

100 Voices

*A plea for more funding, better research
and global awareness for Sarcoidosis.*

I am writing this as one of many hundreds of thousands of sufferers around the world of a “little known” disease called Sarcoidosis.

We are ordinary citizens of the world who can be of any origin, race, color or creed. We are Mothers, Fathers, Teachers, Nurses, Firepersons, Factory Workers, Careers, Police, Dr's, Lawyers, Gardeners, Students, Babies, Grandparents, Unemployed or Retired. We are, or have raised children, we have held down jobs for years or are just starting out and we are your next door neighbor. Sarcoidosis does not discriminate. It is not contagious yet can affect entire families, husbands, wives and children.

We may have Skin Sarcoid which causes blemishes that don't look too bad but cause us pain, fatigue and emotional issues or we may have large ulcerated sores. We may have Pulmonary Sarcoid which causes breathlessness, severe lung pain, fatigue, speech problems and we may require a lung transplant or Neurological Sarcoidosis which causes us speech problems, fatigue, dizziness, headaches, paralysis, severe pain, brain fog, vision problems or blindness and numerous other issues or we may have Cardiac Sarc which of course effects the heart, Spinal Sarc which generally causes paralysis and severe pain. We may have kidney Sarc which causes kidney stones, diabetes, severe pain, fatigue and numerous other issues. We have problems with our bodies showing up as being low in vitamin D but when we take more or get more naturally from the sun we have more issues, such as a buildup of calcium in our bodies, which in turn causes calcification of the arteries, photophobia, and fatigue and end up with more inflammation in our organs. These are just some examples of what someone with Sarcoidosis can suffer from, but there is many more, Spleen Sarc, Sinus Sarc, pretty much you name it Sarc can get into it. Any form of Sarc can be debilitating and can cause or hasten death. Sarcoidosis is a disease which can involve one, two or all organs, its nature is not predictable, and it mimics many other diseases and affects us all in many different ways”.

We are continually told by our Dr's that we are suffering from a rare disease or that Sarcoidosis does not cause pain and that we must have fibromyalgia if we have pain. We are told that almost certainly we will go into remission within two years and that Sarcoid will never return. We are misdiagnosed for several years with things that are considered serious “unlike Sarcoid”, such as TB, Non Hodgkin's Lymphoma, Fibromyalgia, just to mention a few. The only way to get a definitive diagnosis of Sarcoidosis is via biopsy. Chest X-rays can

come back negative and ACE blood levels could be low instead of high. These two tests were the initial ways of testing for Sarcoid but have proved to be ineffective. Depending on where we live, we can see a specialist or not. In Australia for instance there is one known Sarcoid Specialist. In the USA there are now several Sarcoid clinics in different parts of the country. In the UK, there is one major hospital in particular with several Sarcoid Specialists.

We live with the constants of being told “you don’t look sick” or “you look so well” or “do you still have that sore throat” or “Why are you in a wheel chair?” We live with people asking us what is wrong with us only to tell them and then complete and utter disregard as we tell them we have Sarcoidosis, because it is so unknown. We live with fighting for recognition that we are sick and that we may no longer be able to work even though “we look well”. We live with fighting in some places for “disability” payments. We live with fighting to get help in any way, shape or form. We live with being prescribed corticosteroids which are a “band aid” solution to bring the inflammation down but cause innumerable other problems such as diabetes, osteoporosis, obesity, pancreatitis, kidney stones, glaucoma, bloating, etc. Or we live with being prescribed Methotrexate which is a chemotherapy drug which causes its own side effects. Or in some cases we live with having to deal with our symptoms with no help of any kind. We are often not prescribed pain relief because “Sarcoidosis isn’t painful” as we are wrongly commonly told by our Dr’s. We are going to our Dr’s so often with new symptoms only to be told that that is not something that is caused by Sarcoidosis or that we are depressed. We are told that we are “obsessed with Sarcoidosis” and are “looking for new symptoms”. We know more about our disease than the majority of Dr’s who attend a one hour lecture on Sarcoidosis during their several years of medical school.

What we and the Dr’s have in common, is that we don’t know what causes Sarcoidosis. There have been and still are many theories that range from chemical toxin exposure to genetic predisposition. There is no direct evidence yet of what is the exact cause. Some people have their entire family affected and others may be the only person in a large community that has been diagnosed. Another problem is that, as has already been said, many of us are misdiagnosed for many years.

We Sarcoid sufferers of the world want only recognition, which we hope will in turn lead to much more research and hopefully a cure. We do not want to be fobbed off anymore as being lucky “not to have cancer”. We are not lucky to have Sarcoidosis. No person in this world would want the label of having Sarcoidosis as it is not the minor, rare disease we have all been told it is or not heard of at all.

Oh, and if you see someone in a disabled parking bay “that doesn’t look disabled” maybe it’s us. We may not be in a wheelchair but we may not be able to walk to our own letterbox without becoming breathless or dizzy but if we have a disabled parking permit, we need it, so please don’t judge us.

So what does Sarcoid feel like? Let’s take Pulmonary Sarc as an example because it is the most commonly diagnosed form of Sarc. Imagine you have just finished a major marathon, you are gasping for breath, your whole body aches and you just want to lie down, then before you can blink, a heavy weight boxing champion pummels you in the lungs until they ache like they never have before. Your knees and ankles and every other joint in your body aches so much you feel like you are 130 years old. You have trouble lifting yourself up let alone walking the steps required to get to your bed. If you do get to your bed, all you want to do is sleep but you can’t because of the pain and because you can’t catch your breath. You feel like your breathing will return to normal soon because it always does after a marathon but you aren’t really a marathon runner, you really have Sarcoidosis.

We are looking for help and awareness from the medical profession and the general public. We want to find a cure but until then we want treatment and understanding. We want only to be able to live our lives in whichever way we can but with the knowledge that this disease is being researched and a cure is being looked for.

The following pages include 100 different stories detailing how Sarcoidosis has impacted peoples’ lives. The stories are written by mothers, fathers, sons, and daughters. The stories are real, some written out of anger, frustration, desperation, hope, excitement and pain.

These stories are real, Sarcoidosis is real, the funding needs to be real too.

Cher McGuinness

As a physician who treats patients that suffer from Sarcoidosis, I share many of the same frustrations that have been voiced to me from my patients over the years. Many of these frustrations have to do with the lack of targeted therapy for their disease as well as the lack of understanding about how to change or predict the clinical course of the disease. But also, there is much frustration centered on the lack of public awareness and a sense of isolation. That is why I feel so fortunate to be able to tell my patients about the Support Group specifically for patients with Sarcoidosis that is organized by the Sarcoidosis Awareness of Northern California. I think that the vignettes compiled in this booklet will provide insight into the struggles, thoughts, and hopes that patients with Sarcoidosis share. This booklet was put together by patients, each with different motivation for participating, however, one common goal that I think we all share is that the future holds clinical discoveries that could change their lives or lives of patients in the future.

Thank you for taking the time to read them.

So here is my story:

I had health problems in the first place and was very ill for a lengthy time. I had been in a great deal of pain and no one could figure it out. They eventually blamed it on me. Of course this caused a great deal of friction in my family, and with my daughter. Who would ever believe me when doctor's are saying she is crazy, or making it up? Of course, my family and I haven't spoken in five years. Last year in March I had kidney stones, and they thought they found Lymphoma everywhere. Well, then this is the pain! After they took out my spleen, they found after two months of testing "Sarcoidosis". Just like with the cancer, this was systemic as well. My daughter was relieved, and finally felt vindicated as well with the doctor's, but now, it was who to go to for help? Even the surgeon did not know anything about "Sarcoid".

I called everywhere, even Stanford had little, if not any doctor's, UCSF, only had Pulmonologists, and I did not need one. Thank G-d! I did need one that dealt with everything though. I finally found one at Stanford, who, had treated a case similar to mine.

We started treatment with prednisone, and methotrexate, but because of gastric problems, I may have to go on IV shots and do that again. Because it took so long to diagnose, many years, I will be on the methotrexate the rest of my life! This is not a drug you really want to be on with osteoporosis. But oh, well! Over the past 10 years I have learned to live with whatever has been thrown at me from the medical community. It would be nice to be treated a bit more like a human being instead of a lab rat. My daughter is now 16, and she would love it, if she did not have to spend her life in and out of hospitals.

We need more research, and more doctors to help treat this disease so we have more to go on besides what we do have. Dr. Chakarvarty, is only going by what she has seen so far, and that is only a few patients. She has never even heard of Sarcoid possibly in the gastric area. This is a real possibility with me at the moment.

Thank you,

Cindylynn

My name is Richard and this is my Sarcoidosis experience.

Amazingly, I was originally diagnosed with Pulmonary Sarcoidosis in the 1970's when I was in my late twenties. However, at that time I was not experiencing any symptoms. When I approached my fifty-second birthday I started experiencing chronic coughing, shortness of breath and some wheezing. After receiving a pulmonary test and a CT scan my doctor diagnosed me with Pulmonary Sarcoidosis in Stage II. He immediately put me on 30 mg of Prednisone and my symptoms disappeared.

Although I cannot do any strenuous activity I did not experience my previous symptoms. Over the past five years I have been improving my diet and gradually increasing my exercise and have been able to wean myself off of Prednisone. I have continually taken pulmonary tests and CT Scans to monitor my condition and it appears to have somewhat stabilized. However, my doctor has told me that it is not known why this disease occurs, that it affects different organs of the body, affects people differently, and can reappear at any time.

It is vitally important that more funding is directed for research to determine the cause of this disease and hopefully effective treatment for Sarcoidosis. It is amazing to me that so few people know about the disease and how many physicians are unable to diagnose Sarcoidosis. I'm now at an age where I can start enjoying an active, productive life with my wife and I do not want this disease to prevent me from obtaining that. I know that with further research we can improve the lives of so many people.

My name is Karen and this is my Sarcoidosis Story.

In January of 2006, I had a CT of my abdomen, a picture of my lungs was included and it was discovered that I had lung nodules. A Chest CT was ordered to get a better look of my lungs. My doctor referred me to a Pulmonologist who wanted to repeat the CT scan in 6 months. This time there was no change, so they wanted to repeat it again in 6 months. The next CT scan revealed an increase, in number and in the size of the nodules since the previous scan. A lung biopsy was recommended.

In March of 2007 I had a lung biopsy and it was confirmed that I had Sarcoidosis. Since being diagnosed with Sarcoidosis, I have had numerous CT scans and pulmonary functions tests. I am not on any medication now, but I know that can change at any moment, based on my recent test results. I have a sister that has Pulmonary Sarcoidosis and my mother passed away of what we thought was Asthma. I often wonder if she also had Sarcoidosis, and it was never diagnosed. We will never know the answer to that question.

We need more funding for research to help with finding a cause, better treatments and hopefully a cure of this disease. I don't want to see anyone else in my family diagnosed with this disease. I am concerned that my kids or their kids will end up with this disease. I want to see it stop with me and not go any further.

Hi: My name is Bonnie.

I contracted Sarcoidosis when I was 22 years old and discovered red lesions on the insides of my lower legs. Treated by a dermatologist, the lesions went away and I had no further problem with the disease until 60 years later, being fatigued and short of breath , I found I had a full blown case of the disease in my lungs.

Since then, I have been very fatigued and short of breath and have had to change my active roles in life. My pulmonary doctor tells me that the only medications for Sarcoidosis could cause adverse reactions. An inhaler helps with breathing but nothing eases the fatigue. I hope there is help in the near future.

My Sarcoidosis Story

I' m a cyclist. I was a runner and a triathlete. I competed in the Summer National Senior Games. I love competition. A few years ago I did a one week, 500 mile bike ride through the mountains of Oregon, camping every night. Once I did 200 mile ride in one day and once I ran a marathon.

Two years ago I was diagnosed with Sarcoidosis. I have it in my lungs and lymph nodes and maybe other areas. Last week I did a ride of almost 14 miles with the aid of an inhaler.

Pam

Hi, I am Jeanne.

I am a 68 year old California native, retired and on Social Security. I worked for 50 years in the profession of Accounting, not exposed to dangerous chemicals, and yet I have been diagnosed with Sarcoidosis.

August 2003 I developed edema, high blood pressure and extreme weakness. My primary care doctor ran many tests and nothing made sense, she asked me to try to think what I had changed in my diet or life. I remembered that I had put salt substitute in our salt shaker. So I went back to real salt. 4 days later began to get better. She did not diagnose Sarcoidosis even though I showed some of the symptoms.

After November of 2003 most of the symptoms subsided, so I figured I had just had an allergic reaction to the salt substitute. On December 25, 2003 I developed eye problems in the form of black spots, flashing lights, spider webs and pain in sun light. All symptoms of Sarcoidosis.

April 15, 2004 I was diagnosed with iritis and treated with eye drops. This solved many of the eye symptoms but did not cure the iritis, because it is caused by Sarcoidosis.

Dec 2003 pap test showed abnormal. A biopsy was done and ruled out cancer. All pap tests since then have been abnormal but nothing has been diagnosed. I believe it is Sarcoidosis.

March 2007: In an attempt to clear up the iritis I tried a wheat free diet. It didn't help the iritis, but helped many other symptoms of Sarcoidosis. We with Sarcoidosis know this, but none of the doctors seem to know this. Good gastro intestinal doctors who diagnose Celiac disease know to recommend a gluten free diet, but they don't know that it will also help Sarcoidosis symptoms.

February 2008: My primary care doctor noticed an elevated liver reading and ordered an ultrasound test which showed enlarged spleen with lumps, she finally diagnosed Sarcoidosis.

This was 5 years after the first symptoms. She told me that as long as the symptoms were not interfering with my life she did not feel that Corticosteroids were necessary. I found it necessary to then turn to the

internet to educate myself on Sarcoidosis. I learned that my eye problems are really symptoms of Sarcoidosis. Test show my spleen and liver are involved, and I believe my breast and reproductive organs are involved. In addition my ears ring constantly, I have dizzy spells and tingling hands. Yet my primary care doctor does not seem to feel these are related, and told me not to worry that no one dies from Sarcoidosis.

What I don' t have is lung involvement, and the doctors who are most educated on Sarcoidosis are pulmonary doctors. I find myself with no well informed doctors, about Sarcoidosis, available to me.

We need to have doctors educated on this disease. If doctors were better educated on this disease it would not take 5 years to diagnose it. People do die of Sarcoidosis, and the disease does spread and continue to cripple those of us who have it.

We need to have research done on Sarcoidosis. When considering research funding please keep in mind all of the people with this disease that loose their jobs because they cannot work. They often need to rely on government funding to supplement their income and cover the growing health care costs. If the funding was given to researchers to discover the cause and a cure then less would be relying on funding to sit home and be in pain.

D. Jeanne

Union City California

About 3 years ago it started with every time I bent over, water would literally pour out of my nose. I thought it was condensation from the shower. LOL!! Then my eyes started swelling and my asthma was getting harder to keep under control. My feet started being painful. Then it was my sinus's again. Then my eyes started swelling completely shut. Then my asthma became almost constant. Then I started getting sores around my ankles. They itched so bad. My lungs were hurting and the breathing treatments weren't working very well. Last winter it all got worse. The sores around my ankles were quarter size. I could barely breathe.

My allergist had an xray done on my lungs and saw a spot. Then I was sent to a pulmonary doctor. He did a ct scan. Then a pet scan. Then they did a procedure going through my nose to my lung. Then another procedure to take some lymph nodes between my lungs, all the while many, many blood tests.

I finally got a diagnosis 2 months ago. Sarcoidosis. I am now on 40 mg prednisone, but I am still having trouble breathing. I will be seeing my doctor this week and maybe we can change the meds, or??

Thank you for listening,

Susan

I had my first diagnosis of active Sarcoid in 1999, when my eye became infected. I was treated for 6 months with eye drops and an oral steroid. During this time I maintained full time employment, with the only disruptions to my daily routine being the numerous medical appointments I had. I went into remission for the next ten years. In 2009 I had a severe reoccurrence which continues to this day; causing a very disruptive life (with severe body pain) . Although I retired from work in 2002 , the year of 2009 was difficult to manage.

I have received excellent medical care by my health care provider. Aside from my internist, I have an assigned rheumatologist, ophthalmologist , urologist, neurologist, pulmonologist, surgeon, dentist, and physical therapist. But, it remains a challenge for them to treat me. I have been on numerous medications which have been costly. Numerous doctor office visits and laboratory work, have also have been costly. I continue to have test results that change monthly, causing it to be hard for my doctors to treat me. The condition has left me with many unanswered questions. I am taking drugs to counteract other drugs. I am always in a state of confusion. Because I live alone I have unexpected expenditures , such as having to pay for my home to be cleaned. I have to use grocery store home delivery to get food. I use the internet to keep in touch with my church activities. The physical pain and fatigue has caused me to miss attending numerous events, i.e., college graduations, weddings, family reunion, etc. My life has changed dramatically, and I wish Sarcoidosis on no one.

Glenda G.

Here is my story.....

My name is Samantha, and this is my Sarcoidosis story.

In August 2009 I started getting very tiny lumps under my skin, around my knees and on my forearms. At the time I had already been diagnosed with Cushing's Disease and was awaiting Pituitary Gland(brain) surgery in December 2009, so I didn't pay much attention to them. In March 2010, three months after my surgery, these lumps began to grow and I started getting more of them. I had skin biopsies in July 2010 and was diagnosed with Sarcoidosis. My case is unusual because I don't have Sarcoidosis in my lungs or anywhere else(according to the doctors). At age 40 I was diagnosed with a form of Macular Degeneration, yet the doctors don't believe that any of the other conditions are related.

It has been very frustrating dealing with doctors who don't understand or can't comprehend how I am feeling. Many of the doctors have tried to blame an unhealthy lifestyle and environmental factors for my problems, but I have never smoked or drank and I eat a very balanced diet with no wheat or dairy products. It is hard for me to exercise because of my severe fatigue and muscle pain.

We need to have doctors who specialize in Sarcoidosis research and treatment, who can understand all the different symptoms and side effects of the disease.

My plea is for the undiagnosed. As a sufferer of this disease I can share that the greatest agony beyond the pain and suffering of the multiple symptoms and debilitating lifestyle this disease inflicts is the many years of being unsuccessfully diagnosed. This is not uncommon as many others with a confirmed diagnosis have shared they too suffered a similar fate.

Because of the challenges to test and positively diagnose Sarcoidosis, mistakenly we are treated repeatedly for the many symptoms that Sarcoidosis mimics so systemically. We try our best to not hold the doctors at fault or incompetent. Many of us are referred to specialists with the best medical training and knowledge but they too share our frustrations with the challenges this disease presents. We (sufferers') are forced to find additional strength and patience while enduring the pain and suffering to remain hopeful during a time our bodies are under attack.

This disease has many symptoms already identifiable within several other major diseases classified as serious and debilitating. Sarcoidosis should be known as the disease in disguise and my hope is that the research community will give Sarcoidosis a priority commitment to finding its cause and cure so that future potential patients may be quickly and correctly diagnosed to begin receiving relief and treatment.

Hi, My name is Jo Ann. I was diagnosed with Sarcoidosis in 2004 by an ex-ray I had months before that. It was 1 week before Christmas I had just come from my Christmas party for my work. That's when I got the call from the nurse she said the doctor would like to see you first thing in the morning.

The next morning I went to see him he said you have lung cancer and he wanted me to go see another doctor which was a lung doctor. I really like her from the first time I saw her but it took almost 2 weeks to get an appointment with her. I had to go through Christmas and New Years thinking I had lung cancer, worried how I was going to tell my 3 daughters and my grandkids. This was the worst Christmas I ever had. Well I went to my appointment and this doctor said we are not going to think about cancer yet she told me she wanted me to have a lung biopsy done so I went home and talked it over with my daughters and decided that I should have it done. The next week I went into the hospital and had my biopsy done after that I was put into intensive care unit for about 1 week one of my lungs had collapsed I had tubes in my neck .

Well the doctor came in and told me that I didn't have cancer I had Sarcoidosis of the lungs she had explained everything to me about the disease. I was put on steroids and a number of different meds. Over the years I did fine, you wouldn't even know I had this lung disease I didn't have any problems with my lungs no coughing at all, nothing. One day I started suffering with my back really bad I couldn't stand the pain I went back to my doctor and told him about this he then ordered an MRI of my lower back and my right hip which those were the areas that hurt me the most. I was told the Sarcoidosis had traveled to my right hip and lower back that was and still is the most painful thing I have ever had. To this day I still suffer with my hip and back. I can't mop or sweep, it kills me but I am a strong person and I push myself. All I can do is leave it in the hands of the good Lord and a lot of praying.

This disease is so horrible to deal with. Even though I am on 3 different kinds of medicine for pain I still suffer. I don't want to live on pain meds for the rest of my life because they don't get rid of the problem. I want to find a cure for this disease I don't wish this kind of pain on anyone. God Bless everyone that is suffering from the disease. I also am fighting Fibromyaglia, Polyneuropathy, and Diabetes so I am trying with all my heart to go through life each and every day nothing there is no cure for this. - Jo Ann

I was diagnosed with Sarcoidosis in 2001. Prior to that, I had multiple knee surgeries that did not heal properly, septoplasty and many nasal infections, and several other problems that were most probably caused by Sarcoidosis, but not properly diagnosed.

In 2001, I started having trouble breathing and was diagnosed with sleep apnea. Even after Uvulopalatopharyngoplasty surgery to remove the uvula and excess skin in the pharynx area, I still could not breathe at night. I then had X-rays of the lungs where the Pulmonologist thought I had pneumonia, but did not have the proper symptoms. I also had cardiac arrhythmias.

After having a high resolution CT scans, it was determined that I had Sarcoidosis affecting over 85% of my lungs and causing enough swelling in the lymph glands in the chest that the glands were pressing on the heart and aorta, causing the arrhythmias.

I then started treatment with Prednisone. With each increase in prednisone, my Sarcoidosis got worse. After reaching doses of 80 mg per day, I had to be crashed off the prednisone on IV steroids in the hospital due to psychosis and poisoning. I then was referred to Johns Hopkins where I was treated with high dose antibiotics to control the Sarcoidosis. Due to Sarcoidosis and other immune system issues, I was forced to accept full medical disability in 2010.

In all, I have had Sarcoidosis in my tear glands, salivary glands, skin, muscles of the arms and legs, larynx, bronchia, lungs, and lymph glands of the chest and abdomen. When I think they have it controlled, it pops up somewhere else.

To whom it may concern:

I am a 51 year old married mother of 3 grown children. For approximately 8 years I have been suffering from extreme joint pain and fatigue. The fatigue got a little better for some of those years, but recently this spring it came back along with sharp stabbing chest pains, shortness of breath, and a rapid heartbeat. After ruling out heart related causes my physician ordered an MRI of my chest and abdomen where she found that I have lymphadenopathy throughout my lungs, and Sarcoid lesions on my spleen. After my second bronchoscopy this year; Pulmonary Sarcoidosis was diagnosed.

Sarcoidosis has affected my ability to enjoy an active life. I used to bicycle, hike, lift weights, and maintain two jobs not so very long ago. I was in very good shape. I worked as a massage therapist and as a medical receptionist. Now I have gained 60 lbs.; some days I don't have enough energy to do more than sit on the couch. I take naps most days. I have a frequent cough, and get sick frequently also. It would make me so happy to have a cure for this disease. I'm still young enough that I could do all those things I used to enjoy doing. We need more research to help give people back their lives.

I don't have sarcoidosis but my wife does. It has financially impacted our lives with all the different prescriptions as well as the emotionally impact on my wife. When she gets upset, I get upset. The biggest issue is the not knowing or lack of expertise by the several physicians we have seen. Everybody has a different take on how to help her, but they seem to be educated guesses instead of concrete cures.

I first took sarc 30 yrs ago, lung and major joint involvement, went into remission after about a yr. I have had reduced capacity and various flares over the years until about 8 yrs ago they started getting worse lasting longer until about 18 months ago wham this relapse wasn't going away. I thought I would share my experience. I had tried various things over the yrs, the best one was a herb called devils claw it had great anti inflammatory properties and pain relief. Nothing could give me relief this time until i started a new treatment 8 months ago.

It's amazing I'm getting my life back from a point actually where it had gotten so bad I thought I was going to lose it with the last relapse. I have found out the sarc is now in my lungs, heart, liver, kidneys (was in partial kidney & liver failure just before starting), joints, muscle, stomach (bowel), eyes, skin, spleen, nervous system, bladder/prostrate and repro organs. I was an absolute mess needing the bathroom 4~5 times every night-urinary problems, only sleeping 1~2 hrs per night for 8 months, couldn't get up or down stairs without screaming out in agony.

Now I sleep sound each night 6~8 hrs. I rarely need the bathroom, maybe once on an odd night. The constant pain is gone, urinary/repo probs gone, the ibs/gi probs are less than half and I think finally are going(wha Hey- I think this is the best bit for me). For anyone who has Sarc in their bowel it was one of the most difficult painful and totally unrelenting aspects of this disease. I have a ways to go yet it isn't easy or fast but all my other symptoms are reduced. I have went from being house bound for 6 months(crippled with pains/fever/agony) to now working again 5 days for about the past 5 months, just started back to the gym (lightly) and just back from a great euro holiday. During these times I have lost a lot of friends, work and relationships with my family, this disease has taken away the best part of my life, there is a new reality about this disease plus new treatments that need to be out there(validated) and groups like inspire so others don't have to go through what I did to find support and resolution.

Z

I was a successful Children's Book Illustrator, until I began loosing my sight from Sarcoidosis of the eyes.

In October 2008 I began feeling ill with eye pain. By Dec. 2008 I was being treated for inflammation of the eye; Iritis. Soon I had Iritis in both eyes and then within a month my inflammation became more severe, I had developed Uveitis. My ophthalmologist said I had more than and eye problem and sent me to a Rheumatologist, who couldn't help for I had no swollen joints. The Rheumi sent me to a pulmonologist, who couldn't help me because my lungs where clear. In March 2009 I saw an Ocular Immunologist Uveitis specialist at Boston's Mass Eye & Ear infirmary who labeled me a "sarc. suspect". After months on anti-inflammatory drugs (and being treated 2 months for Lyme by an infectious Disease Doctor) the Uveitis doc put me on Methotrexate. A chest biopsy in November 2009 proved I had Sarcoidosis. When I checked my vision after surgery it had dropped to 20/200 (legally blind) down from 20/60. My vision stuck at 20/200 for a year. I developed Cystoid macular Edema in both eyes caused by prolonged eye inflammation from the Uveitis caused by the Sarcoidosis. I have many intraocular injections to try to get this swelling of my macula reduced. I have given up my art, driving and I can no longer read magazines and books or watch TV.

