have not been able to schedule the surgery. This summer has been warmer than previous years, and we have received clouds of dust from the Sahara Desert that have resulted in many days of unhealthy air quality. The island has also been skimmed by two tropical storms and earthquakes can be felt from



time to time. It seems that I will not be able to travel until a vaccine is available. I can only hope that my thyroid nodule stops growing, and the pulmonary fibrosis does not progress to a point where I would need oxygen, especially as we continue to lose power on the island as a result of the storms and earthquakes.

At this point, I am not currently on the transplant list because I still need to have the nodule removed. I need to have that nodule removed as soon as possible, before it turns to something bad, because so far tests have said it is negative for cancer but the last one was undetermined. I will not be on the list if the nodule is positive for cancer. That will be a big problem for me. ■

Hermansky-Pudlak Syndrome (HPS)

Hermansky-Pudlak Syndrome (HPS) is a rare inherited disease, named after two doctors in Czechoslovakia, who, in 1959, recognized similar health conditions in two unrelated adults. Since the discovery of HPS, the condition has occurred all over the world but is most often seen in Puerto Rico. The most common health conditions with HPS are albinism, the tendency to bleed easily, and pulmonary fibrosis. Some other facts about HPS are:

- Albinism is an inherited condition in which reduced pigmentation (coloring) is present in the body. As a result, people with albinism are often fair-skinned with light hair.
- HPS patients have platelets that are not made correctly and do not function well, so the blood does not clot properly. As such, persons with HPS may bruise easily and have other issues such as frequent or heavy nose bleeds.
- Pulmonary fibrosis in HPS occurs in those individuals with HPS1, HPS2 and HPS4.
- HPS patients have reduced eye pigment and during early eye development the eye and surrounding nerves grow abnormally. This can lead to poor vision, the development of crossed-eyes (strabismus), and nystagmus (uncontrolled eye movement from side to side).



Learn more

ATS Patient Education Series.
"What is Hermansky-Pudlak Syndrome?" New York, NY.

<https://www.thoracic.org/patients/patient-resources/resources/hermansky-pudlak-syndrome.pdf>

Sheron Williams

Sheron Williams is a sarcoidosis patient who went misdiagnosed for many years as having kidney and bladder infections or as having been poisoned.



I was diagnosed with sarcoidosis Dec. 15, 1992. I was symptomatic for about two years prior to that, but doctors just simply didn't know what was wrong with me. I went from doctor to doctor. I was told it was a bladder infection, a kidney infection, and I should drink more water, drink more cranberry juice. One doctor told me I had been poisoned! I was very active, I was in my mid- to late-20s, and I just couldn't understand why I was so exhausted. I would have rashes one day that weren't there the next day, my eyes would be blurry.

Finally, a friend suggested I go to the hospital. The doctor pretty much examined me for five minutes and told me I either had tuberculosis or sarcoidosis. I thought to myself "Oh my goodness, I've been going to doctor after doctor for two years and this man just walked in the room and knew what was wrong with me." After a couple of tests came back, he confirmed I had sarcoidosis, but he believed at that

time that I was perhaps at the end of a flare up.

I don't remember if he put me on medication, but after the new year a whole new reel of symptoms started to occur. The taste of food started to really turn me off. I could not eat. It was hard for me to swallow. It got to the point where I was carrying a bottle because I couldn't even swallow my own saliva, so I would spit in the bottle. It got to the point where I was sleeping the entire day, my speech started getting slurred, and my mouth would be moving but only every other word would come out. I didn't realize that the back of my throat was actually closing. I didn't know because I wasn't in pain. Eventually I went back to the hospital, and they found that my sarcoidosis was traveling through my spine, and affecting my nervous system, which is why I didn't have any pain. They worked on me around the clock from that afternoon until two or three in the morning. I was so small that even

though I was 27 years old, they thought I was a teenager, and they asked my aunt to contact my parents to have them sign the consent forms! It had knocked out the uvula in the back of my throat, and that was why I couldn't swallow. It was also affecting my brain and liver.

I spent a month in the hospital with a feeding tube. I went to the library there at the hospital and found everything I could on sarcoidosis.

