HEARD AT THE LIVE MEETING

Voice of the Patient Quotes

Organ Involvement

"This disease is called a snowflake disease. No two cases are just alike. It can affect any organ, including eyes, skin, heart, or lungs."

"I now have chronic sarcoidosis. It started in the larynx and in the skin, and it progressively got worse, until I lost my voice completely. All I could do was whisper."

"At the time it was just pulmonary, but it grew into neurological. And as of the last, I want to say almost a year now, it's also cardiac. So, I've been on quite a journey."

"Neurosarcoidosis-... pulmonary sarcoidosis, and as of my last six-month visit, it's also been found beginning to affect my kidneys."

"Pulmonary sarcoidosis, I have it on my skin, sinuses, and it also caused me to have pulmonary hypertension, which is my heart. And also, they are watching my eyes closely because they think that is in my eyes as well."

"My first sarcoidosis appeared as skin sarcoidosis, but has manifested into neurological, mostly in my optic nerve and my spine."

"It was found in my bone marrow and in my kidney... when they found it, I only had 5% left of kidney function before I had to get rushed to the emergency room."

"Because of PET scans, I know my liver and many other organs have sarcoidosis."

Symptoms (General)

"I'm now 51 years old, and I'm losing all type of bone because of my oral sarcoidosis, so now I have the teeth of an 80-year-old. Nobody told me that, right? The realization is my body is aging, I'm aging, and how does that affect my chronic illness? So the next step forward is definitely stay stable."

"The joint pain used to come and go, but now it's constant."

"At first, it was just occasional shortness of breath, but now it feels like I'm always fighting to breathe."

Fatigue

"Fatigue is the number one challenge: Sarcoidosis already feels like carrying 100 pounds of fatigue, and when medication adds another 50 pounds, it becomes even harder."

"With sarcoidosis, chronic fatigue and body pain are with me constantly, despite the multiple immunosuppressants, IVIG infusions, and large doses of gabapentin for nerve pain."

"By midday, I'm running on fumes. Fatigue clouds my ability to focus."

"I am always tired."

"The fatigue I experience is extreme, and the biggest freedom that sarcoidosis has robbed me of is my mobility. I require the use of a walker for everyday movement."

“With the fatigue and the pain, I came to the realization that I just couldn't work anymore.”

“With sarcoidosis, chronic fatigue and body pain are with me constantly, despite the multiple immunosuppressants, IVIG infusions, and large doses of gabapentin for nerve pain.”

“Today, I look forward to having a fatigue level of six. If I'm having a fatigue level of six, I'm having a darn good day. Right?”

“Sometimes I can’t even get out of bed on bad days."

Pain

“I live with pain and fatigue daily.”

“I'm in constant pain in my lower extremities.”

“...skin pain, stinging, burning, deep muscle aches, headaches and nasal involvement.”

“I used to walk with a cane because of the pain in my body.”

“Because of the characteristics of my advanced disease, I struggle with memory issues.”

“ Pain medications interact with my evening meds, which cause lapses in memory. These lapses make it difficult to care for my dogs, my home, and my son.”

“I purchased over $2,500 in cell phones and smart watches on my parents' account. I have no recollection of these purchases.”

Day-to-Day Life Changes

"I used to hike every weekend, but now I struggle to walk up the stairs."

"Maintaining employment became impossible due to frequent medical appointments and overwhelming fatigue."

"Even spending time with my kids feels like a monumental effort some days."

"I’m forced to plan my week carefully because I never know how I’m going to wake up and feel on any given day."

“Living with cardiac sarcoidosis is not just on the patient, but also affects family and friends. It affects us emotionally, socially, and to a good degree, financially.”

“Sarcoidosis isn't an easily managed disease. It's a complex condition that affects every part of my life.”

“[Her] cardiac sarcoidosis with its related disabilities have negatively impacted our lives and prospects.” - caregiver.

"Sarcoidosis has affected me in many ways. As a bench chemist, my brain was my bread and butter. I couldn't afford to make mistakes. I was unable to stand for long periods and walking was difficult. Like others, fatigue, loss of cognition and pain dominated my life. Most importantly, sarcoidosis has delayed family planning. My window for children is closing."

“I'm forced to plan my week out very carefully. You have to anticipate...While there are so many unknowns and you never know how you're going to wake up and feel on any given day, and there's really no rhyme or reason, I have to plan.”