I am lucky my ophthalmologist realized I had more than an eye problem two years ago. If she had not, I believe I'd be totally blind from steroid drops by now.

I wish there was more public awareness of this disease. Especially for the smaller percentage of people who have eye disease caused by sarcoidosis that go undetected.

I am hopeful my last intraocular injection works and my eyes stabilize after these crazy last two years. My doctor says I will never have 20/20 vision again but he hopes I will eventually have enough to drive again.

**Ever hopeful,
Sarcoid Sister**

I was diagnosed with 3rd stage pulmonary Sarcoidosis in September 2009 after year of tests to determine my shortness of breath and unexplained joint and neck pain. I had always been a fitness geek I did weight training, spin bike classes, yoga and walked my chocolate lab daily. Over the year of testing prior to diagnosis I had given up all my fitness activities except for occasional walks with my dog and yoga on days I had the energy after work.

At the time of diagnosis I was 50 years old with three grown children ages 30, 29 and 20 and a 6 month old grandchild. I had a full time career I loved supporting and planning for adults with developmental disabilities.

By December of 2009 I had developed a lung infection and was put on 60 mgs or prednisone for 7 days to shock my system as my family doctor explained. By January 2010 I made the agonizing choice to leave my work and go on long term disability until I was able to return to normal activities.

My follow up appt with respirologist was bumped due to clinic limitations from January 2010 until April 2010 by this time I was in daily pain waking in the night having night sweats and I WAS NO LONGER ABLE TO WALK A FLIGHT OF STAIRS, TALK ON THE PHONE OR PICK UP MY 9 MONTH OLD GRANDDAUGHTER.

My family doctor sent me to mental health clinic for counseling and antidepressant medication. I would think that not being depressed when facing life limitations and changes as a result of pain and breathing difficulties would be more concerning. But the medical world wants us to smile through adversity so I now take a variety of pain, antidepressant and anti-anxiety medications or yes a PRN sleeping medication if all the others don't work.

My pulmonary, blood and chest x-rays/ tests after 7 months from diagnosis had all declined. The respirologist recommended long term prednisone starting with 40 mgs daily and reducing by 10 mgs monthly until I reached 20 mgs. by my return visit.

After adding pred to all my other meds I gained 40lbs and now had constant back pain due to added weight and deteriorating discs which I had been treated by chiropractor and massage therapist for the past 8 years. My exercise regime had been my preventative measure to maintain back health

and body strength with the sarc I was no longer able to do the activities I had enjoyed daily for over 20 years.

On my now 3rd visit to respirologist the x-ray showed minor improvement in inflammation of lungs, pulmonary and blood tests remained the same.

Disappointed in my tests the respirologist decided to take me off the prednisone over the next two months and she explained that once I lost the extra weight I should do better on pulmonary tests. " I think she must have a sense of humor to say that to me with a straight face ?"

So now I am on 10 mgs going to 5 4 3 2 1 over next months. Pain has returned in my chest my daily activities remain limited due to shortness of breath and constant body joint pain. I wake in the night with upper back and chest pain. I am trying gluten free diet with little effect.

I need friends or husband to be home when I have my now 16 month old granddaughter over for a visit. I remain on LTD through my benefits at work. I have a beautiful pool and gardens in my back yard I am unable to use or enjoy due to the humidity this summer and Vit D sensitivity that can also come with SARC.I continue to have weekly appts with chiropractor, massage therapist to deal with pain, I continue to take medication and attend counselor for depression.

I miss my old life of fitness, career, gardening, vacations in the sun and spending time with my children and grandchildren doing activities we all enjoy :(

It is very discouraging to have doctors explain that treatment for this disease is trial and error that it can go into remission or it can spread to others areas.

I hope my story as well as others can help promote further research.

Lorre housebound and watching others do what I used to be able to enjoy :(

I am a white, 48 year old female who found out I had sarc in 2005 when I was 43 years old. No one in my family has had this disease that I know of. Here's my story:

In 2004 my dentist saw that the bone was receding in my front lower bottom teeth area. I was sent to several other dentists/specialists & none could figure out why the bone loss was occurring. My teeth appeared to be fine. Four root canals were performed, but the bone loss didn't stop and the teeth didn't stabilize. Oral surgery was performed in hopes of saving my teeth, but there was no bone to hold them in. The pathology report ruled out cancer, but I was told I needed to get a head-to-toe check-up because something systemic was happening.

I then went for a physical & when a lung x-ray was performed, there were numerous white spots on the x-rays. I underwent many tests including CTs and a Gallium scan. It was decided that a bronchoscopy should be done. I also had a positive TB test and went through the lengthy mucus testing. I was extremely worried and panicked that I could be spreading a horrible disease to my family & friends. I didn't have TB & the bronchoscopy finally gave the sarcoidosis diagnosis.

After finding out the sarc was in my lungs, another pathology test was done on the bone removed from my mouth. It also tested positive for sarc. My sarcoidosis diagnosis explained the constant, hacking cough I had almost every year for a few months for as long as I could remember. It explained the night sweats I had been having for the six months prior to my oral surgery, which I was told by my gynecologist was probably due to perimenopause. It also explained the sudden, unexplained swelling in my hand that had occurred a few years before my diagnosis, which I attributed to my computer work as a legal assistant. Knowing what I now know about sarc symptoms, I believe I had Sarcoidosis possibly as far back as 1988.

I was put on prednisone (a/k/a Hell in a bottle) two different times for about 2 1/2 years. I was also on Imuran for about a year. In addition I had to take 9 months of Isoniazid for the treatment of my possible TB exposure (which I don't believe I've ever been exposed to). In addition to the the above medications, I had to be on several others due to the prednisone side effects (severe insomnia, gastric upset, etc.). During the time I was on all these

medications, I wasn't working and don't believe I could have worked due to the severe side effects.

I have been off all medication for the last couple of years, but I have found that I can't handle the stress of a full-time job as a legal assistant and I have had to decrease to part-time work. I worry that if I ever have to be on medication again, I will have to quit working. I currently have health insurance through my husband, but I worry that at some point I might not be able to get coverage due to sarcoidosis. Currently, my PFTs are normal and my breathing is fine. But, I have intermittent joint swelling and pain and have currently been having trouble with an elbow. I've learned that the joint swelling and pain seems to ebb & flow. I try to alleviate it by taking ibuprophen when needed. I try to rest when I need to and not get overtired. I'm not able to do all the physical things that I should be able to do at my age. I had a pretty rough time for several years after my diagnosis, but have felt pretty good for the last few years. I feel very fortunate that sarcoidosis hasn't robbed me of a fairly normal lifestyle ... yet.

I hope my story will help in some way to help cure/treat this dreaded, misunderstood disease.

Thank you,

Carol

I am 48 years old and live in Kentucky. I see Doctors at Vanderbilt in Nashville, Tennessee. I had a knee scope last year which led to the discovery after 2 biopsies that I had Sarcoidosis in all my bones, my lungs, my liver, my brain and now in my heart muscle. The pain has been the worst pain I have ever had in my life. I was in a wheelchair for about 2 months. Since being diagnosed I have been on prednisone and methotrexate. The results have been that although it has helped some of my bones, it did spread at the same time. The prednisone and methotrexate did help the pain somewhat but it never goes away.

Quitting work is not an option for me because my husband is unemployed. I have been fortunate that I can rest at work. They hired another person to drive me to work and she is to help me at work. When I get home I lay down and take pain meds. It is a vicious cycle. I no longer enjoy my weekends. They are for complete rest.

I am lucky to be participating in Dr. Drake's Clinical Study of antibiotic therapy on pulmonary Sarcoidosis. Since starting the therapy the bone pain has come back threefold. Why continue with the treatment? Because I believe it is helping me. I went through lots of pain while the Sarcoid spread to all the areas of my body. It only makes sense that it will take lots of pain to get rid of it. After having started the antibiotics, I realize that taking the prednisone and methotrexate could not have been helping enough. I think it was just masking the pain so that I felt better but was not getting better.

Please, please, there has to be money allocated for Sarcoidosis research. I liken this disease to cancer, in that, it can be a silent killer or it can strike with the worst pain you have ever had in your life. Right now there is not enough treatment for this disease. We have to fight with our insurance companies to get the medications that might make this better. We have to worry that we are going to be able to pay for the medications. The more research, the better the treatments, the more likely there will be, if not a cure, at least a better treatment.

Tammie,

Scottsville, Kentucky

I am a 57 year old woman who has had this disease since I was 38, at least that is when they discovered it by accident. I did not have any of the symptoms but my xray of the lungs showed I had it. I was sent to San Diego for a biopsy to make sure it was benign. I did not have any major problems until about 5 years ago. I then began to have a hard time breathing. Before this I only had a hard time if I exerting myself or went out in the sun. I went through 4 specialists to get help and because of their arrogance I went from a level I to a level IV lung capacity within 6 months. My new specialist had given me 6 months to live. This was about a year ago.

Luckily he had sent me to a specialist at UCLA who put me on plaquenil and I am doing better. But because my blood tests did not show that my sarcoid was active the other doctors refused to treat me. I went through a nightmare for 3 years trying to get help. Please help get more studies on this disease.

thank you,

Denise

I was diagnosed with Sarcoid in 2003, Having a difficult time dealing with the Disease itself, been depressed, and Not knowing if i will be here the same time next year with my family. Doctors that i have been seeing have been telling me that this disease is incurable and people do not recover from this disease and there is nothing to do to help my lungs. I do not believe that no treatment is available only steroids! If anyone have any information please let me know.

David

My Sarcoidosis Story

My name is Millicent, and I was diagnosed with Sarcoidosis in 1991. It was a very scary thing because I didn't know what was going on with my body. No matter what I did (work, taking care of my children, husband and keeping a household) I just seem to never have enough energy. Then all of a sudden it became hard for me to catch my breath...I would have to pause so often to regroup to continue on with whatever I was dealing with at the time. I would get like this flutter in my chest and it would seem like if I didn't cough there would be no more air in my lungs for me to breath...finally I went to the doctor and he ran a series of test and the results came back to be Sarcoidosis. I was like what in the world is that?...never had heard of it before and the really scary part was to hear that there was no cure for it and no one knew where it came from.

At first everything was internal, swollen glandular lymph nodes all over my lungs and under my skin especially in my neck and under my chin until finally I had to have the one in my neck removed. I ended up on inhalers because I couldn't breathe okay, if I talked more than 10 or 15 minutes without coughing, talking in the cold air was a definite no, no. Could not inhale chemicals, perfumes, and major dusty areas were affecting me....(all that the world was made up of right?).

Then one day in/or around 1999, I notice something funny on my skin sort of like a chicken pox, the next thing I new as the years went by it multiplied all over my face, arms, back of my neck and chest...I was so frustrated because the dermatologist I had just kept trying different inflammatory meds on me...and with each one he would say "it may get worse before it gets better" I was like I can't afford for it to get worse...and sure enough it would so I would quit taking the meds and I would end up so stressed (which was not good for my condition) and sadden because I looked so disfigured. So I tried to cover it by wearing makeup which in turn made it more noticeable. I didn't like to be around people because they would always ask me what happened to my face, and in most cases I would end up in tears because there was nothing that could be done and it was getting worse.

After many years of seeing the dermatologist and the pulmonary doctor I still didn't seem to be getting any better. Finally thank God my pulmonary doctor

asked me if I thought my dermatologist was helping me and I was like no look at my face. So then she referred me to another dermatologist (Dr. Becker) in 2009 and he took the time to really research and find a medicine that he thought would worked for me (methotrexate)...it made me sick at first and I had to take a blood test every week after taking it, but after about 6 months I started noticing changes and the nodules on my skin gradually started to leave. It has been a little over a year since I started on the med and I look 100% better to me. I am more confident about being around people and don't need to wear makeup unless I just want to....I have some scarring from it but I am so eternally grateful that God touched Dr. Becker and lead him in the right direction and I have been healed on my face and skin. I am doing much better I still have issues with the breathing from time-to-time, but I am so very happy for where I am with it today, I can deal with the breathing issues and the way my skin looks now.

This whole ordeal has given me such a respect for people that have health issues that they cannot control and no cure for, a heart to help in encouraging them in anyway that I can.

I know that is was only by the Grace of God that he sent a miracle my way through Dr. Becker.

There is a rainbow in the sky to let you know that the storm will soon be over in your life, we just have to trust, pray and believe that God has it for you as you journey through life awaiting it.

Respectfully submitted,

Millicent

My name is Nicole and I was activated to active duty in 2004. While I was in Germany I got inflammation in my eye I thought I had scratched my eye but there were no scratches when checked. I also noticed that I was having trouble breathing I would get short of breath at work or trying to exercise a little bit.

When I got home in January of 2005 I was having problems with my joints and I had a severe problem with my sinuses. I had sinus surgery in February and was told that they found something in my sinuses. Long story short I have Sarcoidosis which now affects multiple systems in my body I have continuing problems with my sinuses, eyes, joints, chest and most recently I found out I have cysts in my bones.

My biggest problem I think anyway is fatigue. When I become fatigued a day or two later I have nausea, vomiting and diarrhea. These symptoms can go on for days on several occasions I've gone to the emergency room and by now they know me and my history. Currently I'm on medications for the Sarcoid and pain management, but I also have to take four medications just for the problems with my digestive system thus far no one can tell me what the connection is.

However and thankfully I have an appointment with a Sarcoidosis specialist in October at John Hopkins university hospital in Maryland and I cannot wait.

My life was full I really was moving and shaking: full time parent, full time student working on two majors, in the military and found time to workout on a regular basis. Now I have to plan my activities and there are so many things I can't do. I'm not in school, the military is retiring me, I barely exercise. Travel was my favorite thing to do now I have to plan my trips with the knowledge that I can only do or go to so many places a year. I can't move around physically or geographically like I once did. For me that is my biggest regret.

Hello -

I am a 55 year old female. Before Sarcoidosis - I was active in yoga, tennis, boating, swimming, biking, jogging and loved to be at the beach with friends. Week-ends included enjoying a band or doing karaoke at a local bar with friends.

I was diagnosed with pulmonary Sarcoidosis two years ago. I had never heard of the disease before and I was sure I would beat it - be one of the ones that it didn't have much effect on. Boy, was I wrong!!! I can no longer do any of the things mentioned above - I have fatigue so terribly that most days I feel like I am walking through jell-o. My pain is all over body pain - I can feel pretty good in the morning but as the day progresses I feel worse and worse. I have been to a wide variety of medical doctors as well as a therapist to deal with this disease.

One of the biggest frustrations is that doctors are uneducated about this disease and what to do about it. We, as patients, continue to hold out hope that someone - somewhere - will figure out how to make us feel better or find a cure so that we can enjoy life again, enjoy our family and friends - and keep our jobs. This disease can erase all hope.

Theda

I am a mother of two, grandmother of three and have been very active in my 61 years. My children, their spouses and my grandchildren are the highlights of my life. Laughter is my coping mechanism and I have always said when I lose my sense of humor, bury me. I am retired from public education after 31 years, the last eighteen years working with children with severe emotional and behavior disorders and autism. What a rewarding career that was and laughter is what kept me going back.

I live outside of Atlanta, GA and have lived in this area for all of my life. I have many friends that I grew up with and who still remain in my life. I am truly blessed!

In my life time, I have survived breast cancer (21 year survivor) I have thyroid disease that has never regulated after twenty years; and was recently diagnosed with Sarcoidosis. I am still baffled by this disease and think its diagnosis hit me harder than when I was diagnosed with cancer because I cannot seem to get a clear picture of what I actually have now or what the future holds. I know, according to recent tests, that it is right now in my joints, lymph nodes and my lungs, mostly lymph nodes.....what does this mean? I was put on prednisone for one month and until recently I was only taking ibuprofen for the aches and pains.

Because I was not satisfied with the lackadaisical attitudes of my primary care physician, I made myself an appointment with Emory University Hospital in Atlanta, GA and saw a dermatologist there - she put me on Plaquenil 10 mg (I can increase by 10 mg every three days to a max of 100 mg). I am taking two nightly. I am also taking Hydroxychlor 100 mg. twice daily for itching. I cannot tell that the itching is better, it seems to be getting worse and is in all areas of my body.

Some days are much better than others. I wake up and feel as though I can do anything I want up arising but after a few hours, I am zonked as though I had worked a full day. My home used to be meticulously clean at all times and now it is all I can do to keep it just half way clean. Today I have slept on the sofa most of the day and it was an effort to even walk to the curb and bring the garbage can back to the house. I had to come in and rest. I hate this, it is so unlike me - I could normally work circles around the youngest of people, but no more. I think the worst part is accepting that I can no longer do the things I

had been able to do for years. I now rest when my body tells me to rest because I know I do not sleep at all most nights.

After taking the single round of prednisone, starting on 40 mg and decreasing weekly, the granulomas had disappeared but as soon as the prednisone was out of my system they returned and appeared in numerous other areas. I am now getting swelling in both arms slightly below the elbows and granulomas there, too. I recently had to undergo surgery on my right elbow to remove the bursac which was so inflamed it was the size of a baseball. This surgery was done after three efforts of draining and injecting cortisone. This I am sure was related to Sarcoidosis as I asked on this site if others had experienced this and got many responses affirming the same had happened to them.

Sarcoidosis is a disgusting and disfiguring disease with a new symptom or pain popping up regularly. We need for the NIH to take this seriously and help to find causes/cures for those of us who seem to be confused and scared for what our futures may hold.

The doctors seem to take this so lightly and tell me I will be fine but researching the sites on the web, tells me otherwise. I read about the tiredness, the sleeplessness, the depression, the aches/pains and I have all that including eye problems that I definitely think are a part of the sarcoid disease. Thanks for listening and for caring.

Judy

I was leading a charmed life, had a fall in DEC 2008, and noticed that my L upper quad abdomen area was enlarged. No pain, just larger than it had been and asymmetrical.

Next I got L shoulder pain, and L arm pain, Doc says no biggie... then I got belly area pain, Doc did Xray, that results in CT that finds my Lung Sarc. Too bad I spent 3 months waiting for a Bronch to prove it was SARC - NOT the Cancer I had been told it looked like!!! My PCP told me that IF it is not Cancer, it could be Sarc, since my dad had it in 1963 and there is some theory on genetic predisposition.

After Bronch found my Sarc in Lungs, Spleen and HIGH UA CALCIUM, I started 20 mg PREDNISONE as I have DM2, Hypothyroid and Hypertension! My SARC was confirmed on 6/2/2010 post BIOPSY on 5/19/2010. I have SARC in my Lymph, Lung *including airway involvement*, Spleen. I seem to have some issues with the Left upper Quad of my Heart as well!! No plans for more testing now on heart or liver though both are suspected to be involved in the SARC.

I started to trace my Triggers of looking for other episodes in my life, since I was Asymptomatic till I saw the spleen enlargement after I had that fall.... I can go back to mid to late year of 2006 - even had an EKG at that time from the pain in the LEFT arm/shouldernothing about SARC. Told it was "all in my head" go home, diet, lose weight and get control of diabetes.

And at the same time of my history search, I remembered that my husband, mom, dad and nephew all had an episode with NORO VIRUS in late 2006 just before the new year..... In Feb 2007, My Hubby is diagnosed with Lyme Disease, then Severe Advanced RA,(Due to the side effects, he is no longer on WESTERN Medicine treatment of any kind - sad that he has to live that way - in this day & age)

**** UPDATE Sept/2010 **** Learned that I may now also have Ovarian CANCER. Seems the KUB xray to check my Kidney found a pelvic mass. Had 5 days of testing, planning and review 9/9 - 9/16 2010. I am waiting for a call back with a surgery date as I write this.... Will have a TOTAL Hysterectomy and Liver Biopsy. Never had that before - the SARC was assumed from a result of the mess that I was in at the time of the BRONCH. The plan now if to keep my SERIOUS messed up spleen, as it is HUGE, IT HURTS, but still not eating the platelets so I will have some infection protection in event of Cancer and

Chemo! May need the spleen out at a future date if I elect to stop meds or if it starts being a detriment to my health.

Over read by the Rad Oncologist from the 9/9 CT finds that Spleen is ONLY a mess of Sarc - no belief that it is METS from anything or prime site Cancer.

I have worked in HEALTHCARE IT/SYSTEMS since 1986 - could there be something that triggered my Sarc there??/ Lots of RNs and clinical professionals get Sarc. Also I am a Germafobe from years SEEING the bugs & sickness in Healthcare so I used sanitizers and cleaners that required gloves.... I never used gloves - HmMMM could that be a trigger???

Hi, I am a 33 y.o. male who was apparently very healthy and active until I was diagnosed with Sarcoidosis primarily in the lungs and lymphatic system. This extremely unfortunate turn of events has left me almost in ruins. I have been receiving treatment from numerous doctors across many disciplines in effort to control or maintain a quality life. It wasn't long after my diagnosis that I discovered that there is not a lot of science behind the treatment of this disease. They basically treat the symptoms and hope that it essentially remiss es and in turn back off the medications. The medications that are used all have very undesirable side affects. This disease is often compared to cancer due to its ability to attack almost any system in our bodies and never goes away. I have not relaxed or stopped worrying about my health and my families well being since diagnosis. The insurance companies are very apprehensive about covering this disease since there is not a lot of science backing the treatment and it involves so many different doctors that I am constantly managing the process. It has become a burden worse than I could have ever imagined. I am anxiously awaiting a potential cure or breakthrough treatment.

Bob

My name is Lacy, husband of Karen White, President and Founder of Sarcoidosis Awareness of Northern California. Back in 2007 when Karen discovered she had developed sarcoidosis, information about this disease was under the radar. I've witnessed first-hand her pain and sadness, so she took that pain and sadness and wanted to educate people and bring awareness. She started her non-profit foundation, and since then, she has been overwhelmed with support from sarcoidosis patients who felt the same way. Her website has reached out to more people. Every day someone contacts her for information. Each day is a new journey for Karen, and she tackles the disease head on; however, more research funding and national awareness is critical. Karen has inspired me with her dedication and commitment. -Lacy

In 2001 I was working for ATT in California as a training manager. It was a fast paced job that required a lot of overtime and I had been doing it for years. That same year my apartment complex was being renovated to upgrade all the old outdated features that I loved. I started to get a really bad sinus infection that would not go away. I was treated with several antibiotics and after several months it was suggested I go to a true sinus specialist. I did and he gave me another round of antibiotics that lasted 6 weeks. Still no real improvement. I had started to notice I was very fatigued all the time. I slept 8 hours and still did not get rested. That same year I went on vacation to NM and noticed I could not keep up with everyone walking around. This trip I had made several times before and never had an issue. I ignored it thinking I just needed to get more exercise because I was almost 50. Finally in Dec of 2001 I went to have sinus surgery to fix my infection. When I went to the hospital for my pre opt chest X-ray all heck broke loose. I had spots all over my lungs. I was told I had TB or Cancer and needed to see a pulmonist. I did and he looked at the X-rays shrugged his shoulders and said it was Sarcoidosis. He had done his residence partially in the UCLA Sarcoid clinic and was familiar with it. So after the TB test was negative we did the sinus surgery. My pulmonist requested a sinus lab study to see if I had granulomas. The surgery was performed but the study was not done so we were back to square one. My sinus improved but my fatigue got worst. So bad it was affecting my work. After another year of guessing I decided to go back to the pulmonist and get some answers. He told me the only way to be sure was to do a lung biopsy. Although I was asymptomatic except for the fatigue we scheduled it. In February of 2003 I was diagnosed with Sarcoid. I was immediately started on 40 mgs of prednisone to supposedly shock it into remission. I had no cough and no other symptoms. Well the surgery had some problems and my lung collapsed. I was there in the hospital an extra week. When I got home I could not take care of myself. I could not walk more than a few feet without sitting down and I was always dizzy. The side affects of the steroid added to my problems. My long beautiful hair came out by the handfuls. I could no longer work so I was put on disability. I remained at home trying to heal for 6 months. After coming down off steroids I tried to go back to work again. I could not concentrate and my breathing was horrible. My job was in jeopardy and after several meetings with my boss to get better I chose to take a leave of absence for several months without pay. During that time my father died and I had to go back and forth to Michigan for business etc. Somehow I made it through the travel by

train because I was told not to fly. I retired for my job in Feb 2004 to keep from being fired.

I moved back to Michigan to be around family in May 2004 and was in a mild remission for the first 2 years. However in 2006 when my mother and step father started having health issues I flared again. Being an only child and having them both to care for was too much stress for me and I was started back on steroids. First at 10mgs and then back down to 3. Once I got to 3 I would flare again and we would start all over. I have been in and out of the hospital for all 4 years at least twice a year. My steroid usage is the same but I can no longer get below 6mgs without a major flare up. I am still dealing with dizziness, fatigue, breathing issues, eye issues, headaches and joint pain. The Sarcoid keeps moving around. I applied for SSDB in 2005 and was approved in 2007. Personally I would love to be working again and not be so sick. I miss the closeness of people and feel very isolated. I can no longer have any caffeine or salt or much sugar. When I cheat and enjoy a tiny bit of any I am sick for days. For some reason in 2007 I started having symptoms of chemical intolerance. I can no longer be around perfumes, gas, cleaners, glues, fabric softeners, paints and anything with much smell. I get headaches and dizziness immediately so I wear a mask. This has prevented me from going out and being social because people stare at me and are embarrassed. I feel that the Sarcoidosis and the steroids have ruined my life. I am thankful to be alive but.... Thank You

Bonnie

My name is Judy and I was diagnosed with Sarcoidosis in February of 2010. The journey to the diagnosis was a long one. In August of 2009 I became sick with what I thought was a normal illness that I always got at least twice a year. Normal bronchitis, sinusitis, pharyngitis, etc. So, I took myself to the er when I became so sick that I could not breath. The er gave me some anti-biotics and said to follow up with my doctor. I had no insurance at the time, so that was not an option. I took the medication, and got a bit better but not completely. A month later, I was again in the er. For much the same thing. Again, antibiotics were given and I was sent home. Then one day, I woke up with my thumbs in sever pain. I just thought that I had hurt them wrestling with my small children. Boy was I wrong. Within four days, the pain had moved to every joint in my body and I could barely walk due to the pain. Again, a trip to the er. This time, they took lots of blood, which all came back normal. They could find no reason as to why I was hurting. Again, I was sent home with some medication. Another month went by, and again, had to make that trip to the er. I was sick again! This time they took lung exrays and said I had pneumonia as well as bronchitis. Again, sent home with medications.

