

10th
Edition

Patient Voices

Caregiving Ecosystem: Stories of Advocacy
from Patients and their Allies

A publication of the American Thoracic Society **Public Advisory Roundtable**



ATS

American
Thoracic
Society

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.



In Memory of Jeff Goldstein

This edition of Patient Voices is dedicated to Jeff Goldstein, who was a devoted patient advocate in the lung transplant community and a long-time member of the ATS Public Advisory Roundtable (PAR).

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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 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 highlights a critical component of the journey—



Lynn Schnapp, MD, ATSF
President, ATS (2021-2022)



Karen Collishaw, MPP, CAE
CEO, ATS

the care team and advocates who walk alongside. This year, we are including the voices of the caregivers themselves to shine a light on what it's like to watch a loved one navigate the difficult transitions of lung disease, from the emotional toll of seeing a loved one struggle, to the power of becoming an advocate.

Throughout the book, we'll see how caregiving can take many forms, starting with immediate family and professional caregivers, and rippling out in concentric circles to include neighbors, church communities, and the community at large.

The stories illustrate many ways care teams provide support in the fight against respiratory disease, we're grateful to the contributors for sharing those experiences. We also share in their hope that this edition will raise awareness about lung disease and its far-reaching effects for those impacted.

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

Chair's Message



Michele Manion
Chair, ATS-PAR

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 10, was created to highlight the voices of patients and their caregivers who have helped them on their journey to diagnosis and treatment for their diseases. These stories are vital to understanding that complexities that still exist in treatment and living with these life changing diagnoses.

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. ●



Judy & Bob Luther

Idiopathic Pulmonary Fibrosis

About 20 years ago, my husband, Bob was diagnosed with a hiatal hernia. He had struggled with acid reflux and chronic cough. He was put on GERD medicine. However, his chronic cough, chest pain, and shortness of breath did not desist. Our family physician ordered cardiac testing, which showed normal results. As his symptoms persisted, he underwent cardiac evaluation approximately every two years for many years. Finally, our family physician ordered pulmonary function testing which showed restrictive lung disease with 40 percent lung capacity. We were referred for a CT scan, and Bob was found to have interstitial pneumonitis which eventually became idiopathic pulmonary fibrosis. In addition, the left side diaphragm was barely working which just compounded his struggle with breathing. The doctor informed us in the kindest way that Bob had three years at most to live. He was evaluated by the lung transplant department but found to be a poor candidate.

Bob was a fit man. Before he became sick, he would run two miles, five days a week. In the beginning of his illness, he continued to walk on the treadmill, obviously at a slower pace and less distance. He would keep his pulse oximeter on his finger. I would stand beside him, watch his oxygen levels and breathing, and run to the living room to turn up his oxygen as needed. We were advised by all the doctors and pulmonary rehab to keep exercising as long as he could tolerate it. But what was also important was to keep Bob's frame of mind positive, and exercising was an important activity before the illness. He needed to feel a sense of himself.



With chronic lung disease, come restrictions in public activities. Exposure to illness can quickly compromise lung function. As a result, we were not able to go to church as often, walk around the mall, or go out to dinner with friends. Our friends would have us over for dinner instead of going to crowded restaurants, or they would come to our house for a visit. Every day we took a two-to-three-hour drive in the car. We would drive in the country or around town, often stopping in front of the church for a short prayer. There was such joy for Bob in these drives. He felt freedom from the house and escape from his disease.

As his disease progressed, Bob became almost childlike. He did not want to be without me close. When he could not catch his breath, he would lean forward and point to his back. I was the only one who could talk him down from panic. If he lost his breath, he would become panicked and breath faster and faster. I would hold his hand, look in his eyes, and say, "Smell the rose. Blow out the candle." He would watch and follow my breathing. His best compliment was to tell our girls, "You know your mom is my angel."

Bob had to take many medicines and restrict his salt and fluid intake. I had a medicine and an intake chart recording all day. A typical schedule looked like:

- Woke up three times a night for bathroom, requiring oxygen to be turned up. Once he was back in bed, I had to turn his oxygen back down.
- I would help him shower, and dress.
- He would relax in living room for couple of hours so I could handle laundry, house cleaning, and quick errands, if possible.
- At noon, we'd start our daily two- to three- hour drive by stopping at McDonalds for a chicken snack wrap.
- Once home, he'd walk on the treadmill. I would watch his oximeter and adjust his oxygen.
- I'd get him back to living room and settled, so I could cook dinner.
- I'd clean the kitchen and join him to watch T.V., all the while watching him breathe, and adjusting his oxygen levels.
- I'd take him to bed and get him settled, and he would keep his cell phone so he could call if he needed me, which he usually did at least once.
- Once he was asleep, I'd take some time for me out in living room before going to bed myself.



As you can imagine, this took its toll on my body. Trying to keep weight on him meant higher calorie meals, and our schedule did not allow time for me to exercise. My sleep became fragmented and shallow. Eventually, I had to hire visiting nurses to help. My body could not keep up with demands of disease progression.

We have the most amazing group of friends. If I needed anything, they were there. Our girls, Kari and Dana, called often and came for visits. Both girls lived on the east coast and could not be with us constantly. Our grandson, Trent, came to live with us while he was completing college at Eastern Illinois University.

He helped with chores around the house, and his youthful presence lifted our spirits. He would also take his grandpa for drives sometimes to give me some time to myself.

“In Bob’s case, there was no limit to his oxygen needs. He would be up to 10 liters per minute by the end. He was tethered to a concentrator with yards and yards of tubing. It was never difficult to know where he was in the house.”

Bob had very good medical care from all the medical staff. He used to say that he spent years exercising, eating properly, not drinking because he was worried about his heart, but that it would have been better if it had been his heart because there had been so much research and problem solving for the heart. He wanted research to continue for lungs as it had for the heart.

In conclusion, I want to give advice to families caring for loved ones suffering from chronic illness.