I went home at the end of January and I still had the feeding tube for two weeks. I was on an extremely high dosage of steroids. For a couple of years, I didn't work. My life as I knew it had completely changed. I went from full-time student on the Dean's List, working two jobs, and being in a play to absolutely nothing. It wasn't until close to four years went by before it went into remission again.

Twelve years ago, it started to really manifest again. By this time, I was supervisor in a bank managing several branches. I went to my primary doctor, who was not involved with my pulmonologist. He did blood work, and I remember getting a call at work. The doctor asked, "Ms. Williams, is there something that you want to tell me? I'm looking at your bloodwork here. Is there something you want to tell me?" And I remember being at work and trying to be quiet so people won't know what's going on, and I said, "No, what are you talking about?" and he says "Are you having



a drinking problem?" I was like, "You idiot, my sarcoidosis affects my liver! I am not an alcoholic." That day I knew he wouldn't be my primary doctor anymore. How can you call someone at work and ask them if they are an alcoholic without even really looking at their tests or their medical records? I was so livid.

A few weeks later, I was driving to work, and I felt something dripping and I looked, and I was having a nosebleed. I drove myself straight to the hospital and to my pulmonologist. He told me the sarcoidosis was affecting my liver very badly, my kidneys and part of my brain again. He wanted to do some really heavy doses of steroids. However, they could not do that high a dosage because of my liver and the kidneys. We started using trial and error, with constant blood work. I was in the hospital for a couple of weeks and the doctor told me that when I left, I couldn't go back to work again.

In 2010, they put me on oxygen. As long as I'm sitting or I'm calm, I'm ok but any time I have to exert myself, or I go out I have to have my oxygen. I have two inhalers and I sleep with a CPAP machine so I can constantly breathe properly when I'm sleeping. We also found a medication that works.

Then, in July of 2018, I was diagnosed with triple negative breast cancer. I thought to myself, "You gotta be kidding me!" but because I go every year to get my mammogram, it was caught in time, but I still required a surgery to remove it.

// I don't care what side of the table you stand on. Illness is illness, a sickness is a sickness, a disease could care less when it grabs hold of the body. It's just looking for a host. It could care less about your political views."

However, in order for me to have my surgery, and then do chemo and radiation, they had to take me off my sarcoidosis medication and risk my sarcoidosis hitting me harder.

I started chemotherapy within a month of the surgery and my first day of chemo I almost died in front of my mother. I was allergic to the medication that was chosen for my chemotherapy. I was doing fine on my pre-meds but as soon as they started the chemotherapy medication, I seized. I remember falling back, and my insides were on fire. I heard them saying "Miss Williams, we got you. You're having an allergic reaction." I remembered my meditation strategies, so I thought to myself, "Listen to their voices, they're coaching you through this. It's going to be ok," as my body calmed down. Two days later I went back, and we started a new chemotherapy, and six months after that, I went through radiation. I finished everything on March 30, 2019 and went back on my sarcoidosis medication again.

The entire time, I was still doing my activist work. I helped in getting three bills introduced to the Michigan Legislature. I don't care what side of the table you stand on. Illness is illness, a sickness is a sickness, a disease could care less when it grabs hold of the body. It's just looking for a host. It could care less your political views. I also continued to run the support group I had started – because I wanted a group based on empowerment – and hosted our third annual walk to raise money for the Foundation on Sarcoidosis Research one month after my cancer treatment. This year would have been the fourth year, but it was canceled because of COVID-19. I had it scheduled for a park, and I had all these sponsors and everything, and then the pandemic hit, but I'm not even worried. I know next year will be even better. ■



Sarcoidosis

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Learn more

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"What is Sarcoidosis?" New York, NY.

<http://www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf>

Epilogue

For those in roles with high patient-engagement, such as clinicians, or patient advocates, the patient is never far from mind.

No matter how many medical advancements we make, we will always have things to learn from patients. The experience of living through, or living with, a disease like many of our patients have faced, has made them well-equipped to remind us of the realities of survival.

Taking the time to read their stories reminds us that to them and to their communities, they are not an asthma patient, or a COPD patient, or even a lung cancer survivor. They are a parent, a friend, or a neighbor who has asthma, or COPD, or who has beaten lung cancer. Their disease does not define them, even when it does define their daily lives.