I finally obtained health insurance the beginning of February. At that time, I made an appointment with my new family doctor. I explained what was going on to her and she gave me some more antibiotics and requested the lung exray from the er. Two days later I got a call that stated they had found a mass on my lungs. She orderd a catscan to confirm which she did. The next three days were spent in the hospital undergoing so many tests I cannot count, all of which came back normal with the exception of the pet scan. I was then scheduled for a biopsy.

I went to my family doctor for the confirming results. I was devastated. I had a disease that nobody knew anything about, there was no cure, and only a couple of treatment options. All I could think of was who was going to take care of my disabled husband and two young children. I began to do research on my own which made me feel even worse. As time went on, I continued to feel ill, which impacted my life tremendously. I was unable to play with my wonderful children outside like I used to. I now became out of breath and so weak that all I could do was sit, or go back inside and lay down. How do you answer you children when they ask "why can't you go outside anymore?" I was heartbroken. I am able to do some things now with the help of high doses of

prednisone, but the side effects of the treatment can sometimes be worse than the disease itself. The weight gain, sweating, and reactions to the sun to name a few.

Please, please, please, support research for all forms of Sarcoidosis. I have pulmonary sarc, We need to find a way to give us Sarcys their lives back. Help us to find a way to beat this dreaded disease which sneaks up on you, and has no cure. Like cancer, it can be devastating on a family's life.

Thank you - Judy

I am a 58-year-old female, wife, mother of three grown children and grandmother of two. I live in Wisconsin. I am a retired medical transcriptionist. I had a heart attack in 2007. After they inserted a stent in my LAD, I started hemorrhaging into my thigh. I had a CT to make sure they stopped the bleeding which showed that my lungs were peppered with nodules. They did a bronchoscopy that came back negative. They couldn't do a biopsy because I was on Plavix for the stent. After one year, I was able to stop the Plavix and had an open lung biopsy. There were complications with this, too, as during the surgery, the surgeon said I coughed and he accidentally punctured a hole in my diaphragm. The biopsy indicated probable Sarcoidosis in my lungs which had gotten worse over the year I had to wait for the biopsy.

I was treated with 40 mg prednisone and was on a tapering dose for nine months. I had many, many side effects which were horrible. But it did help my lungs and I have had good reports on all my CT scans since then. I do have some fibrosis in my lungs which will never go away. I do cough occasionally if I'm around cigarette smoke or anything else that triggers a cough, and I do get short of breath at times. I have no family history of this disease that I know of. I have not returned to work since my heart attack, just to keep my stress level down. I was also diagnosed with fibromyalgia about 10 years ago, but now I wonder if I really have it, since the symptoms are so similar to Sarcoidosis. It's very frustrating when I ask my pulmonologist questions that he can't answer and just refers me to a different doctor.

My husband would like me to apply for disability, but I'm afraid that would just cause more stress because it's not easy to get approved, and I try not to think about everything that's wrong with me. I don't want to go back to sitting and typing all day because I need to try to stay moving. I feel anxious most of the time. I was on antidepressants for fibromyalgia, they were causing me to gain weight. Since I stopped them, I have been able to lose 15 pounds, but the pain and anxiety are worse. I try to work out every day which is difficult but does help keep the weight off and I think helps me feel better and sleep better.

The past three years have been a nightmare, especially when I was waiting for a diagnosis. I was afraid whatever was wrong with my lungs was going to kill me. I pray the Sarcoidosis never becomes active again. I don't want to live the rest of my life hooked up to an oxygen tank. I pray someone finds a cure for this disease soon! - Mary Jo Carlton (aka Grandma Jo; aka Nani Jo)

My name is Cindy. I am a 51 yr old woman whom they believe may have neuro Sarcoidosis but cannot seem to get a biopsy to confirm. One year ago I was running with my daughter on a beautiful September day. I had a convulsion and they decided it was due to syncope but life has never been the same again. After one year of testing they can't come up with a name and things continue to get worse.

I was a nurse for 26 years and can no longer work I still spend many days in doctors offices but it is for care. My heart breaks just to go there because I should be in those chairs helping those patients and triaging those calls. You see I have more compassion than imaginable because I am now one of them! Instead my hands tremor, I get dizzy just turning to look at something, I get short of breath just walking to a room. I have searing pain in my hands and feet. It is a lonely road because all of my other 50-something friends work and have social lives. They can't seem to figure out how to treat me because they can't get a definitive diagnosis and my autonomic neuropathy doesn't allow me to tolerate medications well. It truly feels like abandonment from the medical community because when your problems get to big and they don't know what else to try they just schedule appointments further out or in some cases don't even schedule you. They just give up.

How do I tell my 3 children that I have been given up on and that the mother they used to know will never return. I have a son still to graduate from college and a daughter that is getting married. You see we are all humans with lives that we feel are important. We may not have the big "C" know as cancer but we have a major disease that needs further research. Sarcoidosis crosses all age spans and in itself can be hard to diagnose unless you clearly have lung involvement. Then there are so few specialist that work with it yet every place I have gone and mentioned Sarcoidosis someone can tell me someone they know of or have heard of. has it Some of those with Sarcoidosis are children. Please consider doing extensive research on this horrible disease so that possibly the quality of our days are improved so we can enjoy the many things you do . Even if it is our job!

Cindy RN

Hello my name is Jennifer and I have Sarcoidosis. Sarcoidosis has greatly impacted my life. Many days I am home bound because the fatigue is so intense leaving the house scares me because if I get too tired its my own personal hell being that tired and not being able to lie down. Sarcoidosis is affecting my heart as well so I have many PVC's and am now looking at a pace maker. I'm so scared cardiac Sarcoidosis can lead to death. My bones hurt so its hard to walk around for too long without some real pain the struggle is rough. Since I've been diagnosed I have lost my gallbladder and my submandibular gland. It affects my liver lungs and muscles as well. Life is so hard to get through from day to day sometimes I just want to quit and hope to disappear. I have three children and a husband who support me dearly. The guilt I feel because sometimes they have to have sandwiches for dinner because I'm too sore or tired to function. I miss out on family outings because the pain is too much. This disease also affects my stomach so I often have nausea and vomiting. I wretch so hard that it echoes throughout the house so everyone feels bad. I hate that they have to see me like this. There is so little known about this disease and there is no cure. The meds given to treat our illness are just as bad as the illness its self. I suffer everyday I need relief like so many of us. Sarcoidosis is a silent disease that no one understands especially family and friends. No one's heard of it like MS or Fibromyalgia or lupus or sjogrens. People don't understand they think we're crazy or faking it because so often the test results come back normal making this illness very allusive. Research is critical and awareness and education could make a real difference in how those of us with the disease function in day to day life.

Please help end my suffering and improve my quality of life. I'm desperate!

Sincerely,

**Jennifer
Pennsylvania USA.**

My name is Todd and I'm from SE Pennsylvania.

I was dx'd with sarc in May 2009. I started presenting with a cough that wouldn't go away in January 2009, thinking it was my yearly visit from the bronchitis fairy. I would usually get the 5 day antibiotic pack and it would resolve itself and I'd go on my merry way. Not this time. My PCP tried several other antibiotics with no success. Then in February, I started having nausea and vomiting nearly every time I ate. These were the exact same symptoms I had when my gallbladder went south in 2007, so I went back to my GI doc who wanted to check if there were residual gall stone fragments left in my bile duct, I had an EGD and MRI and the results were negative. So, in May 2009, I had a liver biopsy and the specimen was loaded with granulomas.

At this point, I was beyond what the GI doc could do, so he set me up with a pulmonologist visit in September. By early August, I developed shortness of breath and was having bad chest pains. I went into the ER on 8/11/09 and they tested my blood and did an EKG. They sent me home with 20mg of Prednisone for two weeks, but I had to stop taking it after only 8 days because my stomach was so severely bloated at night, I couldn't sleep because of the pain. I called my PCP and asked if he could get me into another pulmie sooner, so he set up an appointment with one who was affiliated with the same hospital physician's group on 8/26. She took one look at my EKG and said I had arrhythmia and set me up with an electrophysiologist colleague across the street the next day.

He had another EKG performed in the office and compared that with the one from the ER visit two weeks prior. At that point I was in partial AV block. He wanted me in the hospital that evening, but I couldn't as my dad had passed away the night before and the funeral was on Saturday, the 29th. He told me I was waiting at my own risk and that my heart could stop at any time. I admitted myself right after the funeral that Saturday night, and at 7am Sunday morning, another cardiologist from the same practice came in with the printout from my heart monitor from overnight. I was in full AV block at that point and by 8:30am I was in the cardiac cath lab having a temporary pacemaker installed to keep me alive! They put the actual ICD in the next day. I felt great after that...but it was short lived.

While I was in the hospital recovering, they did all sorts of blood work and found that the sarc was also in my spleen and both the spleen and liver had severe cirrhosis. It has since spread to from my heart, lungs, and spleen to my lymph nodes, bone marrow, joints, skin, eyes and I have neuro involvement. I am a basket case according to my doctors. I applied for SSDI the day after Thanksgiving last year and was approved, without an appeal or lawyer involvement at the end of February this year.

I had to stop taking classes for my bachelors degree in computer science as I have cramping and tremors in my hands, and my concentration and memory has gone to hell in a hand basket. I'm in pain all time, still have shortness of breath, and can't remember things from one minute to the next. People used to joke that my memory was like a computer. No more. My memory is more like Swiss cheese. I even had to stop playing the piano as my hands cramp up after only a few minutes. I've been playing for 35 years. It's very depressing. I can't do that much any more. I'm tired all the time. The combo of pred and mtz isn't working, so I'm starting Remicade next week. Because of taking pred for over a year (40mg), my stomach looks like a bomb went off in there. I'm still vomiting and having nausea, and even though pred makes you gain weight, I'm losing it again. Last year, before I had the ICD, I lost over 50 lbs. Who feels like puking all the time? Sometimes, I just don't eat because I don't feel like driving the porcelain bus!

My wife and kids are very worried about me...and so am I. Even though I'm on all these meds, this damn disease is still spreading. I'm fairly confident that this is what is going to kill me; directly or indirectly. I'm only 44, but feel like I'm 94 and in a nursing home. I feel useless sometimes and helpless. I used to be a pipefitter, then had dreams of becoming a computer programmer...but that will never happen now as long as my memory is decaying like it is. If I didn't have spell check, you couldn't even read what I wrote here.

This disease deserves the time and effort of research just like cancer does. You tell people you have Sarcoidosis and they look at you like you have two heads or something. I always here "you look OK." Yeah, I look like a really nice house that is about to collapse because it's being eaten away from the inside out by termites.

I'm sick of being sick - Todd.

Over 30 years ago my husband was diagnosed with Sarcoidosis. At the time there was no internet. The doctor told us they didn't know what caused it and either it would go away on its own or he would die. We would know, he said, in about a year. Since that time, my husband has lost his hearing from Sarcoidosis, and he now can barely breathe when he walks uphill or any distance. He is 63 years old.

Almost 3 years ago I was diagnosed with Sarcoidosis, supposedly a rare disease. Chances are that I contacted it from my husband, as spouses diagnosed 1000X more often for Sarcoidosis. So far, it is still in my lymph nodes and muscles. It makes it hard for me to walk sometimes, and I have had to cut down to part time work due to the fatigue. I am 58 years old.

We have two children that I worry about. With both parents having Sarcoidosis, what is their risk of developing Sarcoidosis? Do they already have Sarcoidosis?

My husband and I both have medical backgrounds. He was once a nurse and I was a respiratory therapist. People from these occupations are also a higher risk of being diagnosed with sarcoidosis. There is a lot of research out there showing the bacterial links to sarcoidosis, but little research is being done. What research is being done is not making it past the "Valley of Death" to the beside. This is why my husband and I have elected to undertake the Marshall Protocol, an experimental antibiotic and Benicar treatment for sarcoidosis. So far we are having good results. My chest Xray has improved and my lung function tests are better.

I would like for the NIH to provide more funding directly to researchers within and outside of the mainstream Universities for research on bacterial and inherited factors that may work together to cause Sarcoidosis. I would like for the research to be focused on the CAUSE OF SARCOIDOSIS and not research to develop more drugs to suppress the inflammation, such as designer steroids. These drugs do not cure Sarcoidosis.

Diane

My Name is Melyssa and I have been diagnosed with Sarc since 2003 although after receiving my old records, found out I actually have had it since 1987 if not longer. I was able to work until 2001. Up to that point I would have periods of strange illnesses that would last longer and longer but I was always able to recover from them. Things finally caught up with me in 2001 and I ended up filing for disability in 2003 and was awarded in 2004(retro). My sarc is systemic, I have involvement in my lungs, skin, kidneys, and lymph system. Currently I am on 16 different medications although some are PRN. My biggest symptoms are pain and fatigue.

Sarcoidosis has completely changed my life. I was a fitness expert, a consultant and presenter for Reebok and SPINNING in addition to a personal trainer and instructor. I was living the life that I had worked hard to achieve. This disease has stolen much of that life and has become the center of how I live my life. As much as I would like that to change, we have to work around the illness in order to try and enjoy any quality of life. One of the most difficult characteristics of the disease is how inconsistent it can be. It makes it hard to anticipate or grow accustomed to the symptoms because everyday could be a new symptom. It is also difficult to find doctors who are experts in the disease so you can guarantee you are getting the best help.

New research is imperative to helping those of us with this disease.

Sincerely, - Melyssa

In October 2004, 30 years old, I suddenly started to have chronic kidney stones, almost on a daily basis. The pain made me suicidal. In the summer of 2005 I developed on top of that an episode of uveitis in both eyes that caused some permanent vision loss. I got very tired at the same time and for several years slept most of the day. I also developed a chronic salivary glands inflammation that left me without saliva causing a lot of eating, speaking and mouth problems. I developed joint problems and I had to walk often with a stick. I was put on disability and also developed aggressive skin inflammations causing scars. After I developed a facial paralysis I finally got a diagnosis Sarcoidosis - Heerfordt syndrome. After several years I finally got better on a combination of plaquenil, imuran and Remicade.

My husband was diagnosed with neurosarc one year ago. It took two years to get the diagnosis. He has no pulmonary involvement, but he has difficulty breathing due to the involvement of his phrenic nerve. He has involuntary muscle movements that range from a tremor to very large jerks resembling tics. He stutters. His short term memory is terrible.

Before this disease, he ran \$100,000,000/year business and over saw up to 500 people at a time. Now, he gets frustrated if Wal-Mart is out of the kind of beans we buy, and he will call me to ask what to do. He seldom drives, due to the muscle weakness. He is in excruciating pain all the time. He takes methadone, vicadin, and wears fentanyl patches, and still wakes me up most nights crying in his sleep for help. That is when he does sleep. He will suffer with insomnia often, and then if he gets too much sun, he will sleep for days, barely waking 3-5 hours a day for up to two weeks.

2 years to get a diagnosis. They tested for sarc when he did not respond to treatment for Sinusitis. He was unable to go to work and had to change careers to something less physically demanding, and it was not long before even that was not enough. He was out of work, and certain he would die not knowing what was causing him to be so ill. In two years my family, including my 3 children, went from making a living to living on what we had tithed three years prior. We lost our home to foreclosure and decided that our only option was to move from our home in Upstate New York back to Texas where our families are. I had to have a support system to help me with our children and my husband who at that point (2yrs in) was no longer able to drive due to severe myoclonus. He has debilitating pain that is only somewhat controlled and damage to his Central Nervous System that is debilitating even when all his lab values look positive.

To say that this has impacted our lives in a negative way, is an understatement of biblical proportions. Neurosarc does not even have a written protocol for treatment. We bounce between methotrexate and prednisone. Each of which have their own terrible side effects. I cannot put into words how frustrating it is when even Drs. say, it will take care of its self. Really....I have had my home foreclosed, moved 1600 miles to be nearer to family and taken 3 children with me to do it all. We are now living in an RV, waiting to see if we will have a father with us long enough to get a permanent home and our life back.

I would not wish this experience on anyone. It has been a nightmare for my family. We saw 15 doctors before we found one in East Texas that would do the lumbar puncture that gave us the answer to our nightmare. Now that we know he has neurosarc, we face a new problem. There is not a protocol for treatment. Even the specialists don't know much. Everything is a guessing game. I am confident that short of a miracle I will bury my husband much too early. I hope that someone takes our experience and so many others like ours and puts the pieces of this puzzle together to save other families from what we have been through.

I can not say strongly enough how absolutely vital funding and research are for Sarcoidosis. My husband suffers from Neurosarc. It took us

Respectfully, - Poppy

Hi, I found out I had Sarcoid back in 1988. I have good days and then there are days I can barely move. I have Sarcoid of the skin and lungs. My breathing is very short, I used to have plenty of energy but now I can barely walk from my car to the building I work in. My skin is horrible looking, I have people just staring at me and I know what they are looking at.

Due to all this I still work but have it very hard, need to go to the doctor but need so many different doctors I cannot afford the copay, so I don't go unless I'm really pushed. This disease has taken a toll on me because I really don't like to go places or do things because I do not want people looking at me. We need some serious help with this disease because there are so many people unfamiliar with it.

Thank You

I am a 75 yr. old female. I had worked and raised a family for many years as an accountant and office manager. When my husband became legally blind from diabetes I quit my desk job and helped him in his Blind Vending Work. For 13 yrs I was doing heavy lifting, hard labor, etc. This was from 1988-2002. After my husband passed away I "retired" as such but, worked in my daughter's greenhouses every year from Jan.-May. I was having lots of UTI and my PCP was giving me one antibiotic after another. I was not used to going to a Dr. unless it was an infection that she had to work me in. I was used to her hurried visits. Then I started having shortness of breath and my muscles aching in different places for short periods of time. I made a regular appointment with her with a list of my symptoms. When she came into the office and saw my list she showed much agitation and said you come in here hurting here and hurting there and I have 15 min. to spend with you. I walked out of her office and never went back. I got a new PCP. He was concerned about my fatigue and SOB. He ordered tests related to the two and everything kept coming back normal. He had a pulmonary test done at the local hospital. They said I had asthma. He started me on Advair Disc and told me the muscle pain was probably from a strained muscle and to go home and take Tylenol. I respect the man and had been on a church mission trip with him. But, I wanted to slap him. After two months no better. I was still trying to work in the greenhouses and would have to stop every 2-3 hrs and go inside and rest for an hour or so and catch my breath then go back and try it again. That was Jan. - May 2009.

MY PCP sent me to a pulmonary Dr. He did another pulmonary breathing test and said I didn't have any sign of asthma. He ordered a CT of lung. He said it didn't show anything abnormal to go back to my PCP. He sent me to a Neurologist that did an EMG and muscle electro test. He said they thought I had Myasthenia Gravis and started me on Mestinon but, said they would have to verify it with lab work that takes 6 weeks. The test came back negative. They had the Lab do another test for some syndrome that mimics MG. In a few days I had a sudden temporary vision loss in my right eye and a dizzy spell. My annual eye appointment was in two days. My optometrist diagnosed me with Optic Atrophy, Glaucoma, Uveitis and Vitreous Floaters. All since my last annual visit. Apparently having no idea that they can all be symptoms of NeuroSarc. He gave me drops for the Glaucoma and Uveitis and sent me home. I researched the Optic Atrophy and found it could be caused by a tumor. I

called his office back to see if he had ruled that out. He said, "No, my PCP would have to do that".

My PCP ordered a brain MRI. The night after the MRI I had double vertical vision at a distance of about 6 feet that lasted several days. I called my PCP the next morning to get the MRI results and tell him about the double vision. They said the MRI showed a possible infarct on the Pons and/or brain stem but it could be an Artifact. So back to the Neuro to get a report on the last lab work and for them to see the MRI results. The lab was negative and they said the MRI was nothing to worry about. But, the EMG showed "something" was wrong but, they didn't know what. They made me an appointment with Dr. OH, Neurologist Professor at UAB, AL. He did another EMG and did a Bicep Muscle Biopsy that day. The final diagnosis: Granulomatous myopathy (sarcoidosis). I have it in the nerves and muscles. He started me on 40mg. of Prednisone. It has effected my hearing, vision, sinuses and digestive system also. I'm seeing a Pulmonary Sarcoidosis Spec at Kirklin Clinic of UAB. There is no NeuroSarc Spec within my range. He is trying to wean me off the Prednisone and started me on Imuran.

All of the testing and Doctors was over at least a two year period. When I told my optometrist that I had Sarcoid he said, "much younger people than you are diagnosed with it and mostly blacks. I had to show him Dr. OH's evaluation (of which he already had a copy mailed to him) before he took it seriously. I think our biggest problem is the physicians and health care workers are not being informed and keeping up to date on Sarcoidosis. They take the wordings like 'mostly' and 'rarity' like they were carved in stone and forget about them. I still get very short of breath and muscle weakness on very little exertion because it's in my muscles and, as you know, can effect anywhere in the body. I don't think my medication is working much if any. Of course, they can have some of the same symptoms as the Sarcoid.

Ella

I was diagnosed in 1982 after a routine chest xray showed possible lymphoma. After PFT and a CTscan I was diagnosed with Sarcoidosis. I went to Mt Sinai Medical Center for a skin biopsy to confirm Sarc but the punch biopsy was inconclusive. I had reduced lung capacity according to the PFT but very mild and my only symptom was being out of breath when going up stairs. A year later another chest xray was done and there was no more Sarc. I had been exposed to toxic mold a year prior to the diagnosis but don't know if it is connected.

In 2005 I began coughing as well as my lungs felt like they were burning. A sleep study ordered because I was always tired and my husband said I was snoring loudly. The study was negative for apnea but indicated that while sleeping my oxygen level would drop to 86% several times for a few minutes at a time. I told the doctor about the past Sarc diagnosis while going over the results and he referred me to a pulmonologist for a CTscan. Meanwhile I was being treated for pneumonia by my primary care doctor due to a chest xray they took. After 3 rounds of antibiotics (the coughing had lessened) but repeated xrays showed something was still there he had also concluded I needed a CTscan. The scan with contrast showed granulomas in my lungs, lymph nodes and my spleen was enlarged. I also had problems for several years with my eyes and was being treated for allergies but once the sarc was diagnosed the eye doc did a stain test (sp) and it was positive for sarc so she gave me steroidal eye drops to use. At the same time I developed a lesion under my skin by my elbow. Although no doc thought that was from sarc it was recommended that I have it surgically removed since it was so close to my bone. They removed it and tested it, it was positive for granulomas and that is how the sarc was diagnosed conclusively. I have never been given any treatment for sarc other than eye drops and an inhaler.

Currently I have severe muscle pain and bony spurs on my knuckles and between my fingers. I have bone erosion in my fingers. Nothing concusive as to the cause but suspect it is from the sarc. 2 years ago I was treated for what a doctor said was vitamin D deficiency. I took vitamin D supplements for a year and a half. This is when I started to develop these bone spurs which cause my hands to ache and they have become weak to the point that I cannot grip without pain. I finally got a doctor to order the blood test for D 1,25 and it was high. I stopped taking the D supplement after that but the bone spurs are here

to stay unless I have surgery. No doctor here has wanted to do a muscle biopsy or a PETscan to see what is causing the pain in my muscles. I was given a diagnosis of Fibromyalgia many years ago and they all chalk it up to that. My muscle pain is in my calves, thighs and buttocks muscles this is why I don't believe it is fibro. I take Flexoril at night which helps reduce the pain somewhat but I am always in pain in varying degrees. I also have arthritis in many parts of my body and need both of my knees replaced.

I believe my Mom also had Sarc. She died 4 years ago from kidney failure. They diagnosed her with Polymyalgia Rheumatica but she had most of the same symptoms I have and she got sick after there was a leak in her house which started the toxic mold growth separate from my incident. I believe there is a predisposition in our family and then we both had some type of environmental exposure. My brother has a chronic cough and his doctor told him he has infiltrates in his lungs but no one has done a biopsy to see if it is Sarc. He asked his doctor if he thought he had Sarc due to my diagnosis but his doctor told him he does not have sarc. I don't understand how he can be so sure without a biopsy but my brother continues to have a chronic dry cough and eye issues. I know this was suppose to be 2-3 paragraphs but after having Sarc for 28 years it is difficult to condense my Sarc story into 2 paragraphs. Please let me know if I can be of any help in the future. I have a 20 year old daughter and want to do whatever I can to find a cure for this frustrating disorder with the weird name. Thank you for collecting our stories as maybe the pieces of the puzzle will fall into place.

Regards,

Pam

I was diagnosed with Sarcoidosis in May of 2009 after many multiple lung infections that lasted three years. I was then in college with a 3.8 GPA going for nursing at that time and had to drop out because of my constantly being unwell. Three years of coughing has ruined my gag reflex and my bladder control. After a nasty divorce in 2008 I lost my health insurance. Most insurance companies have deemed me "uninsurable" due to sarcoidosis or have given us a very high monthly premium to obtain coverage. We could not afford to pay for insurance and have since then filed bankruptcy because of so many medical bills we could not afford to pay, mostly for ER visits and Ct scans, x rays, etc.

Last year I began to have severe migraines, kidney problems (inability to urinate for periods as long as 20 hours) and neurological problems. I have oversensitive senses, I have to leave the room when the oven is on as it makes me sick, noises are either overwhelmingly loud or I cannot hear, my eyes have become very itchy, overtired and burn and sting. I have a lot of vision disturbances now. I have severe balance issues and constantly feel like i am carsick or sea sick for no reason. I get severely dizzy and tip over for no reason. I have told doctors of these things for the past year and it still goes ignored or undiagnosed. I used to drive myself around everyday to do things, now I drive maybe twice a month on a very good day. I have severe joint pain, mostly in my spine, hips, neck, and wrists and ankles. I sometimes cannot walk without a cane. I am 41 and used to run 17 miles a week and lift weights almost every day. I used to garden, now I cannot reach the ground TO garden. I struggle to barely go for walks. Some days my skin hurts to touch. I have pets and some days it puts me in tears if they even walk across me. I have also developed tremors in the past year. On bad days i cant feed myself from a fork without dropping food everywhere or hold a pencil or toothbrush. I cannot tolerate wind/smoke/ the cold. Wind puts me into asthma type attacks and coughing fits. Air conditioning does the same, and that's too bad because I now get overheated easily. I used to love camping and cookouts. Now campfire smoke makes me sick and my lungs rattle for days on end. I have brain fog and attention problems now. Another new symptom is reading words out of order. I cannot remember things and have to constantly ask over and over questions about daily activities. I cant help my daughter do her homework because I cannot remember how to do most things. Cool air even puts me over the edge to where I have to cover my mouth to go outside. I can hardly go out for nice

dinners anymore, as I end up with instant diarrhea or stomach cramps so bad and have to cut my meal short and go home. It makes it hard to go have dinner with family and friends as well. In case I have not mentioned it before, I get depressed and angry a lot too.

