

The MS Support Group at VAMC lives on

Having multiple sclerosis is, at times, still a stranger to me. I was diagnosed on Aug. 1, 2008, at Portsmouth Naval Medical Center, Virginia, while serving on active duty as the Public Affairs Officer of the Navy Expeditionary Logistics Support Group in Williamsburg, Va. For awhile I just sat and waited, convinced that my vision would correct itself just as suddenly as it had diminished. One year later, I'm still waiting – but I'm no longer sitting around.

I've learned so much since then, both about the disease and myself. Things that resonate with me include:

- After the shock and denial, after I finally acknowledged this new beast, I realize that knowing this foe is better than not knowing. As a friend once said, 20 percent of life is what happens to us; 80 percent is how we handle it.
- The more I learn about MS, the more empowered I become.
- MS is one of the best-researched, yet most confounding diseases of our time.
- It could be worse.
- I'm not alone
- I still don't know what I don't know.

When Dr. Olaf Stuve, the VAMC neurologist to many of us, called to ask me if I'd consider co-chairing the MS Support Group, I knew this was my chance to give back to all of you – you who walked this path before me and who paved the way for research and recognition of this trying condition.

Dr. Stuve was clearly saddened by the loss of Bill Clifford, the well-known, gregarious “MSer” (as Bill described us) who ran the support group for so many years. No doubt about it, his are big shoes to fill. Which is why three of us have signed on to continue Bill's good work.

Joining me are Karl Jones, who was diagnosed with MS, and Pat Sykes, who cares for her husband and three children – all stricken with MS.

In case you don't already know them, here's a brief introduction:

Karl: *My name is Karl Jones. I served my country in the USAF from 1986 - 1994. My foreign service was spent in Frankfurt, Germany, for two years. The balance of my time was in Austin, Texas at Bergstrom AFB.*

I have been married nearly 12 years with a son who is nine and a daughter who is seven.

A diagnosis of MS came in early 2007 after symptoms appeared in the fall of 2006. My hobbies before my MS diagnosis were saltwater fishing, running, strength training, swimming, biking, reading, playing poker and doing things with the family. My hobbies have not changed. I just am not able to do some of them on the level I used to.

Much of my time from the moment of the diagnosis was spent reading up and learning as much as is known about MS.

I am happy to be a part of this support group and look forward to exchanging information and words of encouragement with you all. Let's make our support group the best it can be through active participation.

TEAM: Together Everyone Achieves More.

***Pat:** Multiple Sclerosis is not hereditary or so we thought. It was with shock and disbelief that at age 29 our son was diagnosed with the same disease that caused his father, Ron, to retire so young. Jonathan, our newly married son, graduated from college in June and in October doctors confirmed what we feared. Rather than a pinched nerve and double vision caused by severe pain, MS reared its ugly head.*

Two short years later our daughter, Stacy, felt numbness travel from her foot to her shoulder blades. Surely not! It isn't possible! Within days the diagnosis confirmed MS. How could this be?

Both children grew up admiring their dad for the way he never gives up. As changes happen, new ways to handle them always follow. Twenty-seven years ago there were no drugs to help "interfere" with the progression of the disease. Exacerbations ran their course. Disability was almost certain.

But not anymore! Today there is more hope than ever – hope for a cure – hope for symptom management – hope for a life full of bright opportunities. Together we are stronger. Together we will move forward! Come on. Let's go!

So, with Karl's TEAM spirit and Pat's enthusiasm, we launch this next phase of the MS Support Group. But first, we need to hear from you. Please take a moment to complete the following survey, then either drop it off at the SCI Group at the VAMC or e-mail it to pdcockerell@att.net.

We all agree that continuing the MS Support Group on Mondays is important to our health and well-being. Honestly, I'm not typically a "joiner." But it seems every time I have a conversation with someone knowledgeable about MS, I am that much better off. Just think of the resources we have at our fingertips. With the help of the SCI Group, the Paralyzed Veterans Association and the organizations that address MS, we can improve our lives and the lives of those like us.

So let's make our MS Support Group a meaningful tool to as many of us as possible. Following is a survey to nail down specifics – please complete and email your responses to me at pdcockerell@att.net. Or drop the survey off at the SCI reception desk. Trust me, we'll listen.

1. Which Monday of the month is best for you to attend a support group?

2. What time of day is best for you to attend? (We have the option of serving lunch at our monthly meetings.)
3. Which location is most convenient: the VAMC-SCI Clinic or the PVA Offices in Garland?
4. What accommodations, if any, would assist your comfort during the meeting?
5. How long should the group last?

When possible, we'd like to invite speakers to discuss various topics that concern us. Please circle which topics interest you:

- New research developments
- The pros and cons of various medications
- The impact of diet on MS
- and MS
- Exposing myths
- Stress Exercise – how much and what type
- Addressing disability compensation
- Who needs to know about your MS
- Employment and MS
- MS and relationships

6. What suggestions or advice do you have to help make the group work for you?

We plan on attending the MS symposium at the VAMC on Oct. 3, so please look for us and introduce yourself. If you have not yet received an invitation to this comprehensive, day-long event, then by all means, let the SCI Clinic know. Bottom line: We want to see you there!