- Make lists and charts. When you stay organized with all the medications, fluid intake, sodium intake, or other information you need to manage, you can manage your day with a clear head. You will be less flustered if you can reference your notes throughout the day instead of trying to just remember all the small details.
- Engage a formal palliative care program early in the illness instead of creating your own patchwork system. This will help to keep loved ones out of the emergency department or hospital and support your decisions regarding care.
- Take advantage of your family and friends' offers of support and do NOT feel guilty for asking for help. It is paramount for your wellbeing. Respite care is important for all involved in patient care. ●

Idiopathic Pulmonary Fibrosis

Pulmonary fibrosis literally means scarring of the lungs. Over time, fibrosis can worsen to the point that patients may need supplemental oxygen to raise low blood oxygen levels, relieve shortness of breath, and improve exercise ability. Other facts about Pulmonary Fibrosis are:

- Pulmonary fibrosis can happen for many different reasons, including autoimmune disorders, environmental/occupational exposures, as a side effect of certain medications, and other causes. In many cases, despite extensive evaluation, the cause is unknown; we call such cases idiopathic.
- IPF is usually diagnosed in people between the ages of 50 - 80 years. IPF is very uncommon in people under the age of 50 years.
- Most people with IPF will have shortness of breath, exercise limitation, and cough as the disease progresses. Many people will require oxygen at some point in their life.

[Learn more](#)

ATS Patient Education Series



Monica & Helen Ramirez

Scleroderma



In 2009, during a trip with my husband, I noticed my fingers changed color when I entered a cold room. I mentioned it to my best friend who was also my primary doctor at the time. As soon as she saw my hands, she saw it as a sign of Raynaud's phenomenon, ordered a test, and referred me to a rheumatologist. The rheumatologist diagnosed me with scleroderma and notified me of the life expectancy, which wasn't long.

When I was diagnosed, I was working as an operations manager in an international bank. I consider myself to be a warrior, and so I began to look for other options and specialists, who all gave the same diagnosis: chronic, degenerative condition, without a cure.

The second manifestation of scleroderma was my gastric reflux, which became so severe that I had to sleep sitting up, taking antacids, and not eating past six in the evening. I also avoided spicy foods, and anything heavily seasoned or acidic. I began to lose weight. No matter which precautions I took, I would still have gastric problems. Food would get stuck in my throat, and I suffered from abdominal inflammation, and vomiting. The gastroenterologist ordered exams that confirmed motility issues and gastroparesis. Medication helped the motility, but the gastric issues worsened. In 2011, after multiple hospitalizations and being otherwise confined at home, incapacitated and dependent on total parenteral nutrition and jejunostomy tube feedings, I weighed 70 pounds, and required a home health nurse in addition to assistance with activities of daily living. My prognosis was poor. All I could think about was my daughter, who had not yet graduated high school and how many dreams she had ahead.

Regardless of what happened, I continued having faith and believing in signs God sent me. In December of 2014 I was hospitalized due to an infection in my PICC line. During my hospitalization I had a cardiac pause of six seconds, which resulted in me getting a pacemaker.

A month after receiving the pacemaker, I had to see a cardiologist for a routine check. He happened to be married to a rheumatologist. I made an appointment with her, and my health began improving immensely.

“For us this was not the final verdict, the doctors had only given a diagnosis but the one who had the last word was God.”

It's been 11 years since my diagnosis and I've had many complications, but I've found my new purpose in life, helping people with scleroderma. The Miami bilingual support group has given me energy and strength. It has blessed me. Though I have scleroderma, pulmonary fibrosis, Raynaud's phenomenon, gastroparesis, hypothyroidism, Sjogren's syndrome, Telangiectasias, and calcinosis, I have an entire medical team who stay up to date on research and make me feel like their favorite patient. On top of this medical team, I have my best friend and the best nurse in the entire world, my daughter, Helen. Helen graduated with a bachelor's degree in nursing last year and gives me 24/7 attention and care. I also have an angel who cares for me from heaven, my husband. He passed away in January 2021 from COVID-19. Most importantly, I have God.



Helen: Prior to my mom's diagnosis I was a rather soft-spoken child, though my parents always encouraged me to be outspoken. At the time of the diagnosis, I was in high school. To say it was world-altering is an understatement. Because my parents had always encouraged me to speak up, I had a foundation that allowed me to not only be a caregiver but also her advocate.

At first the lack of information was panic inducing. There was nothing we could look up to see a prognosis. As my mother's health began to decline, I became her main caregiver. My aunt lived with us and she would cook and look after me. My father worked overtime trying to stay on top of the mounting medical bills.

I worked with her home health nurses so I could learn what to do to assist in her care. I changed her feeding tube dressings and did the feeds.



I also advocated for my mom when things didn't seem right. Once, a nurse came in, washed her hands, gloved up, and then proceeded to pick up trash from the floor. She threw it away and then attempted to touch my mother with those same gloves. I politely asked her to change gloves, and I guess it took her aback that a small, 17-year-old girl was correcting her behavior. She pushed back and said no. I remember my voice was shaking as I asked for her supervisor and requested a new nurse. On the outside I looked confident, but on the inside, I was shaking. I was so scared since I was always taught to respect my elders, but I knew I needed to advocate for my mom.

“I was so scared since I was always taught to respect my elders, but I knew I needed to advocate for my mom.”

Seeing my mother’s weight dwindle down, and hearing a physician suggest we take my mom home essentially to die, broke me. I just thought of all the things I would not have my mom for, like my birthday which was only a few weeks away, and then my high school graduation that spring, my college graduation, my wedding, and the birth of my first child. I remember as my mother prayed to God to keep her with me, I became angry. I remember telling God, “If you take my mom, you're not real and I hate you.” Being raised Catholic and being extremely involved in my religious community, this was rather odd. I remember my mom telling me “Regardless of what happens, I had you and that was my greatest gift. I love you forever, and I'll always be here watching you.”

It's been 10 years since that conversation. Though many things have changed, I am still constantly advocating for my mother. Starting the Miami bilingual support group has been a passion project for us both. I was able to share my nursing school graduation with my mom, as well as my engagement, and my wedding. I'm so grateful to have my father's voice always in my ear telling me what to do even though he isn't physically here with me anymore.