Well, that's all I can think of right now but I cannot think too clearly, I would wait for a better day to finish this up but I keep forgetting TO finish it.

The year was 1997...the year I was FINALLY diagnosed with Sarcoidosis. I had suffered serious symptoms for about 6 years prior to being diagnosed. Although, not very much was/is known about what causes the condition, at least now I could put a name to my issues.

Sarcoidosis affects various areas of my body (skin, eyes, nose/nasal, esophagus, and bones). I have had various surgeries on the esophagus and nose...every 5 years or so, the breathing becomes much to difficult, therefore the surgeries are necessary to make life comfortable.

My condition is being managed with prednisone (10mg/daily) and plaquenil (400mg/daily)...I have steroid eyedrops for my eyes...I also have on occasion taken steroid shots directly in the nodules on the face and nose. These things along with other life changes (diet, exercise, spiritual life) have made living with Sarcoidosis very manageable.

Shawwna

My name is Shirley and I am the Founder of the Denver Sarcoidosis Awareness Support Group in Denver, Colorado. I am a member of the Foundation For Sarcoidosis Research Support Group Advisory Council and the FSR Research Committee. I've served as volunteer webmaster for a church in Denver for eight years and currently serving as volunteer webmaster for Nurturing Our Village Association, a non-profit organization to benefit children with learning disabilities. I've worked for financial organizations, and eventually retired from the United States Antarctic Program. I often talk on the phone to patients from all over the country who know how isolating it can be to have sarcoidosis, because they don't know anyone else with the disease and their family and friends just don't understand.

I'd like to share a short portion of my story with you. I began having extreme pain in my abdomen and weakness in my legs and feet in 1984. I was hospitalized in 1985 for three weeks when I couldn't stand or sit without assistance and given nerve block shots for the pain that appeared sporadically from the top of my head to the bottom of my feet. Three months later a lung biopsy resulted in the diagnosis of Sarcoidosis. I went untreated for 14 years until I found Dr. Ronald Balkissoon at National Jewish Medical and Research Center in 1998.

In 2000 my oldest son Leonard, began having pain in his upper back, shortness of breath, and general weakness. Later he began to drag his feet, and had trouble lifting them a couple of inches off the floor. He sometimes fell when attempting to go down a flight of stairs. Leonard was diagnosed a year later with Neurosarcoidosis. Granulomas and scar tissue is inside his spinal cord and brain. This has led to blindness in his right eye, his mobility and numerous other medical problems. Leonard must use a walker and wheel chair. A chair lift takes him up and down the stairs. Leonard takes medications orally and intravenously. He is treated by an MD, neurologists, endocrinologists, urologists, and physical therapists.

In June of 2005 the "World Association of Sarcoidosis and Other Granulomatous Disorders Patient Education Conference on Sarcoidosis" was held in Denver, Colorado. The doctors were from Denver, and as far away as New York, California and the Netherlands. About a few hundred people were in attendance. I attended a reception the evening before the conference where I had the opportunity to meet with several other sarcoid patients. Listening to

their stories was a life changing experience for me. There was a sense of kinship that was just amazing. I was so inspired by the people I met and how quickly everyone engaged in conversation, and how comfortable we were in doing so. In August 2005, I established the "Denver Sarcoidosis Awareness Support Group". The support group meets bi-monthly and is for sarcoid patients, living in Denver and the surrounding areas. It includes a diverse group of sarcoid patients, our families and friends.

In 2002, four days after I retired, I was diagnosed with stomach cancer. So 20% of my stomach was removed. In 2004 I was diagnosed with high blood pressure, high cholesterol, and diabetes. With all the challenges that life has sent my way, I am just so grateful that I am still here spending joyful times with my family and friends.

We hear about cancer, MS and diabetes every day, but so few have heard of Sarcoidosis. It is my dream that this will eventually change. Our members are from as far away as Colorado Springs, Pueblo, Longmont and Boulder. Some of us have bonded, become great friends, and have found the meetings to be extremely helpful in dealing with this most insidious, debilitating and sometimes deadly disease.

I am not diagnosed, but, left in limbo because doctors are still not taking me seriously, even though, my PET CT showed extensive intensively lit FDG avid nodules. "Because I am still alive it must not be cancer." is the answer I get. The fact that I complain of chest pain and that I can tell it is spreading, am lucky to have four hours of productivity a day (I never wake up rested.), have had to stop driving car due to confusion (resolved itself), can't drive distances in sun without falling asleep, etc. This disease, whether I have it or not, is a serious burden on those with it and the ones having to take up the slack for impaired because of it. More people have it than know and will be apparent in the next decade.

Please let's get to the bottom of this.

Thank you, Barbara, Capt, USAF Ret

I was a very active woman most of my life - a professional programmer by day, a professional dancer outside of work. I never had to worry about my weight, maintaining a weight of 133 lbs at 5'8" until the age of 36. That is when I found out I was infertile and had to go on medication in an attempt to have a child. That same year, I developed a sudden aversion to lots of smells - mulch, perfumes, chemicals, etc. No one could figure it out and I was not having rashes, so it went untreated. Then I began to have problems breathing and was diagnosed with a "weird form of asthma" because my lung tests all read normal yet I had trouble with episodes of feeling like I was breathing through a straw. Inhalers sort of helped, but not completely. My activity levels declined somewhat due to this feeling impacting the ability to press on with my dancing, to the point where, over time, I retired from dancing professionally.

10 years later, at the age of 46 and 35 pounds heavier, I began to feel like I was going to pass out with no warning. I never did, but it kept happening. I saw the doctors many times for this and all of them told me it was stress or in my head - that I needed to just exercise more and stay peaceful and that would solve the problem. Being that they were the doctors and I had gained weight over the years, I took this to heart and began to feel that this was my fault, even though I had noticed that I could never develop any stamina - it seemed like my lungs gave out before my muscles could get enough exercise to get tired during the light dance classes that I still attended. It never occurred to me then that my doctors could be wrong.

Then one day the strap of my shoe was embedded in my right foot. My foot had swollen to the point where it was much higher than the shoe strap in just a few hours! I thought that was strange and went to the doctor the next day. The PCP had no idea what it was and gave me a referral. Within a few days that leg became dark red and feverish, was very painful to touch, and continued to swell. It was so tender that I could not walk or even let that foot stay down on the floor - it had to be elevated at all times and the pain was unbelievable - the OTC painkillers I was given did nothing to help it.

By the time I saw the next doctor, the left leg had begun down the same path as the right leg. I saw several doctors over the next few weeks and still no answers. Lots of expensive tests and no answers. It took 3 months to see the rheumatologist. During all this time I could not walk at all, and could not go to work. If it weren't for the fact that I could work from home on a laptop while

sitting with both feet propped up on pillows, it is likely I would have had to go on disability and potentially have lost my job. The rheumatologist also could not determine the problem. By then I had begun losing weight (25 lbs in 2 weeks) and was having fevers all the time.

Eventually, I began coughing. And coughing. And coughing - it never let up even at night in my sleep. An xray showed swollen lymph nodes - I was told "You either have lymphoma cancer or Sarcoid". I prayed for the Sarcoid, and now I wish I had not because I am allergic to the main treatment (prednisone). Sarcoid was confirmed within 2 weeks - then the medications made me gain 50lbs in 2 months - but hey, my legs aren't swollen and I can stand to walk!

At the time of my diagnosis, I was told that Sarcoid primarily affects African-Americans, and primarily people aged 20-40, and that most people who have it never realize they do or if they are like me and do actually learn they have it, if you have acute symptoms it means you will not have chronic ones and that it will go away on its own and completely resolve within a year or two. I have found this description to not be the case at all for me.

I do not fit the "standard" criteria - I was 47 when finally, diagnosed, I am Caucasian, I had acute symptoms that have turned into chronic symptoms, and I have never gone into remission. My lungs are somewhat better than they did initially, but I still watch people who weigh 300 lbs and/or are 20 years older than me work out twice as hard and for far longer than I can at the gym. I have to ride a cart to go grocery shopping, I have to keep my feet propped up on a footstool at all times (even at work), the painkillers have caused a total of 70 lbs weight gain, sometimes carrying a purse is too much for me to handle, and at one time or another over the last four years, my adopted children, my husband, my friends and my doctors have all indicated that all of this is because I need to lose weight and that if I did, my ankles would stop hurting.

My medications cost (after insurance) between \$150 and \$400 per month, which is good compared to many "sarkies", and the tests that have been run have cost more than \$25K per year for four years straight (my OOP costs for that have ranged between \$3-\$5k per year). I no longer qualify to purchase any new life insurance policy and I need to stay employed in order to retain health insurance due to my now "pre-existing" condition.

My research on this topic and auto-immune in general shows that all the symptoms I have been having over the years as described here (and many others I did not have room to list) are linked to auto-immune diseases such as Sarcoid. I have come to realize that many doctors know absolutely nothing about Sarcoid at all (including even some rheumatologists and pulmonologists, who are the primary experts for this disease) - or even worse, some of them know the "statistics" and "standard treatments", but don't know what to do or who to refer you to when your case does not present in the "textbook" manner (and sometimes this happens even when it does!).

My search for information on the internet was disturbing - for the first three years after my diagnosis, every site for sarcoid that I located had founders that were all dead from issues related to this disease - and yet my doctors kept saying that it was likely that my case was not serious. The support group I tried to join was down to 3 people from 10 - the other 7 having died over the prior few years.

I am one of the very fortunate sarcoid sufferers - I can still work despite my handicaps, my spouse has stood by me even in the face of some doubts, and I knew someone who had the right connections to help me find (after two years) a doctor who is interested in this disease. Many of my fellow sufferers have none of these advantages.

I believe that the statistical information on sarcoid needs to be changed and disseminated in the medical community - it is misleading at best (even in the Foundation for Sarcoid Research's documents) and causes many with sarcoid to remain undiagnosed or improperly treated for years. I also believe that it is very important that the leading sarcoid centers (Cleveland Clinic, NJMC, Boston, and John Hopkins) be promoted to doctor's at-large as the places to refer sarcoid patients for treatment, so they are not left lingering for years without complete and proper workups by experts intimately familiar with the disease. Finally, one primary foundation (FSR) should be built up in the same way as the American Cancer Society, for the purpose of educating patients, doctors, and the public, as well as to assist in generating additional funding for important research into sarcoid.

Leslie

A FAMILY CURSE?

Not one or two but three members of my family were diagnosed with Sarcoidosis. I'M a healthy 52 year old woman, or at least I thought I was until February of 2010. I couldn't stop coughing, I had lost 22 lbs without trying (a woman's dream but my nightmare) my skin was grey, I would have to stop talking during a conversation to get air & all of the sudden I needed to take 2 naps during the day. My eye doctor told me I had Iritis, the 3rd leading cause of preventable blindness, he wasn't sure why it kept coming back. He said this is a secondary problem to something else. So I researched the something else. When I saw Sarcoidosis as one of the main disease associated with Iritis, I knew right then that's what I had. A biopsy proved it the next month. I was put on 40 mg of prednisone daily. I could finally breathe but the side effects of the drug made functioning very tough.

The reason that I knew it was Sarcoid, my mother had it and my little brother was diagnosed in 2007. My mother died with only a 1/3 of her lung capacity in 2000. My younger brother who was never been put on medication for his Sarcoid, stage 1 from his neck to his groins, has been getting worse recently. He was scared to get checked out again fearing he would be put on prednisone. He wasn't making enough money at work for the co-pay not to mention the extensive costs of other tests that his insurance would not cover.

He doesn't have to worry anymore about that, because sometime after 2am on Sept 5th my younger brother (47) took his own life.

The one person that I related to more than anyone in life, who nicknamed me Sarcie 3, because he was Sarcie 2 and Mom was Sarcie 1....is no longer here for me or anyone. The guy that no one ever saw have a bad day, who lifted the spirits of everyone he came across in any given day, felt his only choice was a shotgun. Now what do I do? Who do I lean on? Why is this disease not getting the attention it needs to so we can start saving lives!!!! Why do so many of my doctors not have a clue about treatment and testing? I guess Bernie Mack wasn't a big enough celebrity to get us Sarcies pushed to the front lines of the fight against Sarcoidosis. I will NOT be the next one in my family to fall victim to this disease!

My story with Neurosarcoidosis started in Feb. of 2005. I have another condition called pseudotumor cerebri which causes increased pressure in your brain. On a Tuesday night I was laying down trying to relax when felt like something was wrong. I told my mother that I did not feel well and I thought there may be wrong with me. She called 911 and I was taken to the Hospital.

I had had a stroke on my left side of my brain and I was admitted to the hospital. That night I had an MRI. The next morning my neuro Dr came to see me with the Dr. that admitted me. I was told I had a stroke and that I needed more test done on me because the right side of my brain had swelling. I had extensive testing done. All tests came back negative. One doctor came to see me that was associated with my neuro doctor. Dr. Scott sat down with me and told me that he was baffled by my case and that he was on a conference call with other doctors discussing my case. When they ran out of tests to give me and the swelling was not going away they decided to do a brain biopsy. On March 2, 2010 I was wheeled off to have my brain biopsy. Afterwards Dr. Scott told me and my parents that I had something called Neurosarcoidosis.

I had never heard of this let alone how to say it. For the next five days I was given steroids by IV. Then I was transferred to another hospital 10 days of rehab. My stroke was caused by Neurosarcoids. I am what you call a rare find. I don't have Sarcoids in my lungs or in any other part of my body just in my brain. As a result I was out of work 7 1/2 months.

I have lost so much from this disease. I was let go from my job which I got back at a lower pay. I see my primary doctor every 6 months. I have 2 neurologists, one for psuedotumor cerebri and one for neurosarcoids. I am in their offices every 3 months and if I have a problem we are on the phone. With this disease there are problems. My motor skills are slower, I walk with a limp, medicine makes me depressed because there is so much to take and it's expensive. I work basically to pay for medicine. MRIs and spinal taps are done often on me.

I recently had an MRI done and afterwards I went straight to the ER. I had double vision and vertigo. Again I was admitted to Allegheny General. I was there for a week getting IV steroids. My Neursarcoid was causing the problem. My right eye did not follow with my left eye. With the IV steroids and the increase in my prednisone and methatrexate I had a good recovery for a few months. Then in September of 2010 I got headaches again Dr. Scott upped my

prednisone for and the headaches eased. Then they came back so I had an MRI that showed some inflammation. Dr. Scott is taking me off my methotrexate and putting me on Cellcept. My prednisone went from 10mg to 40mg for 4 weeks, then 20mg and he will taper me off the after that. The side effects from these medications are not good.

My case is not easy for Dr. Scott because it is rare and he has no other patient to compare me with. He has 60 patients with Neurosarc but they have sarc somewhere else in their body and I do not. I am tired all the time. I wake up tired. I am hot most of the time and you even have sweat dripping off of you at times. Not very pretty! You constantly feel like you have the flu 24 hours a day. Countless pills to take and constant blood work to monitor your kidney and other things. You start to feel like you live at the hospital. Believe it or not I have thought about stopping my medication because you feel you can't go on, but I find the strength to push on.

I don't know how I got this disease but when I was a little girl I never dreamed my life would be like this. My friends don't bother with me anymore and that is hard to accept! You're like an outcast! You feel like you were robbed of your life. I don't want to have kids anymore because I don't know if they will inherit Sarcoid. I worry about my niece and nephew getting Sarcoidosis.

I started this horrible journey with Neurosarcoidosis when I turned 36 years old, some birthday present, now I am 41 years old. This disease makes you depressed, tired, lonely, scared and feeling sick most of the time. I don't want Neurosarcoids anymore but I don't have that choice to make. I will not be declared in remission until I am symptom free for 1 to 2 years because I am past the 5 year mark now.

Neurosarcoidosis needs funding for research and awareness. This disease is hard to diagnose and nobody knows what it is. There needs to be more awareness on this disease. When someone asks me what I have they look at me and what is that. Someone that has Neurosarcoids looks like every normal person, but what they don't know is Neurosarcoids is destroying your body from the insides. Research needs to be done on Sarcoid and Neurosarcoidosis. Dr. Scott informed me that my case was accepted into the Medical Journal. I hope my case will help people learn more about this disease.

Thank you! - Neurogirl

My name is Drew. I'm 49 years old. I have multiple undergrad degrees and an MBA. I live in Acton and Lexington MA, this is my Sarc Story

I first started getting sick, and I mean really sick, in early October of 2009. I had a cough, sinus issues, fatigue etc. All of the signs of what I thought was either a respiratory infection or perhaps bronchitis. My PCP concurred and put me on a course of antibiotics, cough meds and sinus meds. A month went by and I was getting worse. I was just lying in bed 24hrs a day, I had no energy. My appetite was decreasing. So back to the doc I went, this went on thru most of December. I went thru 2 more courses of different antibiotics. Then they thought that I had pneumonia. My appetite decreased to the point that I was eating one days worth of meals in a week. My family was getting worried.

I had x rays done, which showed no pneumonia but rather an "artifact" on the x-ray. I was told it was probably nothing but it could also be a sign of lung cancer and I should have it redone in a month. I waited, getting sicker, not leaving the bed, not eating. When they took x-rays again I was told it was early scarring, most likely from the air during 9/11, but not lung cancer. Then they did a battery of blood tests and discovered I was anemic, my thyroid levels were off, and I had liver and kidney issues.

Flash forward to mid April of 2010. I've now been bed ridden and barely eating since October. I was increasingly short of breath to the point where I couldn't walk 10 feet without stopping to catch my breath. I went into the hospital immediately. I spent 2 weeks undergoing every test known to man. Along the way we discovered Plural Effusions, did a paracentesis and drained 2 liters of liquid from between my lungs and my chest wall. Once that was done I could breathe again. Shortly thereafter the word Sarcoidosis started being used and after a bronchoscopy I was told I had systemic Sarcoid of the Lungs, Kidneys, Liver, and Spleen. It was now the End of April 7 months later.

That's not the end of my story. I was put on 40mg of Prednisone. Prednisone has some ugly side effects and I got the worst of them. My side effects include; type 2 diabetes water weight (95lbs in 6 weeks), cellulitis which is now lymphedema, Pneumonia and vertigo.

When I got Sarcoid I was able to walk just fine, now I walk with the aide of a cane, which I am told I will need the rest of my life, even as time goes by I only need it for balance. - DS

In 2004 I started having pains after eating, could not eat very much and was losing weight. The fatigue was horrible, I could barely make it through my work day and sometimes worried I would fall asleep driving home. When on vacation in Mexico Aug 2004 I contracted a UTI and thought that was why I was feeling bad but at work one day I felt horrible pain and my co-worker took me to the emergency room. In less than one day I was having stents put in and a splenectomy. Turns out the reason I couldn't eat very much was that my spleen was the size of a football. Not knowing enough about what was going on the Dr's decided to remove it - like it was just an organ I didn't need. I was first diagnosed with Lymphoma - horrible scare - and then after biopsy was determined to be Sarcoidosis. Prednisone therapy ensued and so did a 40lb weight gain - not pretty on an already size 12 body. I hated taking steroids but started to feel better and then after a year or so I weaned myself off of them thinking "I'm not sick anymore it's gone away."

Fast forward to 2006 - I started having night sweats, migraines, fatigue, sinus infections. I was hospitalized for a week with pancreatitis. Dr's don't know if it was Sarcoid related or not. Also discovered I had Sarcoid lesions on my back (which have now spread to upper arms, and lower legs). Was again put on steroids and gained back 40lbs (although I had lost 25 of the weight I put on the last go round) Again I weaned myself off of prednisone and got better.

Fast forward again to Aug 2008 - wasn't feeling well so went to Dr for general check up and after blood work found my kidney function GFR was at 9 - I was officially in Renal failure. Hospitalized for 7 days, 60mgs of prednisone daily and stents put in as both ureters had blockages from humongous kidney stones. The right kidney was so damaged it will never be the same again.

My GFR is now 40 and has never gotten above 52. I have had stone removal 3x since 2004 due to hypercalcemia. I also have a weakened bladder and have hypercalcuria - I go 3-4x per night so get no real rest.

I have also recently had major dental work as my teeth are crumbling - and in my early 20's had hearing loss and eventually DX with otosclerosis - which may or may not be related to my Sarcoid. Recently was DX with neuro sarc and osteoarthritis in both knees. My neuro symptoms are tingling and numbness in my extremities. Also DX with fibromyalgia and have severe joint pain and extreme fatigue. - Renee

Virgo, 50, Born in Orangeburg, SC USA

Way back in the 80's I was a professional singer getting ready for a tour of England, Scotland and Wales. We kicked off the tour in Ipswich, where I lived since getting out of the USAF.

Diagnosed with Sarcoid in 1986 after being told I had "Mumps, then glandular fever, rheumatic fever, ... by this time I was chewing up pain pills every other hour. My weight went from 130lbs to 95lbs. I was living in Ipswich England at the time and was currently on tour with my band. Naturally I had to cancel the tour. After speaking with my mother in the US, she said get on the next plane home.

Once I arrived in the US, I went straight to my mothers Dr. who asked a few questions. When he asked me if I did drugs or recently had a blood transfusion, I thought (pot doesn't make you sick like this!) Then I realized that I had many of the symptoms of AIDS. I told him "I may not know what is wrong with me but I don't have AIDS". He admitted me to the hospital. After several test, blood work, xrays, liver test...I was told I had Sarcoidosis (Huh!). They started me on Prednisone immediately, as well as breathing treatments consisting of even more steroids. Within 24 hours I was feeling better. I was discharged from hospital after 5 days. My weight picked up, my glands which were swollen, began to go back to normal, and I was now feeling that all was right with the world.

Currently, I am USAF Veteran, and I am treated at the Dorn V.A. Hospital in Columbia, SC I am under the care of a neurologist, dermatologist, internist, pulmonary, Ophthalmology, pain management, and Mental Health.

Primary treatment is Prednisone, Methotrexate, Albeuterol, morphine sulfate, ... I have just had my eyes tested in order to start a different treatment (steroids are making me worse, especially my immune system).

Please feel free to use my name, photos, website journals, and posts from other sites. Anything I can do to bring awareness and assistance to the Sarcoidosis Epidemic that is plaguing or way of life, I will do.

Cheers,

Debbie

Below is an entry into my journal with FSR and Inspire when I was first Diagnosed. about 3 years ago.

Is there anyone out there who has or has had Sarcoid in the breast tissue? I have had a diagnosis of Sarcoid in the breast tissue-in fact that is how I was diagnosed with it. I had a small granuloma in the right breast and it came back from pathology as a sarcoid.

I am now having lots of pain in my breast and have small tender lumps where the under side of my bra sits on the bottom. It is a change for me and I don't think it has anything to do with my bra. I am going to discuss it with my doc again but I thought I would check to see if others deal with this too.

This is me now. September 2010.

I am now 39, still dealing with severe headaches, low body temperature. Been diagnosed with Atrial Fibrillation and passing out, so I have to have an implantable monitor. Not sure when. They don't want to blame Sarcoid for it... but...like my family doc says... "if it walks, acts, and looks like a duck, it's a duck!"

I have Optic Neuropathy, those docs are not sure if its Sarcoid related. Although my primary Ophthalmologist is certain.

Diagnosed with reactive airway disease, is it Sarcoid?... hmmm...not sure, says the doc.

-Reynaud's phenomenon...

-Several bouts of Pericarditis...

-Always swollen and achy joints....

-C-Reactive Protein has tripled in the last year...

-bizarre pains, swelling in lymph glands etc....

-Always exhausted, can't make it a block without feeling like I am going to pass out or I lose my breath completely...

-I don't have classic Sarcoid as it does not affect my skin....

-I have chronic back and neck pain. the headaches are enough to make me want put out of my misery....

-blood in the urine with kidney pain and bladder problems (Cystitis-that happens a lot)...

I also have a lot of neurological issues....

This (not 100%)-diagnosed disease feels like it is killing me. I have a diagnosis of Sarcoid from a biopsy but that isn't good enough for some doctors.

I am in constant pain and the docs look at me as a drug user as I take a lot of pain meds. I need them to get through the day. There are only a few docs that actually believe this is Sarc related. They would be my family doc, Ophthalmologist and my Rheumatologist.

I don't know what to do, or where to go. There are no docs where I live that can give me a definitive diagnosis and treat it accordingly. I must say that I was on Methotrexate and steroids for quite some time. Perhaps it may have helped for a short time but that was it.

IF sending this info is helpful to you or even me that would be great. I would hope this is not a waste of anyone's time as it really hurts my hands to type.

Thanks for taking the time to read this and I look forward to seeing where things go from here.

Bobbie-jo

As a mother of a son (29 years old) diagnosed with Sarcoidosis, it has become a big part of my life: watching him battle depression, withdrawing from society, because of constant pain and fatigue. I am absolutely shocked at doctors' lack of knowledge about the disease and the nine years I have experienced his condition, abhorred at their lack of empathy. Only two doctors actually listened and pursued to discover what was really young in such a young man. As a family, we have all gathered around him to assist him as much as possible, both mentally and emotionally. That is the only reason he has not given up. I urge you to fund research which is really needed and to make the public much more aware of its seriousness. Above all, and just as important, is re-education of doctors. It is a disease that is on the rise - we need to face it now.

To whom it may concern:

September 29, 2010

I was seven months pregnant in May of 2009 when I was having trouble breathing at work. I ignored it because everyone I told laughed at me. They said "honey, you're pregnant". It got so bad eventually I saw a Pulmonologist who ordered every test imaginable. I was asked to have a CT scan and this broke my heart. I was 8 months pregnant! I did it because I was reasoned with that my life is as important as my unborn baby's. Since that scan I have worried that I had made the wrong choice. The scan came back and it showed a great possibility it was Sarcoidosis. I was taken out of work. After my daughter was born my pulmonologist asked me to have another scan and a biopsy. I did both and was diagnosed. My husband's and my life have not been the same since.

I fight depression and have had suicidal thoughts. I have lost a lot of hair. That may sound like nothing, but if you lose your hair you start to feel things you normally wouldn't. The pain in my joints is unbearable, and chest pain is a given now. I feel like every day presents a new health problem and I fear I may not overcome it. Sometimes I think I am losing my mind. I am scared to wake up in the morning. I worry that one day I won't be able to care for my baby anymore. She depends on me and I depend on pills that help me breathe but feel like dying. I have never felt hopeless in my life until now. It seems my life is one fight after another. In and out of doctors offices, ER visits and testing... I now stay at home with Isabella, my daughter, because I can't hold a job. It's very hard to be positive with a disease when trained specialists have no idea where it came from or how to treat/cure it. It is a scary disease and I believe more people are dying of complications of it than statistics show.

