ONE DAY I WOULD LOVE TO SAY, "I USED TO HAVE MS."

PATIENT PERSPECTIVE
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My MS Story

• August 2011 - Life couldn't be better. 😊

• 33 years old and finally on the happy trail of life

• New job as a clinical research coordinator

• Recently engaged and planning my dream wedding

• But soon it would all change and Research would become a lot more than just a job for me!
• How to make new friends at the new job?

• Volunteer to help by becoming a "healthy brain" control subject for an Epilepsy research study. Why not, I've never had any health concerns.

• Uh oh, my brain might not be healthy after all? Shock! Fear! Worry!
Do I really have Multiple Sclerosis?

• 20+ lesions found on my brain MRI

• Symptoms? All seemed "typical" (occasional headaches, fatigue, rare numbness that comes and goes in arms and legs, occasional blurry vision)

• Single mom who had worked 12 hour night shifts as nurse for the past 3 years. Don't these symptoms fit with stress and sleep deprivation?
MS Specialist: Clinical Assessment

- 6 week wait between Research MRI finding and appointment.
- Not all lesions "fit" MS picture
- Completely normal neurological exam
- Not diagnosable!
Now what?

• Just wait for MS to rear its ugly head, while trying to live a "normal" life. Call Doc if new symptoms appear.

• Wedding bells rang! 💍

• Families successfully blended.

• Work became busier and more stressful, but good. I was learning so much about the world of research.
AND THEN IT HAPPENED!

March 2013: Woke up 1 morning with double vision. Next day, vertigo set in on my drive home from work.
What next?

- 4 days of double vision and vertigo led to a full exam at the INI eye center.

- I failed all testing with flying colors...suspicion that the problem is of central origin (my brain)!

- Another MRI completed and a phone call from the doctor. I would be admitted to the hospital for further work up and medications.

- Rule out or confirm the MS diagnosis.
MULTIPLE SCLEROSIS

- 70.4% Numbness, tingling
- 53.7% Headache
- 49% Cognitive dysfunction
- 54% Depression
- 41.6% Dizziness
- 38.9% Vision problems
- 53.9% Emotional changes
- 15.2% Hearing loss
- 63.2% Pain
- 50.8% Bladder dysfunction
- 26% Bowel dysfunction
- 3.9% Seizures
- 29.9% Tremor
- 76.4% Walking difficulty
- 35.7% Speech/swallowing problems
- 13.8% Breathing problems
- 89.6% Fatigue
- 38.1% Sexual dysfunction
- 60.8% Muscle spasms
- 35.4% Itching
Research, A Blessing in disguise

- My prior research MRI was available for comparison.
- The testing could be more focused due to the high suspicion of MS.
- I was less fearful because I knew the likely diagnosis.
- I still had 20+ brain lesions, Vitamin D level was extremely low, visual disturbance and vertigo present, female age 35, and lumbar puncture results came back positive (oligoclonal immunoglobulin bands present).
- Diagnosis: Relapsing Remitting Multiple Sclerosis
- Initial Treatment: 3 days high dose IV steroids! Then I started on my first DMT (disease modifying therapy), Avenox.
- No cure possible! Try to adjust to my "new normal".
My Research Roles

- Participant in research projects: 2 at The Exercise Neuroscience Research Lab and MS Research Center at the University of Illinois Urbana-Champaign (EXACT-2 and VIEWS) and currently 1 in Peoria (PASSAGE).

- Participant in NARCOMS data collection via online surveys at least yearly.

- Support research through fundraising: MS Carnivale, MS Walk, and my grandmother's memorial.

- Advocate for the patient through membership on the MS Advisory Board at UICOMP.

- Volunteer member for this project's planning committee with hopes of remaining an active member and leader on this patient led MS research community we are developing today.

- Researcher: Constantly educating myself by reading about what is being done currently around the globe to help us living with MS. Willing to participate in new research as it comes out.
As patients, what can WE do to improve the MS research in our community which will improve the care WE all receive?
• Share freely today about how MS most affects you and your family.

• Brainstorm together areas of MS medical care which could be improved through further research.

• Support one another today and in the future. WE are all in this together.

• Participate in fundraising opportunities so more research can continue to be funded.

• Speak out in your communities to raise awareness of Multiple Sclerosis.

• Volunteer to participate in research studies you are qualified for, as this may not only help you, but will also potentially help thousands of others struggling daily with MS.

• Last but not least, choose to JOIN our new PATIENT LED RESEARCH COMMUNITY!
TOGETHER, WE CAN MAKE A DIFFERENCE IN THE WORLD OF MS
“TEAM HADDOCK”
fishing for a cure...
Thank you!