"I thought I had things under control, but then the flare-ups started happening more often."

“Being rural (North Dakota) … makes the time cost of this disease a huge burden for my entire family. I travel two hours one way to see my specialists on average once a week. My mom, who also has pulmonary sarcoidosis, takes time off work to travel with me to all my appointments. I also travel seven hours one way to Mayo Clinic in Rochester, Minnesota two to three times a year. We have to stay for about a week each time, which costs a lot of money both in travel and for my mother to take time off work.”

Employment Strain and Financial Strain

“In the past, I would have thrived and known exactly what to do to respond. But when I got out of the truck [ambulance], I forgot all my training due to my cognitive disabilities. I was afraid to treat patients or even start IVs. I knew then it was time for me to give up the career that I loved.”

“I worked as an EMS manager and an advanced EMT for 19 years, a job that I absolutely love and miss every day. I really miss my patients. I tried to continue serving on a very part-time volunteer basis for the last five years, but eventually had to give it up entirely due to physical and cognitive limitations.”

“I happen to have been self-employed and in a career that involved communicating with people and then discovering at times I couldn't understand and had to ask people to repeat themselves or couldn't express my thoughts.’ Clearly, I had to back off. I had to slow down. I had to abandon a lot of the ambition and the aspirations I had.”

“I was once a very active and busy self-employed independent woman. Now, I have become a disabled person. I can only walk a limited distance with the aid of a walker. And, mostly I am in a wheelchair. I have complete urinary incontinence”

“I was forced to retire, do an early retirement from my job because I couldn't do it. Because I have a business degree, so I deal with numbers, and the brain fog, the numbers would just scramble in my head because of the brain fog.”

"I had a lot of difficulty finding jobs over the past couple of years when I didn't have a voice. Obviously, companies want people that have a voice, especially attorneys.”

"Sarcoidosis has significantly impacted my life, both financially and socially. I am now feeling the financial strain of an unplanned early retirement."

Hobbies and Social Life

"Sarcoidosis has impacted my social life with family and friends as I am often unable to fully join in during gatherings and celebrations. It was well over a year before I felt the energy to walk from one end of my house to the other."

“Just not even participating and not being able to join in on a lot of the social events, sending them [family] alone by themselves ... it has impacted my social life.” - caregiver.

“My friends have been amazing, but I think, at some point, they just give up on asking you to go to social events, because you can never promise that you're going to be there. Or even if you try to commit, sometimes, the day just gets away from you.”

“We can't mingle around lunch for association as we did in the past before [my wife’s]'s illness. As you can imagine, this disease has changed the dynamics of our beloved lifelong summer event.” - caregiver.

“I'm doing a 10th of what I have before because of the symptoms and so that's not mentioning the mental and the emotional things.”

“Outings are also very different now. I have to assure that she gets to the closest access point to avoid her walking fatigue.” - caregiver.

“We sold our home to move to a one level home because I couldn't manage walking up and down the stairs."

“I worry about further losing physical abilities or facing additional limitations on my independence.”

“Because of lung sarcoidosis, I use a portable oxygen concentrator to go for a walk, hike, ski, or ride my bike. I carry this eight-pound device in a backpack, and it allows me to be out in nature for about three hours.”

“I find my joints most bothersome because I can no longer ride my bike or walk long distances like I used to. My joints are constantly swollen…”

“My biggest fear is that my husband will lose his ability to breathe without assistance.” - caregiver.

Access to Care

“Often, we make the five-hour drive from Indianapolis to the Cleveland Clinic Hospital for as long as a week staying at the hospital or a hotel. Our boys, their wives, and our friends are involved in making sure our daughter is cared for appropriately, getting her to school and other events. It is very difficult at times to coordinate her care.” - caregiver.

“We acknowledge that our life has changed, and sarcoidosis makes demands on us in terms of time, medical expenses, insurance approvals, inability to do what we used to do, but we continue to try to make the most of each and every day.” - caregiver.

Therapies and Management of the Disease

“Sometimes it felt like doctors were going down a checklist of drug protocols trying one after the other.”

“It's hard to tell if my fatigue, vision decline, and mobility issues are due to reduced cortisol, increased inflammation, or both.”

“I have an automated implantable defibrillator and decided to try steroid sparing therapy. I am now on methotrexate and am stable."