There are many, many people out there who are far worse than me.

Please let these letters help to change the course of this horrible disease. I pray nightly it does because some of us just can't take it anymore. Please help us.

Karen

I am a RN. I have been since 2001. I am a 35 year old female. Smoked a pack a day since I was 15 and quit in 2008. I was diagnosed in October of 2008. Symptoms started with shortness of breath walking on flat surfaces. I let it go for 2 months. I was driving to work and starting to have stabbing chest pain. Went to ER. They did a cardiac workup that was fine. They did a D-Dimer and it was elevated so they did a cat scan and found granulomas in my lungs. They had to rule out lymphoma or Sarcoidosis. I saw a pulmonologist and he tried a scope but there was too much blood. He put me on Prednisone 40mg daily. I gained weight, insomnia, mood swings and I was miserable. They did a medianoscopy and found the Sarcoidosis. Told me to take the prednisone for 2 months and I will never see Sarcoidosis again. I lost my job as I wasn't there long enough to be protected under FMLA. Got off the prednisone after 2 months and gained 45 pounds and they said the side effects are not outweighing the benefits as the weight gain made it hard to breath. They gave me tons of narcotics for the chest pain. Got off both meds. Cat scan showed no changes in the nodules in the middle of my chest.

Got a second opinion from a pulmonologist and he said he will not give me any meds and told me to give it time and it will all calcify. Meanwhile, my primary doctor is telling me it's stress and get over it.

Went to Mayo Clinic. Big joke. They tested for allergies and I have none. I was and do have problem with sinuses but they found no sarc or no problems. Sometimes it feels like I was just punched in the face and I lose my voice....this happens whenever sarc decides to let me know it's still there. No doctor can explain it. Anyways, Mayo clinic did PFT's, which have always been normal because it's not in my airways so inhalers don't help either. O2 sats have always been normal and lungs sounds always clear. No lab work has been abnormal so Mayo Clinic sent me home on Synthroid and iron. Wait, my D-Dimer is always abnormal and is very high and they don't know why.

Had a bad bout of shortness of breath and chest pain in 2009. Went to ER. All labs fine except d-dimer. Did a cat scan and seen it in the right lung. I decided to go to an oncologist. I was fed up with pulmonologists. I also had COBRA insurance and lost it in May of 2010. Applied for SSI . Turned down twice, have a lawyer, hearing to come soon. My parents support me financially.

Went to oncologist. Decided to try methotrexate for 4 months. Total bust. As far as I know as of May 2010, I have Sarcoidosis in my right lung, the sarc in the middle of my lungs are larger, it has spread to my spleen and pelvis. I don't have children and that scares me that I may not be able to have kids.

During this time I have been under a psychiatrists care for depression and anxiety. Had a few inpatient stays due to being overwhelmed. I just started to see a therapist and she says I have to grieve for the person I was in 2008 and find out who I am now and see where I can have control. I am very angry with Sarcoidosis as I feel it's out of my control and is basically refractory to steroids and antibiotics. There are no treatments out there. Right now I'm on my psych meds and Ritalin for energy. I have faith in God, but sometimes I struggle with the diagnosis. I am a recovering alcoholic and addict so it tough when I can't get my pain under control because I have to be careful with the pain pills. I take ibuprofen for pain and Clonipin and Xanax for anxiety as well as Paxil.

So I'm trying to work on my anger since I was told I was in remission twice and I wasn't. I have to deal with having no money and depending on my parents. I have no idea where it's spreading now because I do not have any insurance. I know it's still active because I have symptoms of shortness of breath and chest pain. New symptoms are pain in the right side of my chest and it's always been on the left and fatigue was a new problem back in July. I have no idea if I will be a nurse again and that is heartbreaking. I have no idea if I will be approved for SSI. I am angry that no meds work for me. I am single and don't think I a man would want to have a relationship with me since I get flare-ups whenever. This whole experience has been life changing like I wouldn't believe. I was told so many times "It just has to run it's course". Every year they tell me to give it another year. I live in Iowa and there are no support groups so I do my best to join online support groups. It's hard to make plans because I never know when I will get sick. Sarcoidosis is a thief and I hate it, but I'm trying to deal with the anger. Still overweight from the prednisone. The weight seems like it's harder to lose. I exercise, walk and do sit ups basically. I get my eyes checked every year and my heart checked out good in an echo in 2009. My life was disrupted in 2008 and has never been the same. I pray for remission. I need a medication to treat this and there are none. If you are going to do a trial, please contact me. Help me get a life of some sort, please.

Sincerely, - Dawn

Here is my story.

It is 2006 and I am a healthy, active, productive female 54 years of age. I've been happily married for 35 years. Two of my sons are out of school and starting their own families

My youngest son is in college and has decided he would like to be a lawyer. The boys all started college with a promise. We would pay half if they paid the other half. We provided a used car, insurance and other necessities. My husband has always been our main provider, while my part-time salary helped out with the above mentioned.

I was a certified pharmacy tech at a busy chain drug store for the past seven years. I like the quote, "If I had known what trouble you were bearing, what grief's were in the silence of your face, I would have been more gentle and more caring, and tried to give you gladness for a space." So, while the job helped our family's goals, it also gave me purpose both in and outside of the pharmacy in helping others.

Another fulfilling form of service is teaching first grade Sunday school. However, around Christmas time it all got to be too much and I came down with a sinus infection. Now fast forward 2 months. It is late at night, but my first grandchild is soon to be born and I am making my way to the hospital. The nagging dry cough has not gone away; I make a mental note to find out why. Now it is August of 2007. I couldn't be happier with a grandson living only a few blocks away and my youngest son planning a wedding. Wow, we made it this far in life. We have so much to be grateful for.

I finally saw a pulmonologist and had a biopsy. When I go back to hear the results, he and his intern are happy to report that I have Sarcoidosis. He assures me that six months of heavy prednisone dosing will wipe this out. Sarcoidosis goes away, he tells me, "In-fact many people are surprised to see a scar later in life on an unrelated x-ray".

Trusting his confidence, I start the treatment and continue with my busy life. Suddenly, I can't sleep, night sweats start, anxiety follows me all day and into the bedroom at night. My mind races with to do lists. I can't shut it off. The doctor told me to get my eyes checked, get a dexascan, get a blood glucose meter, not to take my multivitamin or calcium or vitamin D. I need to figure

out what I can take and even eat to improve my health. I know prednisone suppresses your immune system, and can cause osteoporosis. My hormones are off and I am thrown into menopause. He also told me, "You don't want to get sick." Well, up to this point I had been pretty healthy, but cold and flu season are approaching, and in the pharmacy it is a daily occurrence to be sneezed or coughed on. Daily challenges now seem harder to deal with, just when I thought life would be easing up some.

I became aware of so many things that escaped me before and started to feel out of control in my environment. Smells from perfumes, deodorants, household cleaners, soaps, pesticides, car exhaust in parking lots, living near an interstate, toxins from plastics, food additives, sick people coughing in doctor's waiting rooms, x-rays, cat scans, etc.

To lessen stress and worsening Sarcoid, I quit my job, but that caused even more loss of self. I sought various alternative health care practitioners; each had their own take on what causes illness and ensuing treatments. My previous positive, smiling self was eroding, becoming confused and fearful. To make matters worse, taking prednisone resulted in high blood sugar, which did not improve when it was stopped. I will always have to take Metformin now. After a while, I refused prednisone which has allowed "advanced lung scarring" according to the last radiologist's report.

Even so, today through my journey, I have learned a lot and am so grateful for life and my family. I'm closer to God, and have settled on doing the best that I can do on a daily basis. I am hoping that a cure can be found for Sarcoidosis and many people will be spared the sense of loss and despair that I felt. Funding research for safe treatments and eventually a cure, provides not only the individual to live a full, healthy life, but strengthens the entire family, increases productivity as a whole for society, and indirectly affects the future of everyone everywhere.

Thank you for listening.

I quit working before I was Diagnosed with Sarcoidosis. However I did try to go back to work. I thought working out of my home would be a nice way to get back into work field. So I tried working for a company called Alpine access out of my home where I would answer the phone for Office Depot and take orders on the computer. My first day of work, I accidentally unplugged my computer by pulling the cord out of the wall with my foot while I was in the middle of a conversation with a customer. This was a freaky scary moment for me because I had the customer on the phone but I had no information in front of me to talk to the customer about. I had already put all their information into the computer to make their order But I could not complete their order. So after I took all their information I had to tell the customer to please call back and give their informational over again to another agent. As soon as I hung up the phone I started to cry & I melted into the floor. I had no confidence left I was extremely stressed out and overwhelmed. I don't know if I've ever had an anxiety attack but if I did I believe it was then. That's when I realized I just had no confidence to be able to work on the phone in to do a job all my confidence, ability, seemed to be dashed to the ground. I called up my boss and quit on the very first day. I realized I just couldn't handle the stress. And here I thought working out of my home would be so much better because it wouldn't have to deal with environmental chemicals and smells and things that I had to deal with when I worked before. When I worked before I had to deal with people walking in with smoke on their clothes in on their bodies and just really bothered me. In 2002 I quit because I was just not able to keep up I was getting more sick and calling in sick more often than coming to work. Little things stressed to me out and I had migraine headaches, my throat would close down sick headache because of the environmental chemicals that I had to deal with at work, whether it be cleaning chemicals or people's bodies or they're clothes or perfume. I seem to have brain fog was very forgetful and was told by bosses that I was not performing up to par. And being told that made me very insecure, and being insecure made me more emotionally unstable. It was about 2 months after this incident that I was then diagnosed with sarcoidosis. Because I am having so much problems with my teeth and mouth I Got a biopsy of my saliva glands and a biopsy of a growth on my face that I think my be sarc. Waiting 1 week for the results. I think more should be told on TV in the new about this disease because like me when I was finally diagnosed I had never knew this existed I think many people have it and don't have a clue. JULIE

My Sarcoidosis Story

I am a 69 year old white American woman of Irish, English and Italian heritage. I was born in Philadelphia, PA. and now live in Austin, TX.

I was first diagnosed with Sarcoidosis in 2001 during a routine chest x-ray. I had been treated with chemo and radiation for nearly one year, from 1998 to 1999, I was first treated with CMF for 6 months, every three weeks as allowed, Then I had 26 treatments with daily radiation and finally I was given Taxol every other week. When the IV treatment was finished I was put on Evista. The Sarcoidosis nodules were in my medial chest lymph glands and were diagnosed via biopsy done by a vascular surgeon. I had a nodule on my nose, which was successfully removed and one in a lymph gland in a lymph gland in my neck. I was tested by a pulmonologist and the disease was considered very mild. In 2006 I was diagnosed with a recurrence of breast cancer in the same left breast and was treated, after surgery, with weekly doses of Taxol and Carboplatin. Then I was put on Femara. In January 2007 I got bronchitis, then the flu, The following year I got the flu again, then pneumonia, then a serious bladder infection and a dental abscess. Throughout this time my creatinine level kept climbing as did my calcium. I started to get pains in my feet, swelling and neuropathy. I was tested for cancer, bone and metastatic cancer, I was having difficulty breathing and was sent to a cardiologist for test that only showed signs of minimal high blood pressure. I began losing weight; one or two pounds a week and have now lost 34 pounds. Then my left hand began to sting, burn, freeze and became very painful all day. I tried exercise but after 6 months it only made me sore and stiff. I tried eating mostly fruits, vegetables, and brown rice. I tried detox. Now sometimes I feel as if my brain is swelling and I'm getting headaches and my eyes blur. I've been to so many doctors, a podiatrist, an acupuncturist, a chiropractor, an endocrinologist, 2 pulmonologist, a hand specialist, and my general practitioner. No one really knows what to do. I was on strong antibiotics for a while but it only gets worse. Now I am on Prednisone with very little results. Sometimes I just can't move I'm so exhausted. I feel as though my body is fighting with a devil inside. Sometimes I go on oxygen for an hour or so and it helps me relax but I still have the pain, burning, stinging, swelling, blurriness, and stress. The only time I am pain free is when I sleep, with the aid of sleep medication. I pray and I cry every day.

Hello, I'm kind, compassionate, a good friend, and I also have Neurosarcoidosis. Nothing in my lungs, just everywhere else. I also have small nerve fiber neuropathy, autonomic dysfunction, & neuroendocrine sarc. I just found out I have diabetes insipidus. It seems the Sarcoid has hit my pituitary. None of my hormones are working properly...it just keeps snowballing, I'm afraid to know what's next? This all started with Endometriosis at 15, just lived with the severe pain for many years. Now I'm being treated with meds for severe, localized pain my back, (anyone with localized back pain?) . The Endo is not a concern anymore; it was just a start of things to come. The many DX's are my concern, as it's taken everything from me. I was misdiagnosed for over 5 yrs, (based on how I looked, and a normal ACE level). As I got gradually got sicker, my work came to a stop, I couldn't function. 10 yrs. ago I started my business as a creative director/graphic designer. I was very active as a competitive athlete- pro level speed skater, Mtn biker, etc...always having a goal. Also a humanitarian, I volunteered at an AIDS orphanage for 3 mo (90 kids!) in South Africa, Hospice, and just finished Foster Parenting classes when I became to sick to pick up a baby seat. I was in total disbelief for many years, fighting it (the pain), until i couldn't fight anymore. Now, I'm excepting where I'm at, and on disability, and happy I can walk. I just became a Medicare participant as it's been 2 yrs, & now considered 'retired'!...(saw that on a recent med report). I have found a great doctor that can handle all of this (i hope, it's becoming a lot). I've tried Remicaid for about a year. Made me worse than the disease it's self. Now, I've had my third IVIG infusion, we'll see how that works, I had severe night sweats (very common for me anyway) and in bed for a few days. I've read it's the best for your body- not hurting it, while keeping the disease under control. Look it up! My goal, now, is to live in the present and keep my body from getting worse. It's not in my hands, but I do what I can & hope for the best..... 10/2/10, GOOD NEWS. I felt good for the first time in 6 years- for almost 2 weeks! It was amazing! I'll take 2 out of 4. I pray it keeps working. Thank you for your inspiration, stay strong (we are stronger than we think), & God Bless.

PS. Need a roommate? I don't want to live alone with this disease, yet I've found it to be hard finding people that understand....even family. For me, loneliness is the hardest part of being sick.

Inspiration:

I don't remember what it feels like to feel good. But I keep fighting. I was misdiagnosed for over 5 years, maybe much longer. All because my ACE level was normal! I had ALL the signs & symptoms for all the BEST docs from coast to coast, but it didn't matter. They only looked at me (looked healthy), and my blood levels, & said I was fine....I didn't give up and felt like I was in Med school studying whatever I could find to get answers. Don't give up! I have good and bad days. And feel terribly alone at times, that's the worst. Winter in WI has been VERY hard. I just look forward to summer and hope my treatment will help. Just don't give up....MY inspiration is all of YOU!

It's nice to know I'm not on this island alone. Thank you for your support! We need each other. Prayer has helped me as well.

My name is Angela and I am 42 years old. I was diagnosed with Sarcoidosis about six years ago. The most frustrating thing about having Sarcoidosis is the lack of knowledge on the condition. I was diagnosed after 4-6 months of testing due to Lupus Pernio located on the exterior of my nose. My doctor herself had never seen a case of sarcoidosis and quickly sent me to a rheumatologist. I have been on countless medications with none really helping my condition, or the medications that do help such as prednisone have horrible side effects. Six years after being diagnosed, the disease is now in my lungs and sinuses, and I'm hoping that research can be done to stop this from going any further. Since sarcoidosis is a condition that no one can tell you why you have it, and there is no cure so far, it definitely has to be researched to learn more facts and find a cure for this disease.

Sarcoidosis mostly affects the eyes and the lungs. In a small number of people, the disease involves some part of the nervous system. Neurosarcoidosis is a complication of Sarcoidosis in which inflammation and abnormal deposits occur in the brain, spinal cord, and other areas of the nervous system. Neurosarcoidosis may affect any part of the nervous system. Sudden, facial weakness or palsy is common and involves the nerves to the muscles of the face. This happened to me one time during a physical therapy session and the PT thought that I was having a stroke and I was sent to the hospital. Any nerve in the skull can be affected, including those in the eye and those that control taste, smell, or hearing.

I have always had strange symptoms. When I was a child I had a lot of head pain and could not explain to my parents what was wrong. My parents were told that I had severe allergies and chronic ear infections. My hearing constantly changed and I was submitted to horrible "ear popping" treatments. Head banging was the only way to equalize the pain and dull it. My vision constantly changed and my glasses were never quite right. My ability to focus and pay attention constantly changed. I had chronic stomach pains and ended up having my gallbladder out at 21. At college, I was told that I was a "nervous college student" and prescribed Valium. I don't know how I made it through.

I found out that I had Tyramine sensitivities and other severe food allergies after I became very sick. The symptoms kept getting more bizarre as I got older. My sister was ill often and we noticed that our symptoms were similar. The main difference between our illnesses is that she had more cardiac and pulmonary issues. September 5th 2006 she passed away. She was 52.

I got seriously ill in Oct. of 2006. The doctors thought my symptoms were due to stress of that loss and ignored me saying that I had to breathe and relax. Sarcoidosis can be triggered or worsened by stress, so what the doctors were saying made sense, but they didn't look beyond the symptoms. I had more problems with my eyes. My optic nerves were so inflamed that I ended up in the hospital for tests and studies. The Neurologist said I had Pseudo Tumor cerebrii. I was having "symptom of the month". After the eye problems I couldn't sit up or walk. Those episodes passed and I woke up one day totally deaf. Then it was seizures and mild cancers. At that time my doctors began to talk to each other about Meiner's disease, Lupus, MS and so on. The only

thing they could agree on is that it was auto-immune. I was put on prednisone (80mg.) and my hearing improved but I still ended up needing hearing aids.

I had a lumbar puncture which resulted in needing a blood patch to seal the spine. I needed an MRI and an artiral biopsy of the brain, a chest x-ray and TB was also a must for checking for Sarcoidosis. It took almost 9 months for doctors to decide to do a biopsy on my lymph nodes. My doctor even joked, "I've never told a patient to hope for cancer, but hope for lymphoma, we know how to cure that."

There is no known cure for Sarcoidosis. Treatment is on a symptom by symptom basis. Severe or progressive symptoms warrant more aggressive therapies, until a treatment of controlling the progression can be found. Some people have found relief of their symptoms by following a program called "The Marshall Protocol." I tried a modified version of it. By not going out in the sun unless I was fully covered head to toe (including the eyes) and following a strict routine, my symptoms improved. Corticosteroids such as prednisone are prescribed to reduce inflammation. They are often prescribed until symptoms get better or go away. Some medicines may need to taken for months, even years.

I have had numbness, weakness, vision or hearing problems, or other problems due to damage of the nerves in the brain and small strokes, I have had various physical therapies, vision therapy, occupation therapy, swallowing therapy, braces and had to use a cane. I have needed treatments for diabetes, depression, pulmonary and cardiac issues. I have made unconscious and conscious life modifications. I have limited my travels to lower elevations. I travel no more than a few days at a time or a few hundred miles from home and medical care that is familiar with neuro-sarc.

I have systemic neuro-sarcoidosis and I feel sick all the time, but it is compounded because very few people believe that I can have so many things going wrong. Yet, so many things are going awry. One minute I feel like I am on pins and needles another I feel like I am completely numb. I always feel like I am on the verge of throwing up, am dizzy and afraid to move my head for fear of falling. I don't drive at night unless I have to for I get more disoriented at night. I hear "the tinkling of wind chimes" in my ears all the time and sometimes it is that plus certain tones that drown out all other sounds. Often, I

get phantom smells or something like a bolt of electricity that zaps inside my head, making that terrible Tesla coil sound.

As for joint pain, all I can say is fire and ice. Sometimes they burn and sometimes they freeze up and lock in place. One of my biggest complaints is in the neck where it sounds like two pieces of sand paper rubbing together when I turn my head. In the spinal cord, I have this issue of pain and throbbing. At the base of the spine is where the throbbing starts and as it goes up the spine the throbbing gets worse. When it reaches the rib area I have to shallow pant if I am going to breathe until it reaches the base of my skull where it explodes into a massive headache.

If you ask me the worse thing about this illness is humiliation. People look at me like I am drunk. I sway, fall down, drop things and fall out of chairs sometimes. I have trouble grasping for words and "spitting" them out at times. I feel like I can't do anything anymore and am useless. I have let people get to me more than the disease. People don't really know about Sarcoidosis. They know Bernie Mac died due to complications from it and they have heard it mentioned on "House". Most often I just tell people I am sick with an auto-immune disease and they say, "You don't look sick." Looks can be deceiving and I wish people weren't so quick to judge.

Neuro-sarc has strained my immediate family and my extended family beyond repair. With my sister's death, I thought my extended family (mom, brothers and inlaws) would be more understanding about sarc and what it does to the mind and body. I have found them to be more distant and thinking that I am lying about my health to get attention. (BTW, I am 47yrs. and married with two wonderful boys.) My immediate family has had this disease forever imprinted on their minds. My 12 yr. old is determined to perfect the Buckyball to target granulomas and other cells etc. that cause damage to the body. My 16 yr old has basically given up saying, "What's the use, I am going to have it cause I already have some of the same symptoms." He used to be straight A's now he feels like it is all useless. (Of course he is 16 and they all feel the world is constant drama at that age, but this is going beyond that. He is really afraid.) As for my husband, he is just angry. Angry about why this had to happened and angry that he can't leave his job due to insurance worries. He is angry about how we are going to pay all the bills because the hospital is suing us for not being able to keep up with the payments. He is angry at me for

being sick and unemployable. I was a teacher of the Deaf. Now I have no energy and get sick with colds and virus so much, I am an un reliable employee. SS has told me that my husband and I need to divorce to be eligible for benefits. He is angry that since the hospital is suing us, will I still be able to get treatment there? There is so much to say how it has affected us, but not enough energy to type it all. Thanks for addressing our concerns.

Laura

My name is Heather R. Morgan. I turned 40 years old this year. I have a master's degree in Social Work. I was diagnosed with neurosarcoidosis by lumbar puncture and bronchoscopy in August of 2009. This differential diagnosis took four months. During which I suffered a myriad of symptoms which included an aseptic meningitis, which often accompanies neurosarc. It was uncomfortable to say the least. These symptoms, which were eventually treated with prednisone at 80 mg BID for approximately one year (including a three month tapering period) affected me greatly.

Before I was diagnosed, I was losing weight, about a pound a week due to chronic fever and diarrhea. I had problems with my eyesight, which was thought to be conjunctivitis but was eventually diagnosed as iritis (which just "goes along" with sarcoidosis). I had tremors in my hands which made it difficult to do simple tasks like type on a keyboard, feed myself, or dial a telephone. I also had terrible fatigue. Essentially, I was bedridden. Showering every day was impossible. My husband eventually had to quit his job and use Family Medical Leave to care for me. Just being able to ambulate the ten feet from my bed to the toilet and back to bed several times per day was all I could do. Going to doctors' appointments was almost unbearable because of the muscular aches from the fever. And because I didn't have a lot of "signs and symptoms" that were clinically significant I was asked over and over again if I was depressed. Do you run a fever when you are depressed? I felt that I should have been able to make myself better. The guilt over spending all of this money was also killing me, it was \$75 for a bottle of eyedrops every other week there for several months, for example. I met my \$300 medical deductible for the first time in my life, I have always been very healthy, luckily. But the co-insurance is still 20% and there were no specialists in my area, this is a whole other letter, but my pulmonologist and neurologist aren't in my PPO, so I had to pay out of pocket every time I saw them, about \$200 for an office visit. I was so scared all of the time. I was broke, my husband was having to do all of the housework that I usually did, and take care of my 7 year old son. I felt useless. I can't work, I am home laying in bed all day, nobody knows what's wrong with me, I can't even be an effective mother. And I have no idea when I am going to get better?

Fortunately for me, I had an excellent PCP who did a thorough differential diagnosis, and with an abnormal chest x-ray, then chest CT scan, we were able

to get me on the path to a correct diagnosis. After "treatment" with prednisone, I had horrible side effects from the medication. This affected my marriage and my relationship with my son even more. I had frequent bouts of temper, to put it mildly. I was unable to control my verbal outbursts. Even with medication to manage the side effects, sleeping and keeping my emotions in check were constant challenges. I was tired all the time, but had insomnia. I could cry at the drop of a hat. I would lose my temper over the silliest of things, and then cry, and then move on to something else in the span of twenty minutes. Sound exhausting? It was unlike anything I have ever experienced, and the guilt of putting my son and husband through this experience was even more excruciating. This is even worse to admit, but I wanted to have lymphoma, because other people understand cancer, they have sympathy. I love my mother in law, but one year later, she still cannot even pronounce sarcoidosis. It makes me so mad. Like, come on, can you even say it right? She had breast cancer. If I had breast cancer, I could wear a pin, I would get a month. What do I get? A funny look because I walk like I am drunk. My son's friends won't come over for playdates because the mothers all think I cannot handle things at home because I am sick.

I was able to return to my part-time job, but it was extremely difficult to manage my emotions and to mask the remaining symptoms that I had. It was hard to work even 20 hours per week and manage to get the rest that I needed, due to the insomnia from the medication. And to be honest, I know I have lost some of my cognitive function, my memory is so bad. I took medication for ADD before I had neurosarc, but now, it's like I have a brain injury. Sometimes I just have to have a certain level of denial or my anxiety would be so bad I would never leave the house! I cannot remember very simple things, and I write them all down in a notebook now and carry it in my purse. I'll go and look through it, and Google is my best friend for everything else. Where I used to like to meet new people and strike up conversations, I can't because I have such bad tip of the tongue syndrome it is embarrassing. And I can't remember my sons sizes when shopping, or whether or not I read a book or saw a show on TV that I just watched this year.

Due to many factors, my husband was laid off, we had to relocate and move into my mother in law's home. We have lots of unpaid medical bills, but thank God we can afford COBRA coverage because of the subsidy that Congress

passed last year. When the subsidy ends in January, we will have no health insurance and our son will be on Medicaid. We had an emergency savings fund, and we also had a 401k plan. However, no one plans on getting sick and then getting fired. When we moved, neither my husband or I was able to find other work. He is in school now, being re-trained to do other work. I, however, am thinking about another career. I don't know if the helping profession of social work is right for me at present. I really do not like the person that I am. I have migraine headaches now. It is a residual effect from the neurosarc. I take medication that controls them. I also have gained weight from the prednisone, and I am deconditioned from all of the inactivity of last year. With physical therapy, and diet and a lot of exercise, I have lost some weight. I have sarcoidosis, but it doesn't have me. Even if no one finds a cure for this disease, or ever agrees on what causes it, I have to come to terms with it and learn how to live with it. Living with a chronic disease is like having to get another college degree that you didn't want. I used to like knowing things that no one else did. But this is a little ridiculous.