My mother has always been my best friend and I am eternally grateful to God to have shared these last 10 years with her. I'm looking forward to many more, and her meeting her grandchildren. I want families to know that this diagnosis is not a death sentence anymore. It's a rough journey, but there is always hope. ●

Scleroderma

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases. The word “scleroderma” comes from two Greek words: “sclero” meaning hard, and “derma” meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease varies from patient-to-patient. Some facts about scleroderma are:

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

[Learn more](#)

The Scleroderma Foundation



Dan & Deb Kealing

COPD



Dan: I was first diagnosed with emphysema in 2006 at age 55, while in the hospital with a bout of pneumonia. Even before the hospital stay, I knew something was wrong. For many years my wife and I had run 10k races, and even managed a couple of half marathons. We golfed together, travelled, and managed to keep up with two active boys. But the last couple of years before the pneumonia, I had slowed down and quit running because I couldn't handle even small hills without getting short of breath.

It took several months to get my strength back, but my lungs had suffered a significant amount of damage. At the time, we owned a flooring store. My wife Debi took care of sales, and I supervised our installers and made the rounds to job sites. I found I could no longer get upstairs or lift any amount of weight and I slowly became deskbound. Looking back, this was probably the beginning of Deb becoming my caregiver.



Deb: My mother was also diagnosed with emphysema, eventually having complications which ended her life. I told myself that she had been sedentary, but Dan was active. I never thought I would be a caregiver.

Dan: Golf has always been very important to me. I love everything about it, the competition, the exercise, the comradery, and the fact it's the only sport I've found that I was pretty good at.

After I started needing oxygen to exercise in July 2017, I continued to play golf. I tried everything to make it work, from wearing a small tank in a fanny pack, to carrying a tank from the cart to the shot and sitting it behind me, to trying to take the cannula out and walking to the shot and walking back to the cart to replace it. By June of 2018, I finally had to give up golf entirely. For me this was a mental disaster. My anxiety and depression from

having this disease had been kept somewhat at bay because of golf but was now free to run rampant.

In July of 2018, I decided to seek out a psychologist to get some help with the anxiety and depression. The psychologist didn't do much for me, but he did suggest a personal trainer who worked at a major health club to help replace the exercise I lost when I quit golf.

The trainer, Laryn, eagerly accepted me as a new student. I'll never forget the first day of walking into this bustling health club, oxygen tank in hand and saying, "I have never felt so out of place in my life." She assessed what I could and couldn't do on that first visit, and also asked a lot of questions about emphysema. She admitted she knew nothing about it. On my next visit, I was amazed that she had done some extensive research and had a good grasp of the physical challenges I faced. She set up a combination cardio and weightlifting program, we agreed to bi-weekly appointments, and with her optimistic yet firm guidance I made slow but steady progress. She gave me purpose. Just as important, I got positive feedback from others working out and felt a sense of belonging. Laryn has been an integral and important part of my care team. Even after the gym was closed due to COVID-19, she continued to correspond by text. And now that she has been vaccinated and I've recovered from a recent exacerbation, she comes to the house once every two weeks to work with me.

Deb: Laryn is a blessing for both of us. She not only works with Dan; she also is my trainer. She has challenged me mentally and physically. I have never been an advocate of meditation, so she suggested yoga, which became part of my weekly workouts. During COVID-19, the gym closed but she found outdoor places where we could still workout. She is instrumental in helping me take care of myself, something difficult to remember to do as a caregiver.

Dan: By 2010 I was on disability, and we had closed the store. Deb found a full-time job and I tried to keep up with the simple chores around the house, like laundry and making the bed. Bigger chores like vacuuming or mopping were already beyond me.

Deb: Our journey has taken us from oxygen only at night, to portable oxygen concentrators, to oxygen 24/7 with tanks, to medications with a nebulizer. What holds all this together for me is that Dan is a fighter, always researching improvements for this disease.

In March of 2021, Dan suffered a severe exacerbation that required hospitalization. I was nervous, anxious, and fearful. Each day the doctors were increasing the dosage of the steroids and antibiotics. Due to COVID-19 restrictions, I was able to visit each day but could not stay overnight. The doctors said they were doing all they could. On day five I walked into his room and thought I was going to be planning a funeral.

“Our journey has taken us from oxygen only at night, to portable oxygen concentrators, to oxygen 24/7 with tanks, to medications with a nebulizer. What holds all this together for me is that Dan is a fighter, always researching improvements for this disease.”

There was an enormous flood of emotions, like sadness, helplessness, and anger. I had to remind myself to be brave in front of him. When I got home that night, I cried and cried. I thought I was going to lose him. Overnight, the medications started working and I was surprised that day I walked into his room and saw the change. I was so happy. Two days later, he was discharged.

Dan: After those eight days in the hospital because of the exacerbation, I came home weaker and shorter of breath than ever. Recovery is never to one hundred percent of where I was before an exacerbation. Without Debi, I can't cook, do laundry, take a shower, go to the grocery, or make it to a doctor's appointment.

My quality of life is immeasurably better with my loving wife as my caregiver. Without her I don't know how I would survive, particularly with the pandemic.

Deb: Little by little this disease continues to impact our quality of life. I no longer work full time, and do contract work instead. Even small daily activities are difficult for Dan, and difficult for me, as I can only listen and support him as he describes how challenging a simple task can be. As there are now more bad days than good, emotions are a roller coaster. Exacerbations become more frequent, and make you feel helpless. Anger surfaces with equipment failures. Power outages are exhausting and scary. Learning to be a liaison between the doctor and the pharmacy for prescriptions is exasperating. Tears flow some days just as a release of the weight of watching your loved one go through each day. This is our journey, and we are going through it together. ●

Chronic Obstructive Pulmonary Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is a preventable and treatable lung disease. People with COPD must work harder to breathe, which can lead to shortness of breath and/or feeling tired. Some other facts about COPD are:

- Although the most common cause of COPD is tobacco smoke, there are several other factors that can cause or make COPD worse, including environmental exposures and genetic (inherited) risk.
- Common symptoms of COPD include feeling short of breath while resting or when doing physical activity, cough, wheezing, fatigue, and/or mucus production that does not go away.
- Some general classes of medications to treat COPD include those that aim to widen the airways (bronchodilators), reduce swelling in the airways (antiinflammatory drugs, such as steroids), and/or treat infections (antibiotics).