We remain grateful to the patients who share their stories with us, and who remind us that life with these diseases is more than possible – it's critical. They remind us that every milestone is important: every treatment that makes their lives a bit more normal, every intervention that makes breathing a bit easier, allows them to focus less on their disease, and more on their lives. By hearing their stories, we can inform our own work – where do they see a need for innovation? What do they see from their proximity to the disease?

Patient Voices is a great way to remind ourselves of patients' expertise in their own disease and treatment, and once a year isn't enough. That's why the ATS, in conjunction with PAR partners, dedicates specific patient education weeks to individual diseases throughout the year. During those times we bring patient advocacy groups together with expert clinicians and researchers to shed light on disease and treatment, and facilitate a public conversation. We talk about the existing state of treatment, as well as where treatments are headed. By connecting our members and PAR partners, the ATS not only highlights the patient experience, but also encourages collaboration as researchers are able to connect with the many resources our partners offer, from grants to patient registries.

Thanks to input from all stakeholders including, patients, families, clinicians, scientists and researchers, we can continue to move forward, together. ■



Courtney L. White, CAE
ATS Director, Patient Outreach,
Equality and Engagement

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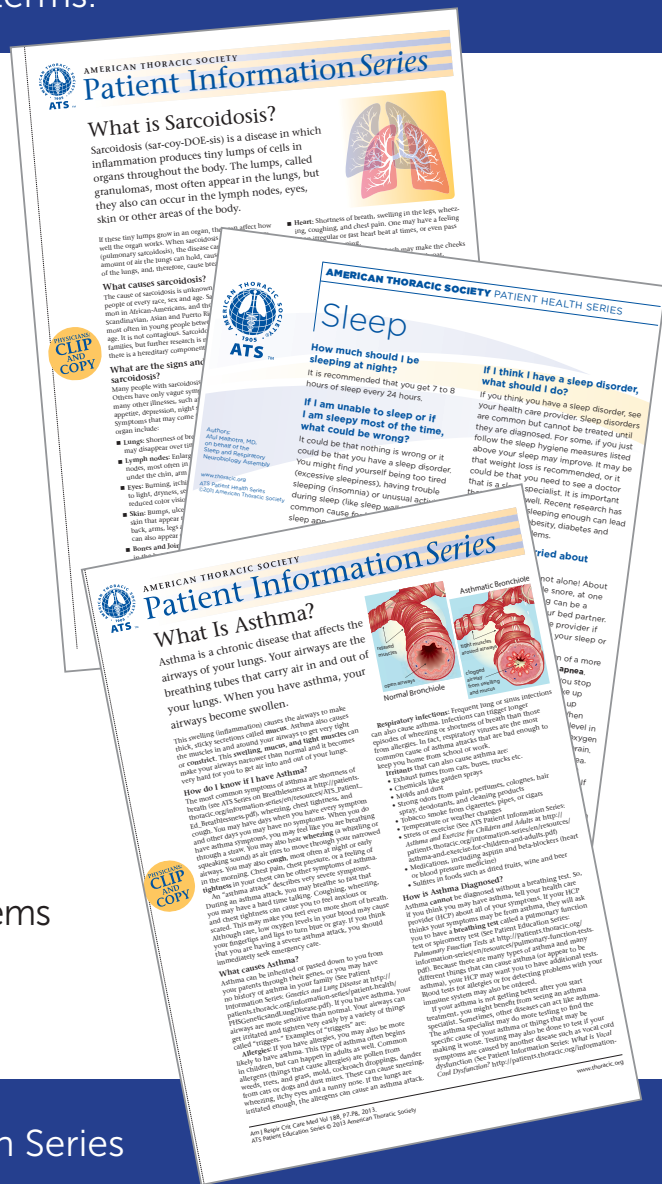
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This publication includes stories of patients with lung disease as told to the American Thoracic Society by the patients or their representatives. The views expressed in these stories do not reflect those of ATS. The ATS makes no claim as to the efficacy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

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—SHERON WILLIAMS

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