I would be happy to testify in front of any committee of Congress that would listen to me. Just let me know when to be there, I'll buy the bus ticket.

Sincerely,

Heather

My name is Andrea, I am a 50 years old German woman. And.. I have been suffering from Sarcoidosis for about 23 years.

Until now my lungs (stage III-IV), pleura and skin have been heavily affected. During the last 10 years I have been forced to take medications with severe side effects. Very high doses of corticosteroids in the beginning have presumably elevated the sensitivity of my bladder, my skin, my mucous membranes, my bronchus, my sensitive nerves in general so that I do have severe problems to tolerate various medications or food any longer. Those are all causing pain or additional breathing problems, when I take them. This is why I am not in the position to switch to alternative medications, such as chemotherapeutical drugs (MTX or Azathioprin) or medications like Pentoxifyllin. By the time I also developed histamine intolerance and a mast cell activation disorder (MCAD), severe tachycardia, steroid rosacea, dizziness and headache.

I hold a Master's degree in Business Administration and additional degrees in English and French as a second/third language. I have always loved my job and have been very ambitious. About ten years ago, I was forced to leave the company I had been working for about 14 years due to my bad health. Now I am on governmental disability and my current income has decreased to 1/3 of what I was earning. I wasn't in the position to care for additional private health insurance coverage, as I became sick in very young years and private insurances don't insure risks such as chronic Sarcoidosis. This leads to additional problems, like being a second or third class patient in our German health system. Instead of spending more time for a chronically sick person, the doctors in general spend less time for you as they are not getting paid well enough for you.

My life has become very limited by the time, although I have tried hard to fight it. I had always been a very active person, travelled a lot and did a lot of sports. I have lost many friends, as it is not very amusing to be with someone who is feeling uncomfortable, cannot eat properly, has breathing problems or is in pain most of the time. I am neither married nor do I have children. I actually didn't want to have children due to the risk of inheriting the disease. My doctors are often speechless and tell me they don't know how to help me. This makes it even worse to cope with the situation mentally. My family is hardly in the position to cope with the situation and tend to withdraw due to this.

Psychologists told me, how can we help you...we cannot take away your pain or your intolerances.

We Sarcoidosis patients urgently do need more funded research for having a life again, no matter where we come from!!!

My name is Mike and I was diagnosed with Cardiac Sarcoidosis in July 2007. Feb 2007 I'd had an unrelated CT scan, where everything was okay. In June 2007 I went on vacation, when I came back I was feeling crappy and weight was going up rapidly. In the July was having difficulty breathing went to the ER and they told me I had CHF (Congestive Heart Failure). First doc said it must be drug or alcohol related and had been coming on for years. I'd pointed out that I didn't do drugs and only moderate alcohol use, I also mentioned the earlier CT scan but he was a closed book. Got shipped to UMass and the second doctor was much better he started checking all sorts of things (SED rates, CRP etc) when he realized the speed at which it had come on. Biopsy confirmed it was Sarcoidosis but I was already down to an EF of around 10%, they put in an ICD and started steroids in August 2007. I had a few months of CHF drugs but by Aug 2008 they had decided I needed a heart transplant. Started the workup at Tufts in Sept 2008. Was listed November 2008, December was a bad month I was in and out of hospital. They put me on Milrinone to improve the heart function. That lasted until Jan 2009 when my left ventricle failed completely. I was on a balloon pump for a few days and then they fitted an LVAD. I had to give up work at this point, just couldn't manage it with all the hospital stays. Was reasonably stable with the LVAD until about December 2009 when I got an infection in the drive line. That was also about the time my wife and I split up. I have been in an out of hospital since then with the same issue but then admitted early September 2010 and will likely be here until transplant now.

Regards, -Mike

Here's my story. Most of my life I have suffered strange bouts of weakness, extraordinary pain, difficulty breathing and overwhelming fatigue. No doctor had ever diagnosed the problem until last December, after months of shortness of breath and fatigue and an assortment of unusually large erythema nodosum. It has also affected my kidneys, causing partial failure. Unable to take medication because of a metabolism that makes me hyper reactive to drugs, I spent most of my life since then barely able to make it through the day. Recent trials of prednisone caused overdose and dangerous, manic-depressive behavior. We are now trying an extremely low dose (10 mg). At this point, my doctor is willing to try anything, as no treatment at all will leave me on a continued downhill slide. We have hope. - Veronica

I was diagnosed with sarc when I had a chronic cough that annoyed me for way too long that started in the fall of 2006. I believe I had a bout in the mid 90's that went undiagnosed and into remission as I had the dry hack for about a year. I was finally diagnosed with sarc in April of 2008 by lymph node biopsy after MRI, ct and pet scans. My treatment was a round of prednisone for 6 months or so and a steroid inhaler. The thing that seems to bother me the most through this battle has been this general malaise and chronic fatigue. The cough is minimal now, but for a guy who used to enjoy and thrive working (often 55-60 hours/week) I struggle doing 15 -20 hours now. Financially it has put the family on the edge. Sometimes I wish it was just me and I didn't have a family to worry about providing for. The thing about sarcoidosis is we "look" healthy and the literature generally says we mostly are. Doctors in general believe we are healthy so the condition seems to get the poopoo. My lung doctor tells me "85% of my patients are worse off than you". It's true I don't drag an oxygen bottle around, but I seriously doubt I will ever get the energy and ambition back to a level that would allow me to work a regular job again. I also have fibromyalgia that I wonder if sarc brought on. Unrelated to sarc I have hypertrophic cardiomyopathy and chronic back pain from a work injury.

Respectfully yours, - Jay

chest pain, shortness of breath, abdomen pain, headaches, weakness, muscle spasms and cramping, neuropathy, flames shooting from the feet, fatigue, cannot sit at the computer more than 10 or 15 minutes at a time. Hard to make a living this way. Fear, anxiety, depression, expenses from all the doctors, testing, travel miles, parking fees and medications. What do we do? Diagnosed with pulmonary Sarcoidosis November 2009. Taking prednisone, was on 40 and down to 15 now. Weight gain of 70 pounds. Cannot do stairs, memory seems to be blanking in an out/ Doctors confused and throwing there towels in on me it seems. Hard to get responses from the Cleveland clinic now, where i went and spent 14,000 dollars for inforamtion. Now back in Houston they do not want to do what cleveland suggested. I am not in a good place right now. Frustrated and broke now. Sheri C

Hello,

I was officially diagnosed with Sarcoidosis (lungs, lymph nodes, eyes) through biopsy 7 years ago. I had just turned 40, although I had suffered with iritis and uveitis for many years prior. I did steroids for a year after being diagnosed. At that time, the doctors I had seen in Colorado didn't know of any other treatments. I ended up with even more problems, cataracts among them, had cataract surgery and hysterectomy at 41 years old. I moved to Iowa and did well for a couple of years. Then recently started having issues again, and was told my Sarcoidosis was active again. I was seen by a pulmonary specialist who did nothing. I changed doctors and was told my Sarcoidosis is not considered severe at the moment and that it won't be treated until it becomes severe. My question was then why would you wait until something is severe to treat it? Why wait until it's maybe too late? I have found an awesome ophthalmologist/retinae specialist who is treating my uveitis and actually has knowledge of Sarcoidosis and is kind enough to listen to my frustrations. I live with labored breathing and pain. I have bad days and I have good days. This has been so frustrating because it seems few doctors have knowledge of this disease and there is sometimes conflicting information. I could go on and on about this subject but will make this short at this time. If you need or would like more information please let me know. Good luck.

Sincerely, - Brenda

I was dx 2years ago with pulm. sarc, had a broncoscopy. My breathing was terrible. I was put on 100mg pred.daily have had all the side effects from pred. including diab.,

night sweats, shakes, lose wght., gain wght., dizzyness and others. Have tried 4 times to lower pred. with no success, have been down to 5mg and had fevers and sickness daily. I'm on 20mg.pred., methox. statin, antibiotic,diab.med.,tramadol,and fosamax, am seeing doc in 2 weeks to review . I expereince dizzyness and fatigue daily. I have NOT had one normal day in 2 yrs. I am 67 this month.

Jim

This is for my daughter-in-law, not me. She was diagnosed in Sept. 2004 at age 33, a few months after the birth of her second child. I do not think there is a day that she feels really well, but when on Prednisone, she feels at least human. She has had various swollen lymph nodes, some granulomas in her lung, fluids around both her heart and lungs, Chronic anemia, Bells Palsey, near kidney failure, tons of kidney stones and hyper-calcemia, not to mention nearly constant nausea. Her doctors in Illinois treat the symptoms, but never want to just leave her on prednisone. Soon after the end of a treatment cycle, something else happens and she "yo-yo's" all the time. With two school age children, she is exposed to lots of colds and viruses and each episode causes a Sarc. flare and culminates in something different. She works full time in a factory (printing), so is in constant contact with chemicals. She is also on her feet eight hours a day and then comes home to two little girls who rightfully demand her attention. Her husband (my son) tries to do as much as he can around the house, but there are a few things that Mom must do. Her nine year old watches her like a hawk and asks if she needs help and often suggests that they just order dinner rather than Mom cooking. My son works longer hours, but thank goodness the plant supervisor knows that Danni cannot work more than 40 hours per week. The plant has also been very good about allowing her time for doctor visits and to heal when she needs it. She has very good health insurance, but recently the plant changed hands and there was a scare about the insurance. Fortunately, it worked out fine and she still has the same insurance with no new deductibles this year. The flares have been coming more often and with more bizarre problems this year, so she and I have asked her team of doctors for a referral to a specialist - she is set to go to MUSC Sarcoidosis Center in Charleston, SC in January for a full evaluation and hopefully some stabilization and better guidance to her doctors at home. Chronic Sarcoidosis is a debilitating disease and most doctors really do not have a clue. They are under the impression that it will flare once or twice, then just go away and not come back. They can diagnose it eventually (it took a lymph node biopsy to confirm her diagnosis), but then they only try to treat the symptoms. I honestly believe there should be a specialist in every moderate size city with experience and knowledge with of this disease. There should be protocols for continuing treatment, including medicines other than steroids, available to many more physicians. The idea of treating each flare as though it is the end of this disease is ludicrous. - Arizona Mom

In the spring of 2001 I had some very strange symptoms, starting with difficulty swallowing and followed by an inability to eat because everything tasted so terrible. Over the next few months I experienced two bouts of Bells Palsy and numbness in my body, dizziness, headaches and weight loss of 35 pounds. I was tested for everything under the sun after about 4 months the symptoms just went away, with no diagnosis of what caused the problem, other than inflammation around my facial nerves. Over the next 9 years I had a cough that would come and go, but was almost always there, a bad case of vertigo which sent me to the emergency room, lower back pain and sciatica and Supra Ventricular Tacchycardia which also sent me to the emergency room.

Toward the end of 2009 I was coughing all of the time and my PCP did an x-ray which showed a nodule which they determined to be a resolving pneumonia. In the meantime, I injured my shoulder and was scheduled for surgery, when I had my pre-op check up, my x-ray showed all of the classic symptoms of Sarcoidosis. I have been seeing a pulmonologist since March. I am being treated with prednisone and all of the terrible side effects caused by it. My lungs have greatly improved, but while on 60 mg of prednisone, I started to develop Neurosarcoidosis symptoms again, including tongue numbness (and taste issues), facial numbness, numbness in feet, brain fog. I have been waiting for months to get in to see a neurologist that knows something about Neurosarcoidosis and I am scheduled to see him in November. I am easily fatigued, have gained about 15 pounds, have a moon face and buffalo hump and am on medication for high blood pressure and acid reflux, all due to the prednisone. My last PFT showed that I had 65% lung function, I will be tested again in a couple of weeks and hope to see that improved.

Karen - Prescott, AZ

I am a white 53 year old female, originally diagnosed with Sarcoidosis in April 1985 after having a miscarriage. After the initial diagnosis I was told that it would "burn itself out" and there was nothing to worry about. Over the years I have had several "flare-ups", with involvement in my lungs, eyes, skin and now my nervous system. It is also believed but not confirmed that I have had sarcoid in my pancreas, as I have had pancreatitis several times and have no risk factors for that condition.

In 1994 I was treated by two different doctors at the Mayo Clinic in Rochester MN, after reviewing my records, Dr. Dunn, Thoracic Specialist, was fairly confident that I have actually had Sarcoidosis as early as 1978. At that time I had a tumor removed under my right eye that apparently biopsied with characteristics of Sarcoid.

I am currently disabled due to Pulmonary Sarcoid and Neuropathy due to Sarcoidosis, this has been ongoing since early 2007. I am unable to take prednisone as I have a tendency to have prednisone psychosis. I have tried the remicade infusions without much of a change, if any, in my lung capacity or other symptoms. None of the current meds used for neuropathy pain have helped, as I either cannot tolerate the pain medication, the side effects are horrible, or they don't even touch the pain, in some cases both reasons. Many years ago I told one of my many Doctors that I am the poster child for side effects of medication, as I tend to not be able to tolerate many medications for a myriad of reasons. I do take Methotrexate at 10mg once a week along with 1 mg of Folic Acid. I also have Advair to help with my breathing. I take yearly Reclast infusions due to Osteoporosis due to Prednisone use (used at a very low dosage).

The fatigue, the pain, sleeplessness, the memory problems, as well as my breathing problems have caused life as I knew it to change dramatically. There are days that I can barely function, there are rare days where I actually feel pretty good, at least for a few hours, but all in all these disease is beyond description to someone that has no idea what it is or what it does to a person, as in most cases, those of us affected with this disease "look fine", I know I've been told so many times "oh, you look so good" in a context that if I look so good how can I possibly feel so badly, they don't understand, AND I don't think may Doctors understand either.

I've been seen by many over the years and most know less about the disease than I do, even some of the specialist don't fully understand what is going on. Of course without a clear cut explanation for the disease, how it occurs, why it occurs, I guess that no one really understands what is going on. However, I feel that Doctors should be more open and understanding when a patient tells them what is going on with them, and not dismiss the new signs and symptoms as nothing to do with Sarcoid. I learned many years ago that most everything that goes on with me has something to do with Sarcoid. With that said, I currently have a great Pulmonologist and Neurologist, but have been through some that weren't so great.

Thank you for your time -Jeanne

Most sarkies could write a 100 page essay on the way Sarcoidosis has destroyed any semblance of their old lives. They have to accept a new reality, which most do not want to accept. Some were elite athletes, who struggle to walk a few steps. Most would swap Sarcoid for being in a life threatening accident as long as they knew they had a chance of recovery to get back to their old life. We go through a mourning period for our old life, being able to work and to only complain about a lousy boss, but instead only a very few of us can still work due to this disease and ofcourse once you lose your job, you lose your insurance putting us on the scrapheap of financial ruin, losing friends and family support along the way because they don't want to understand or couldn't be bothered to.

My story is typical of most sarkies(sarcoidosis sufferers). It took more than 2 years of coughing and presenting to my local doctor and he just saying it was a cold, or the flu, or asthma or pneumonia, all the while not sending me for tests. I complained of exhaustion(chronic fatigue), not sleeping, night sweats and pulse of over 100bpm.Foods like salmon that I had enjoyed most of my life, made me physically sick just smelling it. In that 2 year period I felt like I had aged 40 years. I struggled to make the journey to the bathroom, some days, sleeping or trying to sleep all day long, 5 years later, some days just eating a meal will tire me out and will need a 3 hour nap before I can do anything else. Things as simple as spelling a word, or remember a thought from a few seconds earlier can take minutes or longer to recall if at all. Trying to recall if I had a swollen gland or a doctors appointment, swallows up my days. Pain can come and go like I am being used as a punching bag by a cagefighter - pain in the ribs, then stabbing pain in the legs, then into the chest, then pain like someone is crushing my feet. When I started on prednisone, I had every side effect noted bar 2 bleeding from my nose and mouth, blurred vision, edema that caused my lower legs to near explosion, my ankles measured 18.5 inches, my feet looked like washing up gloves blown up like a party balloon. I was in agony every minute of the day in many ways and there was no relief. Sarcoidosis is a rare disease that affects about 4 in every 10,000 people from what I have read, yet the number of doctors who recognize the symptoms seem to be even rarer. Much needs to be done to help sarkies, from teaching doctors how to recognize the disease, to those that can and make out, that you have a hangnail issue. There is the issue of finding softer treatments that scare people from taking their meds. Some sarkies are experimenting with

curcumin and feel, we have made more progress than some research organizations and would love to see NIH put financial backing into this area. I feel that we are very close to finding treatments that work for the majority of sarkies, if it is focused on curcumin as we believe this will kill off the toxins produced by granuloma thereby stopping the cycle of inflammation.

Many thanks for your efforts - ozealan

Sean's Journey: It took about 7 years, and many doctor visits to figure out what I had. I started with kidney stones with abdominal pain. Then my gall bladder calcified and needed to be removed. I have scar tissue on my left lung, spleen, and liver due to granulomas. I have visited at least 12 doctors, only to find two who knew anything about Sarcoidosis and what steps to take to help ease it. Unfortunately, I lost my insurance and now have Kaiser, and again I'm having problems to find any doctor who knows what to do. They blow me off and take the stance that "it's not that bad" and want me to just take blood work every three months. Due to 9 years of having this disease, I have gone through countless nights of no sleeping because of pain, wasted doctor visits and money to professionals who don't know enough and, at the same time, have battled depression. I worry constantly what will happen next and when. The uncertainty of how long I will still be healthy enough to live, to pursue my dreams, and to decide whether to have a family tend to occupy my mind daily. We need more research and funding to really address the growing disease.

I was diagnosed at 45 years old after complaining of shortness of breath. Xray, ct scan with needle biopsy and then 2 bronchoscopies over 4 months provided my Pulmonologist with confidence in the DX.

I am a lifetime athlete (Caucasian male) and non smoker. I was coughing up small amounts of blood for a year (now stopped), fatigued but functional, and experienced tingling (not numbness) in my arms and hands. My neurologist conducted an mri and an electrical torture test and found nothing wrong. I have little lumps in my chest, that no doctor can sense, confirm or bother with. Sometimes they hurt. In the 7 years since my diagnosis, I have completed two cycles of prednisone. My Chest XRAYs grow moderately worse and I feel fine.

I live a normal life without restriction, feeling lucky but fearful that the Sarcoid lurks in my body and I have only hope as my defense. My eyes have remained normal and my spleen is slightly enlarged. - Daniel

I truly believe I had sarc for a long time before diagnosis, maybe even as a child, but unable to prove it. Here is my reasoning. I was sick with gastritis frequently as a child, (lunch meat-pork products, grapefruit-acid foods) developed canker sores in mouth, not just white spots but open lesions the size of dimes and quarters which lasted for months. Later my joints, back and feet hurt, I hated to run but tolerated riding bikes. At about this time I became aware of shortness of breath (sob) and hearing (in my ears) my heart beat faster when I started swimming lessons (chlorine). My mother kept pushing me and my brother made fun of me so bad I continued through the lessons to achieve lifeguard status before the age of 10, so it wasn't fear, but too young to work at the pool. Later I found these symptoms didn't happen when swimming in lakes, rivers or the ocean ! I grew up thinking everybody could hear their heart and had dancing black spots in their vision! As a junior in high school I contracted the Swine Flu and I BELIEVE this was my FIRST full blown sarc attack. I missed 2-3 mos of school, was exhausted for 5-6 more months and started getting little red spots, like tiny moles on tender skin areas. Exhaustion, verge of depression, tachycardia, mysterious skin rashes, hot spots near joints, lumps and bumps, coming and going aches and pains have been with me ever since. According to my Moms wisdom- "That's what happens when a person LIVES LIFE". Of course she IS right but no one else in my family seemed to LIVE LIFE so much. In the last few years my siblings are starting to show some signs that this may be a bigger family issue than I originally thought. I have started to reconnect with cousins and I believe Sarcoidosis has to be the connection. Of course none of them have a medical background and each of them has fought their symptoms in a different way- according to what each of their Drs. say or medicine they prescribe and most importantly their individual beliefs and inner strengths. There are just so many variables, no wonder Sarc is so allusive. I need to go for now, Vitamins and Pills to pick up, errands to run, all that Happy Crap, cause you're Happy when the Crap is done! Oh Ya this Does include housework, laundry, vacuuming, dusting..... You know--Happy Crap! - Nancy

I typically ignored back pain. Since, I liked and trusted my Doctor I went into him to discuss my pain. He decided to do a quick x-ray. What he found would lead me down a path which would lead my wife and I to several appointments where the results could mean a death sentence. Fear first from the potential of cancer and then Sarcoid itself. We faced each of these sullen appointments with grace and strength. A nearly impossible task considering our baby sitter sits with three children under five years old, one autistic, one born premature and one just plain naughty. It is never a given that we will maintain the grace and strength we have come to know where the Doctor holds the results in their hand and you hold your heart in yours. Is it cancer, is it a fungus, has it moved to the heart, how do you pronounce that. The appointments shot gaping holes in a strong family's confidence that things will be ok. Of course none of us with Sarcoidosis has done anything wrong. We have not necessarily taken illicit drugs, been part of illicit affairs, smoked, abused our bodies or asked for this disease. Waiting in the room for the doctor, the answer may or may not come. Sarcoid will inevitably reveal itself to all but only after countless senseless and expensive tests and only after the one sits in a room heart in hand, loved one in tow, doctor finally no longer confused, patient about to set down the entirely new and arduous path of living with Sarcoid.

The next step begins. Impossible to pronounce. Unpredictable from symptoms to prognosis. Difficult to explain, even to oneself. Then attempt to explain it to your boss. The tests continue, the steroids flow along with the side effects. The family struggles to prop up the confidence as the results once again flow. A good patient has their other organs checked, to stop the damage that could occur and prevent blindness, pain and even death. The costs of are astronomical. Thank God if you can afford it, many cannot. The appointments are supposed to be routine. When the heart doctor calls you take a deep breath, call the sitter, kiss the kids and you walk in. The results are different for all but no one can live without a heart. So you sit in the waiting room for the doctor, the answer may or may not come. He walks in. He avoids eye contact, never a good sign. You sit in a room loved one in tow, doctor no longer confused, heart in hand and now you know it is badly scarred by sarcoid.

Research of Sarcoid could not only lead to other cures for related autoimmune diseases, it could save the medical profession countless wasted hours chasing a very difficult diagnosis and treatments. I implore you to consider funding this research.

Dear friend,

Thank you for wanting to be more informed about my disease.

I have a disease called Sarcoidosis. At this time there is no known cause or cure for the disease. Doctors can only treat the symptoms. It is thought to be an auto immune disease and is known that it can affect every organ in the body. It causes inflammation in organs. This inflammation causes granulomas. Granulomas are cluster of cells that form in tissue that has been inflamed. They are small 'sesame seed" sized and shaped particles that will clump together in the affected organ and can cause scar tissue and permanent damage if not treated. Although it has been found in almost every part of the human body, most patients get it in the lungs, lymph nodes and sometimes eyes and skin. Fortunately, in 90% of sarcoid patients, the symptoms are mild to moderate and the disease will (sometimes) go into permanent remission in 2-3 years from onset. Then there are the 10% that have severe and chronic symptoms that will most likely need treatment for a lifetime. According to my pulmonologist, I am in the 10%.

I was once a very successful automotive illustrator.

In 2001, it was found in my eyes and thoracic lymph nodes. Although difficult, I was able to continue working full time until Dec 2004. I then had to start working from home to allow long breaks from the computer to avoid eye strain. In 2005, I had to stop working and driving (hit a telephone pole that I literally did not see). In Feb 2006, I was officially announced 'legally blind' in both eyes, even though my vision was in that state for months before the official statement by the doctor. In 2006 and 2007, I had 2 separate eye surgeries to remove cataracts, clean out the old viscous fluid, replace with new fluid, and sew in a steroid implant to the back of each eye that would slowly release steroids to the eye for 24 - 30 months. My left eye never regained usable sight. After my second eye surgery (results said to be temporary due to underlining disease causing the blindness), my right eye can now see, but I now have a detached "wrinkled" retina that makes all of my vision wavy (like a fun house mirror - but not so fun). My depth perception is off and I often stumble and sometimes fall if trying to walk unassisted. I rarely venture out of my apartment without the aid of my son or other family member for fear of falling. I do not walk without a cart or walker. Reading

even large print is often a chore and causes severe eye strain, dizziness and headaches.

I am also under doctor's orders to stay out of the sun at all cost. With my disease, my body is unable to process vitamin D, especially the kind produced through sun exposure. My doctor has told me that exposure to the sun will make my disease worse and resistant to treatment. I have found this to be true as I get very ill just minutes to hours after being out in the sun. This ill feeling will go on sometimes for days after only a small time out in the sun

As of September 2007, the Sarcoidosis has now been found in my lungs, liver, skin, spleen, thoracic and abdominal lymph nodes making it difficult to breath and causing a lot of pain. Now, in 2010, it is suspected that I also have neurosarcoidosis. This is due to frequent issues of imbalance, memory loss, hearing loss, severe headaches, additional vision impairments and hand tremors. I have fallen more times than I like to recall (I am currently fighting a nasty infection that resulted from a fall I took 8 weeks ago)

I am taking 2 medications to treat the symptoms of Sarcoidosis, Prednisone and Cytoxan (a chemotherapy drug). They are both used to suppress the immune system therefore suppressing the inflammation and subsequent granulomas formed in the organs. They both come their own set of complications and side effects, but I am assured that the results of not taking them would be worse.

As bad as all of this may sound, I know that it is just different path I am on now. I have more time to raise my teenage son and have met many new and wonderful people that I may have not crossed paths with had it not been for my disability. I still have many blessings to count. For the opportunity to be closer to my family, I even count Sarcoidosis as a blessing.

Thank you for your time to read my story.

Jeri

Hi!

10/2010

Tonight my teeth ache, I feel like I'm coming down with the flu, my feet burn, my stomach is achey, bloated, and gassy, and my abdomen, sides, neck, and face feel swollen and tender. So even though it's Friday, and friends from out of town invited me to have dinner across the city, I won't be joining them. And this has been my year – more or less, with rotating symptoms and days where I've had reasonable amounts of energy and have gotten out and done things, but more and more where I am doing less, and have a constant vigilance towards my symptoms -- my latest involves pressured, slow knees that feel like they're filled with thick gel.... I don't make many plans because I often can't keep the ones I do make.

