

Date: July 9, 2015

Hello, my name is Rhonda, and my husband Bret was diagnosed with Scleroderma in October of 2014. I am 42 and Bret is 52 and we have two teenage girls, 13 & 15 years old. I am sharing our story to hopefully give some information and support to other caregivers as this is not an easy thing to deal with for anyone.

I was not ready for the diagnosis or lack of information that day in October last year. Bret and I were told "it is an autoimmune disease that causes an overproduction of collagen and you should read up on it". I was expecting an antibiotic or similar quick treatment to take care of the abnormal swelling in my husband's hands, not the diagnosis of a very serious disease that we needed to research! I now understand that Scleroderma is incredibly rare and there are not a lot of resources available for patients or caregivers. I do wish our Rheumatologist was able to give us research material or had recommend good sources for it. He did refer us to the University of Michigan right away who has a renowned program for this disease. It was exactly where we needed to be, but the days between Bret's diagnosis and meeting with our new doctor were brutal.

There is a lot of information on the internet that I read that I wish I had avoided. I personally know of Stage IV cancer patients who have been treated and currently have no signs of cancer - that is what I kept looking for! Who has got the best treatment and possible cure? I bought books, a new laptop (as my iPad didn't navigate well enough for me...), and I took a crazy amount of notes. After work every day I would watch videos and research the disease needlessly. I could have accomplished most of what I was looking for by going to the website www.scleroderma.org (the Scleroderma Foundation) or the University of Michigan Scleroderma Program website - www.med.umich.edu/scleroderma. In hindsight, I think that time spent researching was how I was processing the diagnosis - I concentrated on that until I could process it fully. I would definitely recommend skipping the internet surfing on this disease and focus on the information on these two websites.

Bret and I are both independent people with full-time professional careers. When it comes to paperwork or logistics at home however, that is my domain. Bret knew I was researching this illness and he did not. He left the decisions of treatments, doctors, clinical trial or no trial, etc. to me. I felt so underqualified to make these decisions and was researching like crazy until we met Dr. Khanna. Once I knew we were in the right place for his care, I was able to start concentrating on how Bret felt.

We visited Dr. Khanna at the University of Michigan for the first time on December 5, 2014. I'm sure he thought I was nuts. I didn't know who he was as I was too intent on researching the disease and not the lead researchers in the development of a cure. Hindsight is 20/20 right? He didn't give us a long term view of the disease which I desperately wanted. I had chosen not to share the "fatality" statistics or most of the other information I had read with Bret before our visit as I was sure that this would be covered by a professional if it were true. I left our first visit with Dr. Khanna feeling confident that he knew this disease better than most and that he was committed and kind. I learned quickly that he really KNEW this disease and was committed to

helping his patients more than I could ever imagine. I still wondered what this diagnosis meant though. How will our lives change? What can I do to help or change this? What do I do??

Why I thought there would be answers for something like this, I'll never know. Everyone is different and there are no real answers to the questions which is so frustrating for my Type-A personality.

I notified Bret's family and friends shortly after the diagnosis. I didn't want him to have to tell everyone and "minimize" this disease or to have to verbalize the "scary" parts. I still keep them updated so they can help him along the way. I've told them to let me know if I am missing anything. Bret will not tell me if I can do something better or if am missing something although he will tell his siblings and friends. I wanted them to feel comfortable coming to me with this information. I understand that Bret loves me and doesn't want to ask me to do something better as he really doesn't want me to have to do anything in the first place.

I try to be as supportive of my husband as possible while his body continues to change. He is unable to do things that before he did without thinking. I try to open bottles first before putting them in the refrigerator, set out his meds so he doesn't fight with the bottle tops, and remind him to take his blood pressure. What I don't do is pressure him to do the physical therapy exercises or other exercise in general. I believe that has to come from him. I offer the paraffin treatments occasionally if it's been awhile. I realize that this is UNCOMFORTABLE for my spouse and he is in control - not me. I am the helper and secretary who will track and notice irregularities, suggest improvements, make sure he remembers his appointments, etc. I cannot dwell on what he "needs" to do - I need to help him have fun our children, myself, and whatever else comes along.

I would recommend more than anything that you learn your insurance plan and print it ALL. You will need all the info at different times but it is best to read through it all in the beginning to get an overview. Put it in a binder for easy reference. It is not the responsibility of our doctors to know our plan and the associated costs. We want them to be researching and treating patients, not navigating the insurance systems. I would also recommend that you (your spouse) join whatever clinical trials you feel comfortable with. Information is a powerful thing and these trials will help our loved ones and others suffering with this disease.

This is a life-changing event I believe can either spotlight the important moments or completely cloud your days depending on your outlook. I personally have both days but try to spotlight good moments more than clouding my days. I have developed better "happy" habits and our family actually is closer than before. I feel that we have so much technology and science at our fingertips - the right people can and will find a cure. Until then, I try to remember that our loved ones are fighting all day every day against this disease taking over their bodies and the meds they are taking to fight it. When I'm remembering this, I find strength I didn't have before. Bret is the easiest going guy I know and is handling this like a champ, but he still struggles as times. I'm here for him and will continue praying for a cure for all of us.

I wish you all the best in your journey!

Sincerely,

Rhonda