Helpful Multiple Sclerosis Resources

by LIBBY SELINSKY

Reading Through Your MS

Are you newly diagnosed? I remember that when I started feeling sick, and once I was diagnosed I read everything that came my way. I read every article, no matter how obscure or unreliable. I looked for every website that spoke about MS. I even scoured the government clinical trial database. Yes, there really is a government database for clinical trials. Every (real and credible) clinical trial in the United States for every disease is registered in the clinical trial database. Just type in your disease of choice and you will find every clinical trial in the country.

Go ahead, read away. Devour information at will. Reading up can do wonders for feeling some semblance of control over this disease. I am one who believes that information is power, as long as it is credible. And that brings me to my first point. The flood of information, while useful, can be damaging if not looked at with a discerning eye.

We all know that there is loads of misinformation out there and when we are sick we can become more vulnerable to its lure. It can be easy to decide, for instance, that you don't want to take the traditional meds because articles A, B and C said they have 'dangerous' side effects. Or you might say, 'This website has loads of people who have been taking this other drug and scrapped their injections with no problems – I should too!"

I have to admit. I was this person. For the first year and a half after diagnosis, I took Low Dose Naltrexone instead of the Rebif that my neurologist had prescribed. I had believed – because I wanted to and without any scientific evidence – that this would be better for me than the Rebif. Fortunately, my husband asked me to promise that I would start taking the Rebif if the LDN did not work.

A year and a half passed and I felt like I had beat the system. Soon though, time ran out and I had another relapse in the fall of 2008. I tried a clinical trial as soon as possible, ever afraid of those pesky injections. The clinical trial did not work out, and in February of 2009 I took my first injection of Rebif. It had a drudgery of side effects but it worked. If I could go back in time, I would have started the Rebif in the beginning, but I was in denial and I used baseless claims by people, anecdotal evidence, to fit the information that I wanted. Now I base all of my decisions on science and long discussions with my family and doctors.

Clinical Trial Database

This brings me back to the government clinical trial database. If you are looking for an answer that goes beyond the basics, if you are a person who wants to try something new for your disease, or if you just want to read up on what we have in the pipeline about up and coming treatments, the clinical trial database is a great place to start. Look around – you will like what you see. The knowledge and treatments for MS have been progressing very quickly. This is a real time resource.

MSIF

The knowledge of MS moves so quickly that I have found myself almost completely searching online for information. Another favorite site of mine is MSIF.org. This is an incredible resource for finding out what is going on in the scientific community in the United States and beyond.

It is easy to get locked into looking only within the US for information, but there are so many interesting aspects of our disease that are being worked on around the globe. MSIF tends to be a rich resource. They have great newsletters that keep you up to date on recent clinical trials, international meetings and discoveries.

Next page: three more MS resources.

MS Society

The MS Society is great for finding local resources and events. They will send newsletters on clinical trials and such, but I find that MSIF does better in that arena. I believe the MS society is great for connecting you with people, doctors, facilities and fundraisers. It is great to take part in funding research and to be in touch with people nearby. They will be able to give you a first hand perspective on their doctor and the local resources.

For example, The Cleveland Clinic is one of the best hospitals in the country, but their Mellon Center for MS is in an old, run down building. When I was sitting in the waiting room, which consisted of 30 chairs in an open, dark hallway with plastic sheeting mysteriously hanging everywhere, I was left feeling like I was just another head of cattle. Add that to the fact that you will only be seen by one of their neurologists on your initial visit or when you have disease progression – the following regular appointments are just a visit with the staff RN – and suddenly the national awards and ratings don’t seem to matter as much.

It is good to know the reality of the neurologist visit and there is no better way to know that than from someone who has been there. Networking is key and the MS Society is great for that. On a side note, I used to live in Seattle and the Swedish Medical Center is great. Dr. Repovic provided me with the best care I have ever had; I thrived under his care.

Forums

Forums like this one, MS New Life Outlook, are another great source of information. I was initially drawn to New Life Outlook because this site is great at looking at MS from a more human perspective. I swear, if I have to read another article about how someone has lost the ability to do everything they love but is "still happy" I am going to lose my mind.

Nothing annoys me more than reading about how people are battling this disease but they are "just fine" and "never looked back". The old, "I was upset at first but I didn’t want to let MS get me down, so I got over it." That is a total line of you know what, and it sounds trite to all of us real people, who realize that this is a disease that taunts you on a regular basis and getting upset about it from time to time is a natural and healthy reaction.

This site is great because people like me have the chance to put a real spin on this disease without projecting onto you the need to suck it up and act all pollyanna. Reality is important in every situation. Multiple sclerosis is a disease that can really bend your entire reality, so I find it particularly necessary to remain real at all costs while swimming in its wake.

Whatever Makes You Happy

Finally, the best multiple sclerosis resources are whatever makes you happy. I hop from one thing to another for information and coping mechanisms. Through the years, I have realized that there is information all around that can help us carve out a better experience within our new parameters.

I regularly read books on clean living and yoga. I do this because, for me, eating healthy makes me feel better and practicing yoga adds to that experience. Tiffany Cruikshank is my favorite yoga instructor on yogaglo.com and her book “Optimal Health for a Vibrant Life” was wonderful for getting me started on my path towards health and wellness. Yes, I am one of those clean eating, exercise addicts, but that is what floats my boat and makes me feel good.

Find the things that make you feel centered and good in life. There are plenty of resources out there to binge on!