I was completely healthy until a year ago when I caught a cold/flu/something from a bandmate at the end of a tour -- I became wiped out, feverish, achy, and had a small cough -- and it never quite went away. Since then Sarcoidosis has been found in my liver and lung tissue, and though I am taking prednisone I still have symptoms. I am miraculously able hold down a new job -- largely because I haven't had any fevers in 4 weeks -- but now I have uncomfortable side effects from the prednisone (weight gain, sensitive teeth, acne, extreme bloating, sudden weight fluctuations, swollen/tender neck, and random sweating, to name a few) that make it difficult to work as well. I feel pretty hopeless, and I know I've been comparably lucky. My father is a doctor who was also recently diagnosed with Sarcoidosis, so I am able to consult and compare notes with him. And my pulmonologist and hepatologist have been extremely supportive and helpful as well. But with so little known I get frustrated: I don't know which doctor I should be reporting symptoms to because they are so varied, I use more time off of work than a normal employee – just for doctor's appointments and medical tests -- which is stressful, and I find myself desperate to try just about anything to see if it will help. I research complementary therapies as best I can, but as you probably know there's very little reliable information out there, so I'm basically trying a number of different things that my pulmonologist calls throwing my money away... But what can I say? Standard medicine doesn't have any great reassurances for me either. Prednisone doesn't cure anything, and it's not a terribly benign feeling. Until doctors can offer more information, insight, and hope to those of us with Sarcoidosis who have completely unpredictable lives

due to the ups and downs of these random symptoms (in my case: fevers, aches, nausea, gas, bloating, fatigue, night sweats, persistent cough, sore abdomen, sore feet, itching hands and feet, aching under my ribs near my liver if I exercise, etc.) We're going to continue on with a fair amount of desperation and frustration. The highlight of my day was reading a description of Sarcoid that suggested sufferers whose symptoms came on suddenly may be more likely to have the kind of Sarcoidosis that goes away after 2-3 years, because I convinced myself briefly that my symptoms came on strong. I can't imagine living like this for the rest of my life. 50mg per day of prednisone is the only thing keeping the fevers, aches, and exhaustion at a somewhat manageable level, and I know prednisone is not a long-term option. Even short term, the side effects that I can actually feel are challenging enough to make me desperate to try a number of complementary options (acupuncture, traditional Chinese medicine, various herbs (some even scammy sounding), massage, etc.) to get down to a lower level of prednisone as soon as possible.

Please find a real cure/treatment for this condition.

Hello,

Sarcoid has been active in my body for 4 years now, without a break. I lost sight in my left eye, the doctors suspect was Sarcoid related. I am fighting to save my right eye now. My right eye has suffered constant inflammation. I am now on Methotrexate to keep the inflammation under control.

I almost died last year because my kidneys came under attack. Fortunately, I made it through.

I am so tired of fighting a disease that no one seems to know anything about or come up with safer ways to treat the disease. All Sarcoid patients get is bad medicine. I refuse to take any more Prednisone and I don't even like what I'm on now. If my eyesight was not in such danger I wouldn't even use Methotrexate.

Hope that NIH has an answer soon.

Sincerely, - Gwendolyn

I was 47 when first diagnosed with Sarcoidosis. It started with a rash on my ankles that was first misdiagnosed as an allergic reaction to a mild muscle relaxer I was on (I had hurt my back at work). I felt terrible as the symptoms got worse. I got granulomas on my arms and legs, looked like aliens were trying to come out my skin. I hurt so bad...wanted to just curl up in a ball. I lost 25lbs in a month though I was eating. Finally after about 4 months the diagnoses came back that I had Sarcoidosis. My doctor at the time said don't worry it will go away on its own. Well another two months went by with me in and out of the office, with heart palps, pain beyond anything I have ever had, headaches, etc. I was put on prednisone which caused me to have suicidal thoughts, crying jags..etc I couldn't stand myself. I stopped the meds and went to a new doc, a Rheumatologist. He put me in Plaquenil. It has helped with the bumps but I still hurt a lot. I wear out fast, heart still hurts from time to time but since the docs don't worry about it, I work thru the pain. I now have a "raw" feeling in my lungs but the doc said my O₂ level is good so they aren't too worried about it. I am very frustrated with the lack of care I seem to be getting. I never had these symptoms before so I am saying it is the sarc. I do have fibromyalgia but never have had the pain I deal with on a daily basis now. I am still working 50 to 60 hours a week. All I am told is to quit my job and get a normal hour job so I can get 8 hours of sleep a night. It will help my body heal. That isn't a leap of faith I want to take with the economy we have now. I need the insurance and money coming in. Doctors need to get more knowledgeable of this disease. We NEED to be taken seriously. I was one to never get sick, now it is a battle to get out of bed some days. We need someone to help us get the medical treatment we need to live half normal lives.

Thanks for listening

I am currently on prednisone but I still have pain and burning in my hands, feet, ankles, legs, joints, chest, and head every day. I have neuropathy in my left hand and in my toes and I think it's related to a lymphodema and tendonitis. I get, what I call attacks, which pretty much knock me out for anywhere from an hour to nearly all day. I don't eat much because I'm afraid it is related to something I am eating. Sometimes I feel a burning in my digestive system and my hemorrhoids become painful, irritated and swollen. When an attack begins my vision gets blurry and my ear rings and then my entire body feels as if it is under attack. I have lost 23 lbs in 8 months. I do some light water exercise and physical therapy to try to keep up my strength and loosen taunt muscles. I don't know what triggers these attacks but I think I am getting worse. For some reason eating watermelon, ice cream or a small square of dark chocolate can cool me down for a while. Drinking a cup of rose petal tea in the morning has a modifying effect and using the essential oil of thyme for a minute or two seems to reduce the swelling when it gets bad. I am concerned about taking curcummin or turmeric because I am on prednisone so I don't use it. I had breast cancer twice, 8 years apart, and was treated with chemo and radiation. I have had several sever flu's and a pneumonia which I got after receiving the vaccines but before the Sarcoidosis avalanched out of control. I am an interesting case and I hope my experience helps your research.

Shirley

I have been diagnosed with both MS first than Sarcoidosis later. I am 57 now. MS since 1980s, officially diagnosed in early 90s. Doctors in Buffalo, Boston, Cincinnati, and Cleveland confirmed the MS. Treatment in early 90s prednisone IV megadose 1gram and then quick step down worked with some lingering of symptoms with each episode. Avonex for 5 years with no MS exacerbations of consequence. MS issues banding around waist (take amitriptyline), loss of use of left side arm and leg, numbness and loss of feeling in hands and feet, ringing in ears, spastic bladder(take Detrol). Had a detached retina reattached successfully at Cleveland Clinic several years ago not attributed to MS or Sarc.

Sarc started with skin lesion about 3 years ago. Wife bugged me to get it checked. Biopsy revealed sarc. Follow up CT scan determined small granulomas on lung decided to monitor annually. This past March, bowel obstruction relieved by surgery and untwisting of bowel. Next at home a few black outs while sitting in a chair or laying down. Next heart palpitations and irregular heart beat at internist office caused Dr. to call squad. ER thought heart attack so catheritization done, found no blockage but my heart stopped for 8 seconds during procedure. Many tests later at hospital Dr. asking questions found I had history of Sarc. They put in ICD during that stay. F/U found more irregular arrhythmias could not be controlled by pacemaker/cardiologist. Suspected cardiac sarc, f/u at Cleveland Clinic - PET scan/echo/EKG/pulmonary evaluation/24 heart monitor holter etc. determined sarc scarring of heart.

Began 30 mg prednisone treatment. After 6 weeks to 20 mg. I started aqua therapy guided by a fitness therapist, 1 hour workout 3 days a week - recumbent bike, 45 minutes now 2-3 times a week - mindfull meditation 45 minutes 2-4x a week (Jon Kabat-Zinn, PhD CD). Last PET scan 3 weeks ago, Dr. Culver indicated remarkable improvement. A follow up at MS clinic indicated a lot of improvement. I went from walking with cane to no cane needed. 2600 irregular heartbeats monitored by initial holter in 24 hours to 26 last monitoring. Overall I feel better. I still gained 10 lbs so far on prednisone. I have High Blood pressure, I am overweight and I have osteoarthritis in left foot/ankle and lower back. I lost my job in 3/09 not related to illness.

Recently learned one of my aunt's on my mother's side had lung Sarcoidosis - she dies from weak heart after years on prednisone.

My son has had Sarcoidosis for 20 years. It was diagnosed with a lung biopsy in St. Louis, MO. The Sarcoid was in what they called the delicate lace of the lungs. When I saw the x-rays, it looked just like a lace doily. The Doctors in Michigan put him on prednisone, and then tried to wean him off. Each time he got a lung infection, the prednisone would be increased. Then they would start the process of weaning him off again. I don't think that he has ever been off prednisone since the beginning. He was hospitalized with lung problems several times. Once he lived and worked in Germany. He was living in the Detroit area when he went to Ford Hospital to see about a lung transplant. During the testing it was discovered that the Sarcoidosis had invaded the heart.

The disease affects the electrical system of the heart. A defibrillator with one lead was implanted in the heart. It shocked him to the floor once. A pacemaker/defibrillator with three leads was then implanted. The next year there was a recall on this particular device. Ford Hospital replaced the device immediately.

He spent three and a half years going to Mayo Clinic, first every six months then every three months. It appeared that the transplant was eminent until the surgeons became involved. The lung Dr. said that there was probably scar tissue grown around the ribs and that my son would probably bleed to death trying to take it off. The heart Dr. said that he would be on a respirator for a long, long time and what kind of a life was that. So when my son got the news that Mayo would not do the surgery, he checked with his insurance and called Cleveland Clinic. This was August of 2008. We saw Drs. just before Christmas of 2008. He went again in mid winter. We went the last of May 2009 and he was put on the transplant list for a new heart. Three weeks later June 25 Cleveland Clinic called that they had a heart. Drew has AB+ blood so he was put at the top of the list for a transplant. My son was still working so he had everything in his car if he got a call. He had two friends that had cleared with their bosses that if they ever got a call from Drew, they were gone. The weather was so bad that the airplane that was to pick him up couldn't fly so Drew drove himself to the Clinic. He got the call shortly after noon, picked up his friend then called us (mom and dad) about 2 o'clock. We also had our things packed so we were on our way. Drew got to the Clinic about 5 o'clock, we got there at 8 o'clock. We saw him until 9:30 when they took him in for the

rest of the pre-op. The heart was there at 11o'clock. The Dr. came in at 1:30 A. M. and told us that the heart was in and working fine. He had the respirator for only two days. We spent two months in Cleveland. Our son came to our home for another six weeks and went back to work in four and a half months after surgery. He works at a computer all day, he joined two golf leagues for the summer. He will always have trouble with his lungs and the Sarcoid seems to be stable at this time. I am so proud of my son as he has a marvelous attitude toward his illness. "There is nothing that I can do about what I've got so I might as well be happy." We are so happy to have him with us as the rejection fraction was less than 10% when he got his new heart.

One thing my son did was to learn as much about Sarcoidosis as he could. He even could tell the Sarcoidosis specialists a thing or two. It's amazing to me that as long as this disease has been around (1880'S) that it is not widely known. It seems that sarcoidosis sufferers are coming out of the woodwork the last few years. It is a tricky disease on several levels. It can attack any part of the body.

I do hope that NIH will take these stories and run with them. A lot of research needs to be done. It also needs to be put before the public as much as possible. It is as debillating as arthritis, heart disease, diabetes and many other diseases people hear about.

Due to us having to be short with our stories, there's more for me to share, but it'd be a book! So here's a condensed version...

I'm a Sarcoidosis sufferer that has struggled daily with a very painful chronic debilitating disease throughout my entire body. Ever since I can remember, I've had symptoms, but for many years never knew why. Unfortunately, as time went on, the symptoms worsened. I had relinquished my career due to the persistent problems with my illness. Medication couldn't allow me to function, as needed. Years later, after many tests, emergency visits, specialists, and surgeries, I was finally diagnosed, because it finally revealed its true self.

Having years of experience dealing with this disease, we don't seem to receive proper medical care, because the majority of the medical profession doesn't treat it seriously, like the more common diseases. So what is a person like me, to do? There's no cure to ever have a normal life. How would you feel if doctors told you, that you're imagining everything? I have a confirmed diagnosis, but they feel Sarcoidosis doesn't cause these types of complications that I struggle with daily, due to outdated medical publications.

My life is not as fulfilling as I would like it to be, no matter how hard I try. Those of us that have Sarcoidosis are not the only ones that suffer. My family, spouse, and friends also suffer along side of me, since I miss most major life events. Besides, they feel so helpless. It's especially difficult when they don't fully understand this disease or believe it to be serious, because after-all it's not 'officially' critical in other people's eyes - yet!

Until you have a loved one, or personally go through the same that many of us have, you cannot even begin to understand this life-long debilitating disease. There's so much frustration, embarrassment, disappointment, extreme pain, loss of a normal life, and complete suffering due to this disease. Please give Sarcoidosis the same fairness of treatment, research, funding, understanding, and respect that other diseases already have.

Thank you for listening and giving me the opportunity to express my thoughts.

Hi, I heard you are looking for stories about people's experience with Sarcoidosis. In my case, I have been sick since my early 20's but was misdiagnosed as having depression and fibromyalgia for many years. Then in my early 30's I was diagnosed with Sjogren's Syndrome and treated with high dose steroids because I was having neurological issues. The steroids caused massive bone destruction (avascular necrosis) causing me to have bi-lateral hip replacements and a shoulder replacement. I was still told I had Sjogren's Syndrome until finally, when I was about 49, a skin lesion was biopsied and the diagnosis of Saroidosis was made - the Sjogren's diagnosis was then dropped.

I have heart problems that are thought to be from Sarcoidosis. I have bradycardia, which led to a pacemaker being implanted in 2008. My heart is getting worse and now I'm on heart meds. The other Sarcoidosis issues are hand, wrist and elbow arthritis, many skin lesions, a sleep disorder, and possible neuropathy. I also have something going on with my muscles thought to be a seperate autoimmune disorder. Between the Sarcoidosis and avascular necrosis, I take 12 different meds including morphine (my ankles are inoperable). I am in a motorized wheelchair as my muscles will not allow me to walk on crutches or use a regular wheelchair. Due to the heart issues I don't feel as though I have much of a future, but I never give up.

I should mention that I am divorced and my second partner left me when I got "too sick".

Best regards,

Michele

My name is Debra, 58 yr old, white female. I started with a dry hacky cough. My physician treated me with antihistamines first, for GERD next, with no relief from the cough. Chest x-rays suggested further evaluation but none was completed. (I am a nurse at a large teaching facility and saw our doctors) Thankfully it was also time for my yearly gyn checkup. She found swollen lymph nodes and instantly referred me to an ENT specialist. CT of the neck and chest showed swollen lymph nodes in the neck and chest area. I had a pulmonologist, oncologist, surgeon, and ENT all tell me it was lymphoma. Lymph node biopsy of the neck showed Sarcoidosis. Great I have a diagnosis after over a year. PET scan was next and given the diagnosis of Sarcoidosis and stage 3 lymphoma, which resulted in a bone marrow biopsy. Sarcoidosis again was the final diagnosis.

I have Sarcoidosis in my lymph nodes, liver, spleen, lungs, and bones. Prednisone has changed me into someone I no longer recognize when I look at myself in the mirror. With Prednisone and MTX both we are attempting to suppress my immune system (with no good results). I miss my energy the most, 60mg of prednisone daily gave me a "normal" my old self type of energy.

There is no one in the area that specializes in Sarcoidosis and there are many of us here. Drugs we have are double edged drugs. They help and hurt. I now have GERD because of the MTX, fluid retention because of the prednisone, folic acid because of the MTX, ulcers... I could go on and on. Chronic fatigue is not even addressed and the only way I can keep going is to continue "putting one foot in front of the other" I have slept an entire weekend and was still so tired I hated to go to work on Monday. Routinely go to bed by 8:30 if I don't go to sleep on the sofa prior to that.

We (Sarcoidosis patients) are tired of not too many and not too good options for us. We are told it will go into remission; well some on us are chronic. We need more studies, ex Dr Drakes study regarding antibiotics, more involvement or interest with local physician to be involved with studies.

I am a female, a wife, a grandmother, sister, daughter, aunt, cousin, friend, and a nurse. I have Sarcoidosis. Prior to my diagnosis, I had a life that I want back. I am tired of being tired.

Please help us all - Debra

Hi, I am a 42 year old Caucasian male. I am type 2 diabetic, but other than that, until a few years ago, with the exception of occasional allergy problems causing sinus infections, I never had to see doctors except for injuries, broken bones, strained muscles, etc. Then in September of 2008 I started having problems. At first it was just a lot of coughing, sore throat and my chest hurt. My primary care physician thought it was might be bronchitis because I had a sinus infection a few weeks prior to that. He tried treating with antibiotics. Over the next 4 months I got worse, dry coughing was almost constant, my chest was tight and hurt, shortness of breath developed; I stayed fatigued and just felt bad, all the time. My doctor tried a couple of different antibiotics, inhaler, inhaled steroids, even tussionex to stop the cough, nothing worked. Just before Christmas he did another chest x-ray and thought I might be developing some pneumonia so he tried to treat that and said if I didn't get better we might have to see a specialist. I agreed, whatever was wrong with me was interfering with my personal life and my work life. My constant coughing had people staring at me, and this was a time at which the H1N1 Flu was a big worry, so I really got stares and people shying away from me.

I didn't get better over Christmas, so I was referred to a local pulmonologist. He was worried right away. We did all of the testing he could, PFT's blood work, a bronchoscopy (which did show granulomas), cat scans which showed huge nodes in my chest, induced sputum to rule out all bacterial and viral infections and the a mediastinoscopy. So, after 7 months since my symptoms appeared, we finally came to the conclusion that it was pulmonary Sarcoidosis. As you know it's a diagnosis of exclusion. Then we started treatment with 40mg daily of prednisone. That made some of my symptoms better, but brought on its own problems, especially weight gain, messing with my blood sugars so bad I had to go on an insulin pump, and then when we tried to taper my dose to see how I'd react, and apparently did it too quickly, I had such bad effects that my work was affected again.

So, we increased my prednisone back to the original level and my symptoms did get somewhat stable again finally, although chest x-rays, CTs and PFTs showed no improvement, and when we reduced my prednisone again the symptoms started coming back. My pulmonologist was scratching his head and ready to try methotrexate or something else, so in August 2009 I found

out about, and decided to join, the Atorvastatin clinical study with Dr. Joseph Fontana at the NIH.

Now, just over a year later, I have finished the trial, and although testing shows I am actually a little worse than when I started it, I don't feel it was a waste of time, not at all, because I learned so much from the staff at the NIH during the study, and if it helped anyone else it was well worth it. In fact, you can tell Dr. Kiley that the staff in Bethesda was very helpful and knowledgeable and should be commended for their hard work.

I had never heard of Sarcoidosis before I found out I had it, then I found information was hard to find, even for someone that considers himself very "internet savvy", and not very much was really known about it. I know I'm not as bad off as a lot of people out there, but this disease has affected my life, for over 2 years now, I even sold my motorcycle because I found it harder to breathe when I rode it after I got sick. I've ridden all my life so that was hard to do. I want more information, I want more help, I'm so afraid when I go back to see my pulmonologist in a couple of weeks, now that my clinical study is over, he's still going to be scratching his head and not know what else to do with me. I'm afraid that I'm going to get worse. Yet, I'm still doing what I can to help our cause, the study, this letter, and I'll do anything else I can. Dr. Fontana gave me the names of other researchers that I intend to contact to see if there is any other research I can take part in. I'm too young to have to be impaired because of my lungs. Help us. Thank you.

David

I am a 57 white female with pulmonary Sarcoidosis. I was a participant and completed the NIH study on the use of Lipitor instead of prednisone. I was diagnosed with Sarcoid in December 2005. The disease was actually found "by accident". I had an awful cough and allergies. I also got out of breath coming up my driveway to my home and had some other serious issues. No one, however, found the Sarcoid until I fell in a hole and broke 4 ribs and my scapula. After that, I had a sinus infection and the allergist became alarmed when a respiratory test performed in her office showed marked reduction. I was then sent in for a more thorough test in a hospital lab and that demonstrated a serious condition. It still took almost 1 year before I was diagnosed by an open lung biopsy.

Prednisone caused a large number of side effects and actually made me feel sicker than I felt without treatment. During the NIH study, I was taken off prednisone and put on placebo or Lipitor. While on the study, I was tested and evaluated every 4 to 6 weeks. Now, I will be lucky when insurance pays for scans every 3 months. My primary pulmonologist has seen me but I have not received any treatment. His reasoning is that plaguenil and methotrexate cause pretty severe side effects and are largely experimental with unproven track records for treatment. I also, apparently, cannot remain on them indefinitely. Currently, blood tests, including the ACE, show increased inflammation but I appear to be functioning O.K. My doctor feels strongly that I need to show more problems before he puts me on new medication. This is despite the recommendations of the doctor I saw at NIH.

I cannot walk uphill, I sometimes have difficulty concentrating and we are concerned with deterioration in my health. Being told that the treatments available are not proven and might actually make my quality of life worse is very difficult to fathom. It appears that, though I live in a major city - Atlanta, Georgia - I will have to fly to another city for treatment. We can find 33 miners buried under stone from one mile underground but a disease identified in the last century remains a mystery.

Any work done to find a treatment for this disease is past due but greatly appreciated.

Sarcoidosis for me apparently mostly was hereditary my mother died at 46 in January 1967 and reportedly she suffered with it as a teenager. Also it was thought to be tuberculosis and that's what she was treated for initially. I apparently had it as a teen and didn't notice it in high school but I would have pain bilaterally in my shoulders and severe sinus headaches which may or may not be attributed to the Sarcoid. I was always fatigued and slower than my classmates in speed, strength and endurance. My breathing was always shallow and I fatigued way to easily I attributed to being fat and lazy but at the time I was 6'0" and about 185lbs.

As an auto tech I worked with harsh chemicals and the exhaust fan was broken for several years. I'm sure these things weren't any help coupled with smoking marijuana and snorting cocaine. As it turns out the cocaine was an excellent treatment, it arrested the disease however each time I'd refrain from using it the Sarcoid would get exponentially worse.

I received a spinal cord surgery at T11-T12 a ruptured disc with cartilage embedded in the right nerve root at the same level which I walked around with for 6 mos and then the surgery was more of a drive by shooting than a surgery. It was clear on the MRI 2wks after surgery there was a great lump of fusion material protruding into my spinal canal and no one informed me or told me I would never walk again. A Russian neurosurgeon Yakov Koyfman and an Arabian thoracic surgeon performed this surgery at Christiana Hospital in Delaware and didn't use the orthopedic surgeon. Then I found out they don't do the surgery at that hospital. 6mos later a team of doctors at Rothman Institute and Jefferson Hospital redid the surgery and patched me up the best they could I guess by cutting away over half my vertebrae and grafting a piece of bone in from T11 thru T12 to L1 disc and a titanium screw through the bone into the L1 disc. If it's possible I like you to investigate the case I know it's been almost 16yrs I can't sue I'd at least like to know the truth of the matter.

The stress and trauma from surgery coupled with the misalignment of my body and chronic tightening of hamstrings and all the muscles below the knees created optimum conditions for Sarcoidosis to thrive along with constant constipation and dependence on pain killers to this day. I walked with crutches for 11yrs, but when the steroids gave me diabetes and a slip caused a complete rotor cuff tear in my left arm my ability to stand was no

more and I'm reduced to a wheelchair now. I'm in stage 4 for almost 4-6 yrs and after receiving the proper meds and O2 I'm doing about as well as can be expected as long as I don't exert myself. I'm OK it doesn't take little of nothing for me to be winded and both arms are torn up and Sarcoid is in the bone now [Any suggestions would be greatly appreciated] This is my story sad but so very true. I can't let it get me down or make me blue. I believe JESUS is LORD and HE'S brought me through. I still get joy from the few things I can still do. GOD bless each and every one of you.

I have suffered for 7 yrs. It took 2 1/2 months, 3 trips to the ER, and me telling the ER Dr. that I refused to go home and die, they admitted me and called in a specialist. I spent 15 days in the hospital. I have lived on Prednisone since. It has affected my lungs, joints, right side of my face and eye.

I have had to live for the moment because planning is not an option, it is day by day. I have good days, good hours, or good weeks. I was in school, working and had foster children, I can no longer work or go to school because of the roller coaster ride in which I live with. There are so many times I feel isolated, even from my family because I do not feel up to the activity. My family does a lot of hunting and 4 wheeling, means high altitudes. I am no longer able to go because of my lungs and the lack of oxygen at those levels.

I feel that my life has become surrounded by the four walls that make our home. I try to keep up a positive attitude. I do what I can until my body says no more, if I push it (which is small compared to a healthy person) I end up in bed for 3 or 4 days. Traveling is difficult; I am on oxygen at night. I no longer go camping unless without electricity. It's difficult to pack a concentrator around in and out of hotel rooms, and tanks are risky to travel with.

Side effects of Prednisone, besides the weight gain that I have had to deal with is muscle fatigue, sweats, and Thrush,etc. I am tired of listening to Dr's tell me that I need to look at the quality of life over the quantity, I want both. I am a new grandma and would love to be one, not the one that is known as "the sick grandma". I am not sure that they would think the quality of life on Predinsone is that wonderful. - Thanks for your support - Judy

Hello, I am a Certified Nurse Midwife working long arduous hours a few days a week. We providers are not allowed to call in sick unless we truly cannot get through a day. Approx 3 years ago I did just that. It was 2 plus months that I felt terrible. I was exhausted, had pain along my back. I was coughing and had hot and cold sweats. I thought that perhaps I had the flu since it was winter, so I just kept trying to do my job. In the evenings at work I would walk around with hot towel heating pad on my back as it was uncomfortable. I used electric heating pads at home. Then one day in the office, with 3 patients left to see I just slid down the wall and said I needed to go home to rest. I knew I was on the next 48 hour weekend that was just 2 days away. At home I would just lie down anytime I could. I think my family thought I was depressed, I actually thought it as well, as my son was in the Marines and deployed to Iraq, and my mother had passed away the Spring before.