[Learn more](#)

ATS Patient Education Series



Rhonda & Wayne Nelson

AERD



Wayne: Rhonda's symptoms began early in 2001, just before she turned 34. They included two-to-three-hour sneezing attacks at about 3:30 a.m., sinus headaches, and difficulty breathing due to nasal polyps. For a couple years the condition was treated as allergies, but the tests were never conclusive regarding what she was allergic to. One test came back saying she was allergic to everything.

In 2003, we moved from Tennessee to North Carolina and all her symptoms got worse, despite a nasal surgery that had removed all the polyps the year before. Her new ENT had just returned from a one-month seminar with Max Samter, MD, the doctor who discovered Samter's Triad. The three prongs of the disease are nasal polyps, asthma, and allergic reactions to most pain medicines, progressing to anaphylactic shock.



He diagnosed Rhonda's condition as Samter's Triad, now known as Aspirin Exacerbated Respiratory Disease (AERD), within a few minutes.

The disease was very underdiagnosed. For years, we would have to explain in detail to emergency rooms all that was going on when Rhonda had a bad reaction to either mold or chemical smells like bleach or cigarette smoke. After moving to Florida in 2011, she had another nasal surgery that removed the entire lining of her nasal passages. That allowed her body to rebuild that lining, but the result was that she lost all the function of the cilia, so her nose couldn't clear itself of any foreign matter. She rinses her nose twice a day with a saline solution dissolved in distilled water. She also lost her sense of taste and smell almost 20 years ago. That has become a common indicator of the disease now.

And oddly enough, when she contracted Covid-19, she got her smell and taste back for a few days. It was overwhelming to her and made her nauseous.

About five years ago, the Allergy Asthma Network (AAN) realized how prevalent this disease was and lobbied for it to be added to the list of chronic asthmatic diseases. AAN has done wonders exposing the dangers of asthma in children and adults, and AERD has been brought under its umbrella as a major cause of suffering for patients that have been misdiagnosed like Rhonda was. The AAN provides important statistics about all asthmatic conditions, including eczema, AERD, and childhood asthma, which is the leading cause of school absences in the U.S.

Rhonda has become a spokesperson for AAN and acts as a patient activist with drug companies that are realizing more and more just how widespread these diseases are. They lobby the U.S. Congress for lower and fairer drug prices for people who can't afford the medicine, and/or don't have insurance. One of Rhonda's meds would cost almost \$50,000 per year were it not for her insurance and the work of AAN.

As bad as Rhonda's case was, her medicine has finally made life more bearable. Her flare-ups are fewer, and don't last as long as they used to. But she's on a couple of forums where people describe life-altering symptoms. Without treatment, the disease is miserable for patients and families to live with. One of the most difficult issues to deal with is that the violent and constant sneezing hurts the whole upper body, and the pressure from the sinus headaches is intense, but AERD patients can't take most pain relievers. And at this moment, there is still no definitive cause that can be detected. There are lots of theories yet to be tested, but no solid evidence yet. That makes it even more exasperating. ●

Aspirin Exacerbated Respiratory Disease (AERD)

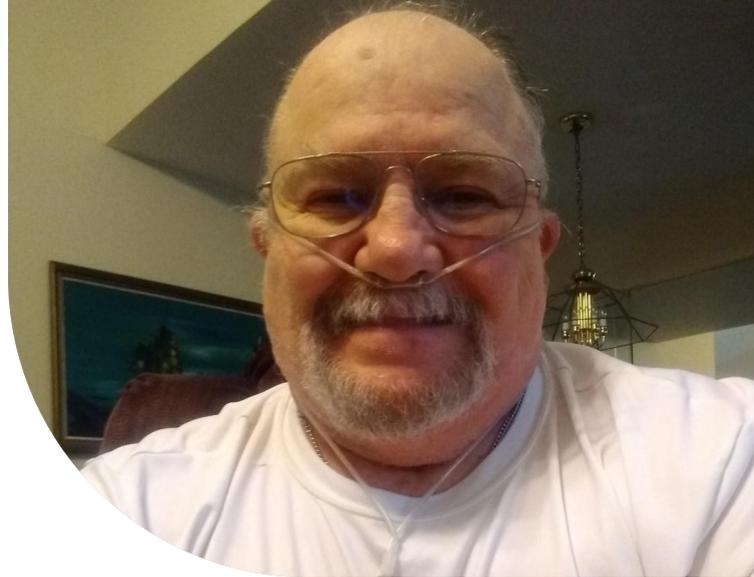
Aspirin (acetylsalicylic acid, or ASA) is a non-steroid anti-inflammation drug. It is used to reduce pain, decrease inflammation and block platelet activity. Aspirin can have serious side effects, such as stomach ulcers and kidney injury.

In some patients with asthma, aspirin can cause an asthma flare. The typical symptoms (Aspirin Exacerbated Respiratory Disease, AERD) include:

- Asthma
- Nasal polyps
- Aspirin-sensitivity

Jimmy Slover

COPD



From 1998 to 2004, I was in the hospital for pneumonia every February. In 2004, I had a serious attack and my doctor told me that I had to stop smoking. He showed me tests he'd done on my lungs and scared the living daylights out of me. I was ready to throw away all my cigarettes, but when I looked back over at his office as I got into my car, I saw him smoking a cigarette on the balcony. I thought "What a crock," and went to the store to buy another pack.