“My monthly infusions also take so much time, eight hours a day, four days a month. Last year, I had a port placed in one side of my chest as an alternative to numerous IVs damaging my veins. The infusions treat inflammation, brain fog, and nerve pain caused by small fiber neuropathy. As you can imagine, this is a huge time commitment around which we have to plan our lives.”

“The changing prescriptions are hard for me to cope with, and I worry about the benefit versus side effects of the treatments, but trust and am comforted by her doctors who have extensive knowledge and truly care.”

“I have a spreadsheet of all of the drugs I have been prescribed since diagnosis in 2018, and there are more than 30 drugs, not including just dosage changes. Many of these drugs are expensive and require prior authorizations, and sometimes the insurance companies will question the prescription that my specialized doctors want me to be on, and recommend something different that is less expensive. The arrogance of someone who doesn't know me or my history to second guess my doctors is unbelievably frustrating, not to mention stressful. And stress is not good for sarcoidosis.”

“Hearing those words from your doctors, (running out of options), is very scary.”

Steroids

“The prednisone has caused some debilitating effects. I, currently, now, have type one diabetes. I have early onset osteoporosis, as well as different side effects from prednisone."

"In the three years I have been on Methylprednisolone, I have gained 80 pounds, been diagnosed with Type 2 diabetes, hypertension, sleep apnea, severe depression and anxiety, and many other ailments."

“I was on prednisone for 11 years straight and have been on and off steroid inhalers since 1992. The deterioration of my bones came from prednisone, and I’ve had to manage complications like osteopenia and back surgery.”

“I have been determined to find a way to manage my symptoms without relying on steroids. Unfortunately, my neurologist, and I agree that for now being completely free of steroids is not the best decision for me.”

"I currently take prednisone daily. I tried methotrexate but hated the side effects. A treatment to reduce lung granulomas and inflammation without adverse side effects would be fantastic."

"I manage neuro symptoms with gabapentin, steroid drops for my eyes, and steroid inhalers for my lungs. Physical therapy helps with pain from bone deterioration."

Immunosuppressants, Immunomodulators, and Biologics

"I am on azathioprine. This is a wonder drug because I couldn't take methotrexate and I really needed to come off of prednisone. It has me in a controlled state, but it doesn't help with the debilitating fatigue I feel three times a week."

"I tried methotrexate but hated the side effects."

"I currently take prednisone and hydroxychloroquine daily. Methotrexate had too many side effects for me."

"I'm currently on Infliximab and leflunomide . It's loosely controlled, and we've had to change my infusion frequency to every six weeks. Adalimumab was completely ineffective for me."

"Adalimumab has actually been the most beneficial. And had another one, but it caused cataracts. I can't remember."

"Adalimumab has been the one medication that truly minimizes my flares and reduces how often they occur. Prednisone, surprisingly, works to stop a flare immediately, and then I rely on Adalimumab to maintain control afterward."

"She's on Leflunomide. But I worry about liver damage. Methotrexate didn't work at all and I had horrible side effects. I still get flares on daily medication and take prednisone during those times. So again, multi-drugs being used as we know for treating sarcoidosis."

"With the methotrexate, which has chemo properties. My hair falls out, I get headaches, nausea, unsteadiness, and severe fatigue."

Non Medication Therapy

"Yes, pulmonary rehab. I've also bought one of the things that you blow with the ball up that they told me to take home, so I do that three times a day for about 10 minutes. What they tell me is that it's exercising our lungs, just like our legs, just like our arms, that has to be exercised, so it's really important to do it if you can."

"Pulmonary rehab is so important. I'm also on fluticasone and salmeterol. Because of my pulmonary sarcoidosis, I now have asthma, but I do kind of like the breathalyzer with the ball, and I also do deep breathing and I swim. Swimming is so good for that full body workout, but definitely work in your lungs."

Trial Desires and Challenges

"A treatment to reduce lung granulomas and inflammation without adverse side effects would be fantastic."

"I've been disqualified from trials because my organ involvement wasn't strong enough or because I wasn't on prednisone."

"I'm hopeful the drug will work, but the trial is torture with multiple spirometer procedures each month to the point that I have to plan to spend the whole next day in bed to rest my lungs." So, some of these trials can be challenging, depending on the drug and the research that they're doing."

"What would it take? Anything that does not have anything to do with steroids would get me to a clinical trial. And as long as I could still stay on my [infliximab] without having to change."