Luckily, I went to see my provider a Nurse- Practitioner. At first we thought it was a virus and depression. She gave me an anti-depressant which I couldn't handle. The side effects made me more tired. During this time I continued to try to work. It was awful. So I went back another time, telling her my temps would come and go the highest being approx. 101 but mostly 100.8, 100.6 etc... The cough continued as well as rib pain on my left lower side. She did an x-ray, and saw diffuse involvement, calling me back the next day for a CAT scan. I was told that I needed to see a thoracic surgeon. Two days later I was walking into the thoracic oncology center. I was told that I had Sarcoidosis, to go home and rest. That was it. So I tried it, it didn't work. I became so weak that I could barely come down the stairs to get my own water. My husband took me back to the DOCs and I was admitted for more testing. 3 days later 3/17/2008, this was after a whole body MRI and a Bronchoscopy where they found Sarcoid nodules. I was placed on Prednisone, 60mg per day to start. Months went by, for the first 2 -3 I just stayed home and rocked on a big ball to try to get rid of the rib pain, which I don't think my Doc thought was related, but I know it was. I was out of work from March till October. We had to add Methotrexate to the regime as my Pulmonologist thought it was in my joints as well. My eyes have been spared.

I came off all meds except for Singulair in May of this year. I have been working full time. I have been coughing a bit lately and my joints are not great. I used to be a runner - running 5K 3 times a week. Now I can't but I am

walking a great deal. I see my Pulmonologist this month and finally will see a Rheumatologist DEC. 30. Another very strange thing happened. When I stopped the meds I got bunions on both feet that are agonizing at times.

The Prednisone made me crazy, and I hope never ever to go on it again. Methotrexate made me lose a day of work, as the day after I took it I was ill, and I had constant mouth sores and tongue discomfort. I truly hope I don't relapse. I am way to active of a person, and need to work 14 more years to finish putting my children through college. I love to Kyack, and hike.

This is my story - we are going to test for Berryliosos as I grew up downwind of a Chemical Plant. I have other auto-immune issues as well. So do many of my siblings.

Thank you, Middie

To Whom It May Concern,

It has been brought to my attention that Sarcoidosis is really not a disease that needs much funding because it doesn't effect that many people, or impact that many lives.

So whomever may read this, I beg to differ. My name is Denise. I had been a professional dancer for the last 25 years of my life. Now I live what is left of it. In 2003, I was a mother of four children, ages at the time, 2 to 13. I taught extremely high levels of tap, jazz, ballet, and hip-hop. I had energy. I took care of my children. I cooked dinner. I did laundry. I kept a clean home. Two of the four oldest were my step children. When I wasn't dancing, or being a mother, I embroidered clothes, or sewed Halloween Costumes, or was the room mother at school, or did volunteer work. I did it all.

In 2003, all hell broke loose. I lost the use of my left arm. They said it was herniated discs in my neck. It felt like I was having a heart attack from the chest pain. I was put on high doses of steroids for the swelling and got steroid injections in my neck and told I may need to have my neck fused. After seeing an alternative Chinese healing doctor for over a month, and being put on large doses of Neurontin, I recovered the use of my left arm, however, I lost my sense of smell. They said I was imagining things.

Then I had extraordinary back pain, out of nowhere. I have never had a bad back. Your getting older they said. Degenerative disc disease they said. The pain extraordinary, I could no longer lay flat or stand for any length of time.

Then I had the random bouts of incontinence. That was fun. Waking up having soiled the bed or calling my husband to bring me a change of clothes because I had urinated on myself. At the ripe old age of 35. So they gave me pills for an over active bladder.

I had excruciating knee and hip pain. No findings for it on any film studies. Now the Doctors were starting to think that I was a hypochondriac. I was sent to a rheumatologist who told me I had Ehlers Danlos Syndrome.

My husband decided I had become a burden to him. Too much time at doctors, too much money on prescriptions, and on tests only to get no results. I filed for divorce.

Then the unthinkable happened. My step son raped my daughter. He raped and sodomized my ten year old little girl, and molested my five year old little girl. And to top it all off I found out I was pregnant.

I went through the joys of a divorce, a criminal trial against a child I raised, and a pregnancy alone. My former step son eventually pled guilty. My ex screwed me over royally on the divorce because there are only so many wars one person can wage, and I had a baby girl.

Three months after the birth of that little girl, I broke out with huge hard purpley pink nodules on the front of my shins. Again, I was accused of being a hypochondriac and told I had a rash and to put calamine lotion on it. I went anyway. My general practitioner only knew that it "looked auto immune"

I went to the rheumatologist who instantly recognized the bumps as erythema nodosum and said "you don't normally get that unless you have Sarcoidosis, have you had a chest x-ray?" I said no, and for the first time since 2003, I think someone actually started to have a clue.

I had Sarcoidosis. That was when my youngest daughter was 3 months old. I could bore you with all the further details about how even knowing that I had Sarcoidosis, my pulmonologist told me I needed to see a psychiatrist when I was throwing up food for 6 months and lost 70 lbs, or how since my initial diagnosis, it has taken three and a half years to get the diagnosis of neurosarcoidosis, because, for some reason, your profession just isn't that interested in those of us that are trying to survive this disease.

However, I want you to know what life is like now. I spend full days asleep from the exhaustion. I simply have nothing left. My body is too busy waging war with itself. In order to spend time with me now, my daughter comes to see me in bed. That is the one that was two when this started. She is ten. My youngest has never known a time when her mother was healthy. I no longer cook. I no longer clean. I'm not room mom anymore. I no longer dance. My former step daughter dropped out of school to come home to care for me, and her younger siblings.

If I had cancer, there would be a world of resources out there available to help. But I don't. I have a nameless faceless disease that nobody has ever heard of, except perhaps on "House" but even then, just by name.

Perhaps if you are reading this, you might be able to tell me, who will care for my daughters if I die, seeing as they can not go to their father, since he has custody of the child that raped them?

And if Sarcoidosis effects so few people, I think that all the kids that I have taught over the years would beg to differ. At forty, I succumbed to this disease, and gave up teaching. In the 25 years I did teach and dance, I taught literally thousands of kids through adults, and I have hundreds of letters about how I have changed peoples' lives. Imagine the lives I could still be changing.

Who inspired you to be who you are today, what if they died before they ever had the chance to be that inspiration for you? What exactly is the number of people that need to suffer for suffering to become intolerable?

Thank you for your time, it is something I don't take for granted anymore.

Sincerely - Denise

My name is Steve; I am 59 years old and have Sarcoid about thirty years that I know of. I will make this as brief as I can due to the time constraints.

I used to be in the entertainment industry as a technician, working for major entertainers on a worldwide format. Some of the entertainers are Neil Diamond, Madonna, Earth Wind and Fire, Huey Lewis and the News, Pink Floyd, David Bowie and Elvin Bishop to mention a few. I started out as “A hippy in the crowd” and ended my career as “Head Carpenter” for Neil Diamond. During that time I was able to do everything short of playing musical instruments. I was very fortunate to be able to tour with those aforementioned performers, but had to quit in 1997 due to not being able to breathe good enough to do the often very strenuous work.

Thank you for your interest in this disorder. - Steve

I was diagnosed with lung Sarcoidosis in the late 1980's by a lung biopsy after my internist told me my chest x-rays looked like lung cancer. I have never had elevated ACE levels. I thought the Sarcoidosis had gone away when follow-up chest x-rays showed clear and just some minor scarring by 1989. Then in July 1994 I had a small blood vessel stroke that the neurologist thought was probably caused by neuro sarcoid, but after a year of anti seizure medication I was almost back to normal. Then in 1996 I began having shortness of breath again but the cardiologist said it was lungs and the pulmonologist said it must be heart because lungs appeared clear! Then I had nosebleeds that wouldn't stop and ended up at an ENT who operated and found Sarcoid tissue in the nasal tumor as well in the sinus tissue he removed. I've since had a 2nd sinus surgery that found more Sarcoid tissue. Since 1997 I have had eye involvement, off & on gallium scans showing active Sarcoid in my lungs, right bundle branch blockage. Currently I have pulmonary hypertension that is being treated with adcirca and high blood pressure that's being treated with 3 different medications as well as water retention that's being treated with a mild diuretic. The last right heart cath showed only mild pulmonary hypertension until 1 cycle on the bike when it tripled, so new cardiologist now says keep blood pressure top # under 120 which is difficult while trying not to go below 70 on the bottom # --- at 62 I'm not too bad for the shape I'm in! -

Jim

My Sarcoidosis Story

I was always an active, relatively healthy woman. I was married, had four children, worked full time and found time to clean, cook, sew Halloween costumes, be a homeroom mother, help in the classroom, care for pets, go to my kid's activities and play with my children.

My symptoms began in 1994. I was fatigued, felt generally unwell, always tired, had asthma problems, frequent cough and also the mother of four children. Although I did consult the doctor, they did not find a problem. They attributed it to getting older (I was 34).

Over the next few years, I was able to continue my life; I just had to slow down and worked part time. By 1999 I went back to work fulltime. I was working hard to take care of myself, sleep enough, eat well and exercise.

At the beginning of 2000, I slid on ice, twisted and broke my leg. The doctor said it was an odd break; people don't usually break their leg walking and just slipping without falling. I had broken both bones in my lower leg. They couldn't explain why my leg broke, just a freak accident. Research has proven that Sarcoidosis can cause bone weakness.

From the time I broke my leg my symptoms became worse. Constant total exhaustion started. I was diagnosed with carpal tunnel syndrome and trigger finger for which I had repair surgery on both wrists and 6 fingers. Also sleep apnea, narcolepsy, GERD, frozen shoulders with 4 cortisone shots in each shoulder, arthritis in my knees and neck were diagnosed. Depression for the first time in my life, the doctor said maybe from the Sarcoidosis, itself, or just from trying to live with it. My husband turned to gambling and drinking. How do I continue to care for my family myself?

In 2003 after my daughter's third open heart surgery she received a wish from "Make a Wish". Her wish was to go to Hawaii and meet her Uncle. When we returned from Hawaii, I got much worse. I started developing new lumps on my hands, than arms, than legs. I consulted several doctors who could find no problem. The pain in my bones and muscles dramatically increased at this time. I was referred to a Dermatologist. This caring doctor told me that I was probably going out back and banging myself against a tree. This is where I thought I was crazy. My family didn't believe me, the doctors didn't believe

me. I wondered if you know you are crazy when you are. At a loss my primary physician sent me to another dermatologist for a biopsy of one of the bumps. When the results for the biopsy were in, I called the doctor for the results. Fortunately he was on vacation. I called the lab and was told that the lab report indicated properties of Sarcoidosis. So, I am not crazy? I made an appointment with my doctor when he returned from vacation. This educated man told me that I did not have Sarcoidosis; if I did it would have said that in the report. I was devastated. I searched everywhere for help. After tons of praying, I finally found a phone number for a Sarcoidosis specialist. I called the office just to find out if it were possible that I had this disease. The nurse made an appointment for me and said that I would have to be evaluated by the doctor, but yes, of course I could based on my symptoms and the biopsy.

Finally I was diagnosed with Sarcoidosis. I was started on Methotrexate and was sick every week for 3 or 4 days after taking it, however my lungs got some better. The horrible fatigue, exhaustion, pain and brain fog got worse. I was sent to a rheumatologist to be evaluated for fibromyalgia or another condition. He said that he didn't believe I had fibromyalgia or the pain that I claimed, it was in my head. Again, I thought maybe I just can't deal with being this sick. On my next visit to my Sarcoid specialist, he advised me that it was not in my head. It is a known symptom with Sarcoidosis and referred me to a new rheumatologist.

In 2005 I had used all my FMLA and was fired from my job. I applied for Social Security Disability, but was repeatedly denied because Sarcoidosis is not a debilitating disease and does not prevent a person from being able to be employed. By now I could not walk up stairs, I could only walk about 5 feet before I had to stop and rest. My leg muscles froze up on me. My arms ached even to wash my hair. Hypertension, hypothyroidism, chronic fatigue and high liver enzymes were diagnosed.

Currently I have Sarcoidosis in my lungs, muscles, lymph nodes and skin that we know of.

It is very telling when someone wishes they had a different known fatal disease so they could be helped.

In early 2007 I had two instances where I couldn't breathe and ended up in the ER. They did chest x-rays and blood work but found nothing and sent me on my way both times. They recommended I have some GI testing thinking I might have something going on with my esophagus or stomach. I had an upper GI and they determined I had "a little reflux". I couldn't imagine reflux causing me not to be able to breathe and to be in the pain I was in but I accepted that diagnosis and really I didn't have further problems for another year.

Then in early 2008 I started itching on my scalp. I went to the doctor and got the usual short course of steroids but as soon as I got off of them it came back. Then the itching spread all over my body. I was miserable and have never had itching like that in my life. I saw dermatologists, allergist, had visits to urgent care and nothing helped. The allergist tried tons of different antihistamines and at one time had me on 17 pills a day. I can't remember the names of all of them but I was completely over-medicated. The other symptom I had at that time was a swollen left elbow. It was hot and painful in the joint but I had recently taken kick-boxing classes so the doctor thought it had something to do with that so he didn't pay much attention to it. Out of frustration he sent me to the medical school here in Dallas. I waited 4 months to get an appointment and this idiot doctor came in and didn't do an exam. He said, "Well it doesn't matter what's causing this. You just have a case of chronic hives and it will be with you for awhile". He told me get some zyrtec and he sent me on my way.

I've had hives in the past and this was nothing like hives. It was so severe and at times would whelp up like hives but that was rare. Mostly it just looked like a faint rash with little red bumps. So I took the zyrtec (4-5 per day) and it helped but I couldn't imagine that it was hives. The zyrtec would wear off quickly and I would itch so bad I couldn't do anything. I stopped working and couldn't sleep at night. I scratched so hard the skin broke open and I developed these horrible looking sores that wouldn't heal. But everytime I went to a doctor they would just tell me to stop scratching and let the sores heal. Looking back, I realize how condescending that was and I'm really changing my opinion of a lot of doctors out there. Anyway, the itching continued throughout 2008 and 2009, and in late 2008 my doctor put me back on prednisone long term. I went back to work and could function but gained 45 pounds!!! Then when I was tapered off the prednisone the itching came right back.

In 2009 I began to swell and other joints became inflamed and sore so I knew the elbow problem was not from the kick-boxing. My lower legs, ankles, feet, arms and hands were swollen. That's when I saw my first rheumatologist who took x-rays, did blood work for lupus and RA. Everything came back normal. Even the x-rays but on exam she could see that my joints were inflamed and I was swollen. So she put me on methotrexate and plaquenil. They helped but I started getting really concerned that I was on these powerful medications yet I didn't know why. It's like no one was digging to find out what was going on so I knew I had to do it myself. That's when I changed to rheumatologist number 2, who did the same blood work and x-rays. Again everything came back negative. I was still itching and swollen and sore but still had no answers. Then I started having shortness of breath so rheumatologist #2 did an ACE test and sent me to a pulmonary specialist who did a CT of my chest and pulmonary function tests. The ACE came back slightly high. The PFTs were normal but my CT showed granulomas that the pulmonologist felt like they were not Sarcoidosis but were healed over from an old case of histoplasmosis that I never knew I had! He made that diagnosis based on the fact that I grew up in East Texas where histoplasmosis is common and said that it's most likely that I didn't even know when I had it or possibly that I thought it was the flu.

So this is late 2009 and I still have the itching, pain/swelling in my joints, swollen legs/feet, difficulty breathing, an abnormal CT of my chest and an elevated ACE. Despite all of that I was still on no medication except the zyrtec, up to 3 per day. Then I began having swollen lymph glands in my neck and weird pains in my abdomen and groin. I also had a knot in the back of my neck that is hard and sore. Rheumatologist #2 ordered a CT of my neck and sent me to an ENT. The ENT didn't want to biopsy because the knot in my neck was on a muscle and he felt it would be difficult to reach and he didn't feel it was large enough to worry about. He did do a salivary gland biopsy to rule out Sjogren's Syndrome. That biopsy came back negative. The CT of my neck showed enlarged lymph nodes (duh!) possibly due to an "autoimmune phenomenon".

I wasn't getting anywhere close to a diagnosis so out of frustration I started over with a new primary doctor. I started having a lot of pain in my lymph glands and along with that I was having tingling in the left side of my face along with ringing in my left ear. She was really concerned over this so she sent me to ENT #2. He immediately sent me to a neurologist who had success

diagnosing and treating autoimmune diseases and because of the tingling in my face and ringing in my ear he felt it might be neurological.

This was my big break because the neurologist tested my reflexes and told me I had peripheral neuropathy. I had lost feeling in my lower legs in some places and my reflexes were bad. He did an EMG and nerve biopsy and it showed small fiber peripheral neuropathy. At that point he began to test me for all the diseases that can cause peripheral neuropathy and the only one that came back abnormal was the ACE test for Sarcoidosis. He also ordered an MRI of my brain to rule out MS and it showed white matter lesions which can be the result of neurosarcoidosis. Peripheral neuropathy can also cause extreme itching which was one of my first symptoms.

Anyway, that's how I was finally diagnosed. To date no one has actually seen or verified that I have granulomas but all of my symptoms along with the elevated ACE can only be Sarcoidosis. I think the granulomas in my lungs are really Sarcoid granulomas, misdiagnosed as "old histoplasmosis".

But he believes that my difficulty breathing could also be a result of the small fiber neuropathy. It affects the autonomic nervous system which controls heartbeat and breathing. I have irregular heartbeats and have just recently been through a battery of cardiac testing. I don't know those results yet.

I'm classic neurosarcoidosis and it took a neurologist to figure it out. But if any of the doctors I had seen had done a simple reflex test where they tap on your legs, they would have discovered the neuropathy long ago. It's so frustrating.

I was diagnosed last month so I'm still not on any treatment. I'm seeing rheumatologist #3 and she's ready to start me on prednisone. I'm going to try to talk her into something else because I don't want to gain more weight but she said it would be low dose and if I start feeling better I'll probably become more active. All along I've been fatigued and depressed. Hasn't had a life in three years. Family and friends look at me like I'm a hypochondriac and make comments like I'm just stressed out so it's been a real challenge.

This is such a frustrating disease. What I've learned is that you have to keep pushing for answers and eventually you'll get them. I didn't mention all the doctors I've seen but at last count there were 16. I just wasn't going to accept the fact that there wasn't a cause of these symptoms.

How Sarcoid has affected me.

I was officially diagnosed with Sarcoidosis in 1999, but I believe it has been with me since 1978. Severe migraines and sinusitis made my last two years at school difficult. I chose to do an agricultural college course, throughout which I had horrendous sinus problems. When the sinuses were finally attended to in 1980, the doctor said he never saw so much pus, blood and mucous come out of a person's head.

In 1981, I still had headache problems and left-sided facial numbness. I lost my first job as a racehorse strapper because the boss didn't think I was strong enough for the work. I had menstrual problems, pain on defecation and micturition, but also during the acts of standing and/or sitting. My job was very physical, and therefore a sheer hell. No doctor took my symptoms seriously, as I was so young. The doctors believed my problems were psychological and would go away when some stressor was removed. At one point, I found myself in group therapy for agoraphobia. However, these agoraphobics were truly afraid of trains and shopping centres. I was merely afraid of my symptoms, fearing I had a brain problem. I was finally diagnosed with a pituitary adenoma and also severe endometriosis late in 1981. I believe this was the actual beginning of the Sarcoid. Thankfully, my tenured position had ended by the time I was having side-effects from the drugs they gave me for the adenoma (Parlodel) and the endometriosis (Danocrine). These drugs made me nauseated and dizzy; and the Danocrine gave me severe leg cramps at night. I had been a problem for my parents, so I made a painful decision never to get involved with men, marry or have children, so as to make my life simpler, and not to be too great a burden to others. I don't know if this was a self-fulfilling prophesy or premonition that ill health might return once the current problems were "cured".

One proviso of my second job had been that I complete a technical college certificate in a science-based area. I chose pathology. Despite my continuing problems, I completed this course. My father was severely ill with lymphoma, so my complaints went on the back-burner. The facial numbness disappeared, the endometriosis got better, but I was still plagued with severe headaches. I found a job at a scientific research institute. I could cope with the physical work with sheep. I also worked with lab animals. Nevertheless, when I was moved to a building to work with fruit fly, I had difficulty coping

with the amount of ether in the atmosphere and air conditioning system. The high concentration of ether in the air had me choking on my lunch. I developed a severe heaviness on the chest and began coughing up blood. Although I tried to hide it, word got to my boss and I was given the push.

Eventually, I found my first job in a pathology lab. I still had headache problems and sinusitis. While at the lab, my boss discovered I had an underactive thyroid (idiopathic) and the girls in microbiology found I had abnormal numbers of red cells in my urine – something which continues to this day. As Kidney function was normal no biopsy was performed though the cells came from the kidney. My sinus attacks became so severe I often had to have prednisone to get rid of them. I took up Scottish Country Dancing while working here which is a vigorous cross between highland and square dancing. Soon I was dancing twice a week and eventually got to a stage where I could dance between 2 to 6 nights a week. I was hoping to become an RSDCS teacher. I was very fit, but still had headaches. I moved to a couple of different pathology labs. At my third lab, my health began to decline more. I started catching every virus that went through the lab. I started getting rashes and my “strange” attacks were difficult to explain but shortlived. I suspected I had lupus but tests proved otherwise. I got a lot of gastric and vomiting attacks at this lab and, eventually I was given the push again. I suspected that I had an autoimmune disease so I decided to go to university in order to train out of my current work arena, and also get my health under control.

During my first year at university my health began to take a further nose dive. I had pneumonia during first semester. I was still dancing, but less often, as it had become difficult and painful. I looked at my fellow dancers, many of whom were retired and wondered why dancing, which I loved, had suddenly becoming a difficult chore. I thought age was catching up with me. I looked at older and fatter people and wondered why I didn't have the same freedom of movement. I had difficulty getting up and down stairs now.

During my second year at university, the facial numbness of my late youth returned and was accompanied by swelling. I began having trouble with my eyes. The ophthalmologist found I had one dry eye and the other only just in normal range. Both eyes now have no tear film. I was tested for SS but was negative. I was sent to a specialist who found I had a raised sed rate and CRP but negative for all the major autoimmunes. My BP was raised, I had a nose

bleed during an exam and troubled by night sweats. I ran a slight fever and began eating less. Just getting about campus was exhausting and I had at 30 mile drive home. I had pleurisy and two attacks of bronchitis neither of which I had ever had before. Dancing was now beyond me. I was having difficulty going through just one 32 bar section with shortness of breath let alone a full round. I never had any shortness of breath, even when I first started dancing. I began getting rib pain and tightness in the chest. The facial numbness and swelling continued.

I did well at university despite all this, but my supervisor wanted me to do honours over two years because she didn't believe I was strong enough to manage it full time. I often coughed all through her seminars. People who see you daily, see far more than specialists you see for ten minutes once every six months. In any case, with my pathology background a great uni doctor was prepared to supply me copies of all results and specialists' letters. It was me and not the doctors who put the pieces together and came up with sarcoidosis. I was officially diagnosed with sarcoid after a mediastinoscopy. I was sent to a chest doctor who did it knowing my full history but believed I would be free of sarcoid within two years.

At the two year mark, he sent me on my way, and I have never seen a chest doctor since. I took only NSAIDs for three years. The doctors didn't believe I required treating. But my mobility was not great and I had difficulty getting one leg off the ground. A steroid injection fixed this and made me feel considerably better. So I went looking for a doctor who would treat the sarcoid with something other than NSAIDs. I was put on 5mg of prednisone and 40mg of Plaquenil which induced a short but welcome remission I won a scholarship to do a PhD and went overseas for three months researching. Within days of my return home, the glands came up round my neck, under arms and in my groin. I had drenching night sweats, and had to shower, wash hair and change bed and night clothes in the middle of the night for a few weeks. Finally the facial problem was also diagnosed as a manifestation of sarcoid. I graduated with a PhD eventually, thanks to prednisone.

I have not had my blood reports completely normal now since 2006. The drugs cannot keep the disease in control anymore. Shopping, making beds and gardening have become difficult chores. I need seats or chairs handy when I do any of these things. I haven't seen a lung doctor since 2002, but CTs

and lung functions show Sarcoidosis is still an issue, even though it was supposed to be “gone” in 2002. Biopsies show I have sarcoid in both thighs and in lesions on my knee. Things that took me a couple of hours to do a few years ago now take me days. I have been painting the garage for over a year now. I was never led to believe, I would have difficulty doing everyday tasks. After graduating, I tried to find work but all the travel and timeframes made looking for work more difficult than working - so eventually I had to apply for disability, feeling a complete failure. Australia’s Centrelink suggested I do and my doctors supported me in the application which was granted. However, even in Australia not all Sarcoid sufferers are approved. Doctors here know less than their US counterparts.

Denise from Sydney Australia

My name is Dustin and this is my Sarcoidosis Story.

In June of 2009 a chest x-ray revealed abnormalities in my lungs, at the same time my wife and I learned that we were pregnant. A follow up x-ray in December indicated that the abnormality was spreading. In February of 2010 I had a lung biopsy and was diagnosed with Sarcoidosis. On March 11th my son was born.

Over the past couple of months I have been trying to learn as much as I can about Sarcoidosis. What continually amazes me is not only the lack of information about the disease but also that much of the information that is available is contradicted around each turn. Is it an auto immune disease? Is it a lung disease? Is it a manageable disease? The answer to all of these questions is - it depends.

I am not willing to tell my son that this disease will get the best of me. While I function as I did before I knew that I had the disease I am terrified by the fact that the disease could become progressive and destroy my body before I have a chance to teach my boy to play ball. I am not a pessimist but it's hard to focus on the positive when there are more questions than answers. I'm turning into a hypochondriac as I pray that the disease doesn't present itself in other parts of my body. I just keep my head high and continually submit myself to more medical testing. Then I pray to God that I will have quality time with my family for as long as possible. I want to be one of the people who go into spontaneous remission but with Stage 4 lung involvement it is unlikely.

The disease progresses (and regresses) on a different path for everyone who has it. Even the doctors who treat us are often perplexed by Sarcoidosis and the best way to treat it. Ironically it is not as uncommon as you may think, in spite of the fact that very few people have ever heard of it. Significant developments in the treatment of Sarcoidosis seem rare. Funding is thin and the work load is enormous but Sarcoidosis is not going away on its own and we need to start putting more resources towards understanding it and reducing the impact it has on us.

These stories are only a small sample of how people have been affected by Sarcoidosis. We are requesting more funding and more research for the understanding, treatment and potential cures for Sarcoidosis.

Regards,

The Sarcies

E-mail:

sarcoidosisstories@gmail.com