Five years later, I had my first appointment with a pulmonologist who looked at me and said, "I can tell it's going to take something detrimental for you to quit smoking." My last cigarette came the very next day, because at 3:20 the next morning, I was rushed to the hospital in respiratory distress. I woke up from an induced coma two and half weeks later, with a tracheotomy. I spent the next several months re-learning to walk, and a

month after that, I was diagnosed with stage 4, end-stage COPD. It was a devastating wake up for me.

I have an in-home caregiver named Jill, who comes in several times a week to help me provided by the V.A. I know many people don't have access to in-home caregivers, but she makes my life so much better. She saves me hundreds of breaths a month, and she's like a daughter to me. Jill's work takes the pressure off my immediate family members because they don't have to try and fit my needs into their daily activities. Jill handles the basics, and they're able to focus on being family, because they know my caregiver will take care of me. It is a win/win situation.

When Jill comes in, she asks me how she can help me. It sounds simple, but it's important to ask, because I may want help, but it may feel awkward reaching out sometimes.

There are also times I need help in certain specific ways. It's important that any caregiver not assume that they know what's 'best.' She helps me dust, vacuum, sweep, make my bed and do my laundry. She goes to medical appointments with me so we're always on the same page and changes out my equipment. Sometimes, I just want to be heard. Listening and just being there can go a long way toward making people feel cared for. Jill also knows I'm not as good about staying hydrated as I should be, so if she ever sees me without a bottle of water she stops, goes into the kitchen, and gets me some water!

One of the best things Jill did was to learn all about the disease to know how best to help me. For other COPD caregivers, I'd recommend learning as much as possible about COPD. For example, understand the types of COPD, like chronic bronchitis and emphysema. These diseases are both forms of COPD, and a person can have one or both conditions.

It's also helpful to know the signs and symptoms of COPD, as well as COPD exacerbations. COPD is a progressive disease, so it's important to report any worsening symptoms and exacerbations to the doctor. That's why it's important to also note how COPD changes over time. As COPD progression moves from one stage to another, the treatment plan may need to change.

It's one thing to want to help, and another to know how to help. I have a golden rule when someone is trying to help me in my home: If you pick something up, you must put it back just exactly how you found it. I am an independent person and at the end of the day when I am struggling the most, I can't afford to try and find something that was out of place because it was moved on me. If you've ever struggled to breathe, you will understand this one hundred percent. ●



Karen Allison

Idiopathic Pulmonary Fibrosis

My life before IPF was full, but simple. I've been married for 48 years, raised four sons with all our hearts and not much money. I worked several part-time jobs to help financially, but the cost of daycare for four was too much. I retired when IPF and COVID-19 hit simultaneously in 2020.

For about two years I had a nagging cough and general feeling like I was always on the verge of starting a common cold. I lived on pseudoephedrine.

My husband insisted I go to my primary care physician for a chest x-ray.

As previously, my primary care physician thought my problem was postnasal drip and /or a viral infection. I asked if I needed a chest x-ray. He listened to my lungs and said he didn't think so but gave me a referral to an ENT.

The ENT didn't find anything unusual about my sinuses, but he listened. He prescribed an inhaler for my cough and ordered the chest x-ray.

In March of 2020, the results came in, and I googled every word. The conclusion was not good. Next was a CAT scan, which confirmed the findings of Interstitial lung disease/usual interstitial pneumonia / idiopathic pulmonary fibrosis. It was a death sentence. Life expectancy is three to five years with no cure or treatment that has been proven to extend your life, other than a lung transplant.

I researched every article I could find. Due to Covid-19, getting an appointment with a pulmonologist was going to take some time. It was hard to be patient but knowing there were people very sick and diagnosed with COVID-19, I waited. I remember feeling a bit like I was set aside on a shelf, with an expiration date.

I knew I was terminally ill. IPF was FATAL. How long would I last?

COVID-19 and IPF kept me isolated at home, but not lonely. I decided to get a puppy! I thought it would be good to have a special kind of friend to lay on my bed with me on bad days and listen to my every word with a smile, and hopefully take me for walks, who wouldn't offer advice, or wishful thinking, or unrealistic expectations of my future days. My Bernese Mountain Dog puppy, Bella, was a ball of fur with a wagging tail and just what I needed.



I was also constantly out planting things my son brought because he knew it would keep me busy and happy. My flowers would help me start conversations with strangers at a distance, and I would tell them about my joy of gardening and the reality of my disease. Strangers listened. Strangers shared their stories and lifted my spirit.

Once I finally saw a pulmonologist, my IPF diagnosis was confirmed. I wasn't far enough along to be considered for a lung transplant. At that point, I was just short of breath, constantly coughing and tired. I knew I would need supplemental oxygen in the near future, but I didn't want to start it yet because it felt like "the beginning of the end."

I saw an ad in our little local paper about Wescoe Pulmonary Fibrosis Support Group and I called late the next night. This wonderful lady called me right back and instantly I felt her warmth and caring. I knew she was an angel. The Wescoe PF group was a collection of beautiful people who were walking along a similar path, who shared their experiences and reached out with open arms. This disease has brought so many beautiful caring people into my life. It feels like oxygen for my soul. I'm so grateful to feel this joy more than I feel the sadness.

I started pulmonary rehabilitation and needed to have supplemental oxygen to walk or do any activity. I had put it off as long as possible, but I needed oxygen. If I wanted to stay active, I had to breathe.

The supplemental oxygen was delivered to our home. At first, it felt like I was connected to a 50-foot hose that felt like a dog leash to reach around the house. I was constantly tangled, tripping, it got caught on everything, our cat would chew holes in it, and my husband was always trying to keep the tubing unkinked. It was terrible.

I decided I had to think of it as the beginning of better breathing, instead of the beginning of the end. My doctor gave me the idea of putting my oxygen in a baby stroller! I put a tank in the stroller, my sweet husband stabilized it with bungee cords, and I connected a 50-foot tubing so I could continue to do my gardening. I was finally free to move.



It wasn't pretty, but it worked. I even learned to take Bella for a walk with the stroller and oxygen tank. It was difficult at the beginning. Bella would pull and not heel. Eventually, though, I got that huge puppy trained and together we met the challenge. We walk several evenings a week at least a mile or more. Medicare wouldn't pay for anymore respiratory therapy, so I needed to keep moving.

“This disease has brought so many beautiful caring people and circumstances into my life. It feels like oxygen for my soul. I'm so grateful to feel this joy more than I feel the sadness.”

The more I moved, the more oxygen I needed. The medical supply company constantly got it wrong. I explained I needed more tanks; they would deliver fewer. One customer service person even said that because I had a home oxygen concentrator it wasn't like I didn't have any oxygen. I responded “Well, how should I take that down the sidewalk?” They told me I had to have a new six-minute walk test in order for them to supply enough supplemental oxygen. Their records were not up to date. They had me at two liters when I had been using between three and five liters for months. I just wanted to breathe the best I could and for as long as I could.

I cried, I called my doctor and the next day received a call from the supervisor at the supply company. I was only able to get 30 tanks of oxygen a month, as a result of Medicare rules. My doctor's office did their best to make sure I got what I needed.

That winter, one of my sons did some research and found a clinical trial in its third phase that looked hopeful. I read as much as I could, and I decided to give it a try. I didn't want to just put my time in and die. I was excited to be a real part of science and be useful.



To participate, I had to be sick enough, but not too sick. I had no other medical problems. I pre-qualified as a candidate for the trial, but everything was on hold due to COVID-19.

Finally, once we were fully vaccinated, we headed to Temple Lung Center in Philadelphia. I had to pass testing before I would start the infusions. I assumed there would be no problem. I was healthy other than the IPF.

A couple of weeks later I got a call with an unpleasant surprise. My testing showed my liver enzymes were acutely elevated, and I could not participate in the clinical trial unless my liver was healthy.

After more tests and gastroenterologist consultation, I still have no symptoms and no real diagnosis, just acute liver disease for now. Even the doctors are puzzled. There seems to be some fibrosis in my liver now also. Could it be in connection to lung fibrosis?

My story continues... ●



Zaria Nyaholu

Lymphangiomyomatosis

In January of 2007, I woke up in the middle of the night, coughing up blood. At the hospital, my pulmonologist was very clear that I did not have pneumonia, as I had thought for many years. While I thought he was crazy, I agreed to do the tests he suggested. On June 7, 2007, I had my first CT scan, which I planned to have reviewed at an appointment two weeks later, but on June 13, I suffered my first lung collapse. My lung was 90 percent collapsed on one side and 40 percent collapsed on the other side. The ER doctor gave me two choices: either a chest tube then and possible surgery later, or immediate surgery. Either way action was required, as I was so critical that I would have been dead in less than an hour without intervention. It was a miracle I was alive! The doctors put in my first chest tube. All they could tell me is that I had cysts in my lung. It was a whirlwind of events and emotions. The next day, with my mom, sister, niece, and pastor all in my room, the pulmonologist finally arrived. As he described what he thought I

had; I felt as though I had been hit by a brick wall. He continued to explain this rare disease as I dried my tears and the fog cleared. He asked, “Are you okay?” My reply was instant and life changing. “God’s got me! Yes, God's got me.” With this new revelation of lymphangiomyomatosis (LAM) I was given three to five years to live, and lots to do to address this disease. My family and my church family were there caring for me from the very beginning!

The insanity of dealing with a rare disease that is debilitating, progressive, has no treatment, no cure and has already crippled your life is hard to describe. Before being placed on oxygen, I was often bed ridden. I relied heavily on my mom and church family for meals, cleaning, rides, and more. I had gone from being independent, pursuing a successful career, and doing my own thing to being dependent upon others. My needs were great, and they were met with love.

Once on oxygen, I slowly began to be able to get out and live life more abundantly. I pursued a new passion for gardening, and adopted a phrase, “gardening from the chair,” after I was given a wheelchair. For years I couldn’t load and unload the large tanks I used for longer trips, like for church and hanging out with friends, but I had help. I also had smaller tanks I often used for shorter trips to the grocery store, picking up prescriptions and such. While being oxygen-dependent is often considered a curse, I was so happy to be out of bed I really didn’t mind it so much.

By the time I was placed on high flow oxygen I was going through a large tank of oxygen every 45 minutes to an hour. Just attending church required that I bring at least four to six tanks minimum, but I was finally able to load and unload tanks on my own most of the time.

On May 9, 2018, I got the call for a lung transplant. After one of the longest nights of my life, I was wheeled into the scariest surgical room I had ever seen. I had new lungs 14 hours later.



“I cannot imagine my life without my care providers in it. I realize that I am blessed to have more care providers than most people in my situation can even imagine. Each one is a divine gift that I thank God for placing in my life. I never imagined I would need them as much, or for the many years, as they have been caring for me. Their love, aid and provision in my life have been essential to my story.”

While I had been well prepared for the process, I had no way of knowing my own transplant journey would be so difficult. I was in the ICU for 23 days, in two separate comas. The first one is when I believe the “alternate reality” began. I just knew they were going to take my new lungs. I begged everyone who visited to rescue me, while I still had my lungs. This alternate reality is the only memory I have of that time. For me it was real! My delusion morphed into a belief that they were trying to kill both me and my sister. I felt that as hard as I tried, she just didn’t get how serious I was.

As they decreased the drugs my mind began to clear. I still couldn't even stand, walk, eat, remember certain basic information, hold a pen, or write my name.

The physical therapists came in each day and helped me learn to walk, and even eat, again. Eating was so horribly painful I could only eat a few bites. This also made exercise and basic functioning extremely difficult. I also made great progress mentally. At first, I could not remember what day it was. Finally, I began to grasp and communicate days, times of day, names and details about life going on around me. I was released just over a month later, to a hotel nearby.

It was several weeks before I was able to make it all the way to our room. My poor mom had to push me. She also made every meal, cleaned up after me, bathed me, clothed me, got me to all my doctor appointments, did all the shopping, dishes and helped me exercise when I wasn't at pulmonary rehab. My process was insanely slow. Finally, about two months out, I ate almost a full serving of food. A couple of weeks later we were finally allowed to go home.



My first week home one of my friends from church stayed with me overnight as I needed 24-hour care. It took a few weeks, but I slowly began to care for myself. This was an incredibly painful process. When asked if I'd do it again, I quickly replied "No!"

About nine months after my transplant, I decided I wanted to try to run. After some discussion with my pulmonary rehab team, we decided to give it a try. I had not been able to actually run for almost 15 years. That day I ran for one whole minute! Elation only begins to describe how I felt! I had finally reached that place. My new answer was "Yes!" If I had to do transplant over again, I would do it. Yes, it was worth it. I am now over three years post-transplant. Without God, my donor, care providers, family, supporters, and these beautiful pink lungs I would not be alive today. ●

Lymphangioliomyomatosis

Lymphangioliomyomatosis, also known as LAM, is a rare lung disease that mainly affects women, usually during their childbearing years. LAM is caused by mutations in the tuberous sclerosis complex (TSC) genes. These mutations lead to growth of abnormal cells that spread by the blood stream and make their way into the lungs. Once in the lungs, these cells create holes in the lung tissue (called cysts) that can weaken breathing and the ability to take up oxygen.

- Elevated VEGF-D levels can help confirm the diagnosis of LAM without needing a lung biopsy.
- LAM causes multiple air-filled holes, called cysts, in the lungs. Often these cysts can rupture and cause air to leak outside of the lung, leading to lung collapse.
- There is a possibility that pregnancy may lead to progression of LAM, so consult your doctor if you are pregnant or considering pregnancy.

[Learn more](#)

ATS Patient Education Series



Alicia Maciel

Cystic Fibrosis



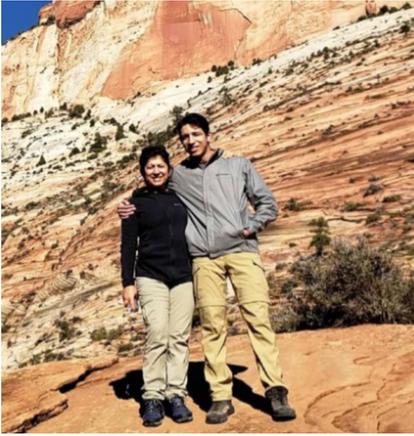
My name is Alicia Maciel. My husband Peter and I have two sons. Our second-born, Marc Anthony, is 19 years old, and has cystic fibrosis (CF).

When one becomes a parent, one simultaneously enters the role of caregiver. Babies require round-the-clock care that usually decreases as they grow older. However, for parents of children with a chronic illness such as CF, the role of caregiver takes on a whole new meaning.

From birth, Marc Anthony exhibited breathing and digestive problems that were misdiagnosed by his doctors, leading us down a frustrating path of hit-or-miss diagnoses until he was finally accurately diagnosed with CF at the age of six.

Initially, I thought dealing with my son's medical needs was something I could simply add to my standing to-do list. However, as I immersed myself in the caregiver role, it was sobering to discover the extraordinary demands it placed on my time and physical and emotional energy. Soon it became impossible to downplay the strenuous implications of dealing with what felt like a constant juggling act: endless medical appointments, insurance bills, prescriptions, medical equipment, and daily treatments. Yes, let's pause here to collect ourselves after going through that list. I decided to go on a quest to find caregiver support and thankfully, discovered that I was not alone.





Over time, my approach to caregiving has morphed from checking tasks off a to-do list to adapting to a new way of being. At a certain point, effective caregiving is no longer about doing more, it's about caring more for what you're already giving. This begins with remembering to care for myself and to nurture my resilience; that precious resource that enables me to care for others. I'm better at loosening the grip on the way I think things should be. This enables me to stay open to receiving and learning from what life brings so that I can continue to evolve along with my son's needs.



The CF community includes a robust ecosystem of caregivers consisting of dedicated doctors, nurses, specialists, researchers, pharmaceutical companies, and CF patients and their families. For the past 10 years, my husband and I have been involved with the annual Cystic Fibrosis Research Institute's (CFRI) National CF Education Conference.

“Over time, my approach to caregiving has morphed from checking tasks off a to-do list to a way of being.”

I have chosen to embrace my role as a caregiver by aligning opportunities within the caregiver ecosystem with the things that I’m skilled at and enjoy doing. The more involved I become in the ecosystem, the more nourished and equipped I feel to support myself, my family, and others on a similar journey. Caregivers give care through sharing their time, skills, and energy. As individuals, our capacity is limited, and one can only give so much. Therefore, I focus on expanding my impact in caring for others by working with organizations that value the patient and family perspective. I currently serve as a member of the CFRI Diversity Committee and the CFRI Embrace Mothers Retreat Planning Committee. Simply mentioning the Embrace Mothers Retreat brings a smile to my face. This event has shown me that amidst the adversity of a caregiver’s journey, it is possible to experience joy and fulfillment from building loving, connected relationships with others who can relate.

I’ve also led the creation of a Parent Advisory Council at the CF Care Center at Children’s Hospital of Orange County (CHOC). And have served as a CHOC Parent Partner on the national Cystic Fibrosis Learning Network.

Looking back at 2008 when Marc Anthony was diagnosed with CF, I could have never predicted how my journey as a caregiver would evolve. Over the last five years I've transitioned my professional skills and expertise to serve others as a resilience coach and a mindfulness meditation teacher through my practice called BeingWell.life. Each day I feel more content and fulfilled than ever as I look forward to learning from and supporting others, as I feel blessed by all that I've received. I'm inspired by the possibilities that lie ahead. ●

Cystic Fibrosis

Cystic Fibrosis occurs when a person inherits a mutated (abnormal) copy of the CFTR (cystic fibrosis transmembrane conductance regulator gene) from each parent. It is an autosomal recessive disease meaning only people with two CFTR mutations have the disease. While there is no cure, life expectancy has steadily improved 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.
- 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





Donna Appell

Hermansky-Pudlak Syndrome

Our caregiving journey began like most, with the birth of our first child.

When Ashley was born, we were surprised by her full head of white hair. We discovered at her two-week “well baby” visit that she had albinism. That was the last time we had a “well-baby” anything. Christmas Eve of that year, we were told that our daughter was legally blind. I remember it how upsetting it was to think that your child was never going to be an astronaut, though I imagine that there aren't that many people who become astronauts. I wondered how she would do in school, and whether she would ever be able to drive.



Ashley's issue of low vision consumed us until we started to notice the bruising. I couldn't understand where they were coming from. I brought her back and forth to the pediatrician four times and was totally dissatisfied with his explanations. Eventually, I called the author of a pamphlet on albinism that I was reading because it mentioned a platelet defect. This expert sent me a test tube in the mail, and we drew Ashley's blood and sent it to him. He told us she had a disease called Hermansky-Pudlak Syndrome. I wanted to move to his neighborhood in Minnesota and have him be her doctor! We didn't move, but he guided us in learning about this disease.

When she was two years old, she hemorrhaged to shock from the inflammatory bowel disease of HPS. I raced her to the hospital. She was there for three months, and got 36 units of platelets and 6 units of blood. She lost so much blood that she had a traumatic brain injury from lack of oxygen.

After that hospitalization, my husband and I decided that no family should ever be alone in this again, so we started the Hermansky-Pudlak Syndrome Network. We began to research HPS and discovered that many individuals with HPS die of a lung disease called pulmonary fibrosis in their young adulthood. That was Ashley's type of HPS, and her genetic fate.

Care for our daughter was not going to have an end date until the unthinkable.

I think the hardest part of caregiving is the feeling of helplessness, that loss of control. No matter how hard you try to make things better, the disease just progresses relentlessly. I'm not a researcher or a pharmaceutical company, or a physician with a prescription pad. I can't create a treatment or change the course of things. But I could teach my daughter how to cope with her medical challenges, or at least I can be a positive influence. That was something in my control. So, my caregiving responsibilities were not only just which doctors or specialists to take her to, or what medications to give her but how I could help her cope.

“I think the hardest part of caregiving is the feeling of helplessness, that loss of control. No matter how hard you try to make things better, the disease just progresses relentlessly.”

First and foremost, people model what they see. I tried very hard to remain composed and calm, and that helped everyone to stay more relaxed. I worked actively, not passively, on teaching coping mechanisms as part of caregiving. I felt that as much as the doctor’s work on her body, my caregiving needed to work on her spirit. I thought of all sorts of ways to fill her “coping toolbox.” Distraction of course was high on the list. We would often engage in positive imagery. When she was having a procedure or having blood drawn, we would talk about a vacation trip or a happy memory. We had little reward system for her bravery during IV insertions. She would get a little wrapped gift, a reward, a trophy, if she would keep her arm still. These gifts were small and certainly not elaborate. For a while, her gifts were colorful combs! She built up quite a large comb collection because she was so ill with so many IV’s. It became a trophy of how brave she was.

As life went on, I realized how much time we were spending in the waiting rooms of doctors' offices. That was precious time to plan happiness! I would be packed and ready with a new book to read to her. As she got older, I packed puzzles to work on and games to play. Now that she's an adult, we have done yoga in the doctor's office while we're waiting, we have rearranged office furniture to do mailings, and we have been known to dance and have a sing-along! Life is an adventure, and it was my job to make it fun. To cope with the harshness of health challenges I felt it was important to see different perspectives. Things could always be worse. So, at a young age I had her support others with difficulties worse than hers. Volunteering to help others is a sure way to stop focusing on yourself. It is a proven coping mechanism. That "attitude of gratitude" also helps grow positivity. When we leave the hospital or the infusion center, where she has received an IV infusion every five weeks for the last 21 years, I pull my car off the road and have her applaud and clap for all the doctors and nurses that got her back on the road again! Providing hope was also high on my agenda. I would look for opportunities to inform her of all the people working on trying to cure the disease. I gratefully brought her to the ATS International Conferences to see how many researchers dedicated their lives to lung health. The "scenes of science" at the ATS is so uplifting it is like medicine itself.

I'm not sure if anything I did or still do really makes a difference for her, but I do know that my daughter teaches me resilience, kindness, and strength every day of her precious life. I am honored to be caregiver, but caregivers need support too, particularly when providing care to adults.

Though it was not the intent of the privacy laws to make care giving so difficult, its interpretation has been tremendously variable.

This difficulty with “caregiving” is growing with a “new” population of complex medical young adults surviving childhood with diseases that would have previously been terminal in childhood, and older adults living longer and longer. While obtaining Guardianship is one answer, it will not be accessible to everyone. A Health Care Proxy allows a person to appoint another person to make health care decisions only at the time they become incapacitated and incapable. There needs to be something accessible in the middle. The Enhanced Health Care Proxy would enable the signer to designate someone that could speak on their behalf immediately upon signing rather than at the moment that they became incapacitated. Co-signed by a physician, the Enhanced Health Care Proxy would allow an adult to have a caregiver involved and there would be no HIPPA violation.

In 2011 I brought this idea to our State Legislators and a bill was created. It had multiple sponsors in the Senate and the Assembly and was referred to the Committee on Health. It was fully supported by the NY Nurses Association. It fell by the wayside because I was too busy “giving care” to lobby further for caregiving. ●

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. 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.

[Learn more](#)

ATS Patient Education Series



Epilogue



Courtney White
Senior Director
Patient Outreach,
Equality & Engagement

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. ●



Disclaimer

This publication includes stories of patients with lung disease as told to the American Thoracic Society by the patients or their representatives. The views expressed in these stories do not reflect those of 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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“I had gone from being independent, pursuing a successful career, and doing my own thing to being dependent upon others. My needs were great, and they were met with love.”

Patient Voices

Caregiving Ecosystem: Stories of Advocacy
from Patients and their Allies