

DEVELOPMENT OF A PATIENT-LED MULTIPLE SCLEROSIS RESEARCH COMMUNITY

Community Meeting #2: March 1, 2016

- Welcome to all M.S. Patients, Caretakers, Researchers, and community stake holders.
- Facilitator: Kimberly Haddock, RN, BSN, CPN, CCRC and M.S. Patient
- Guest Speaker: Brooke Bisping, RD, LDN



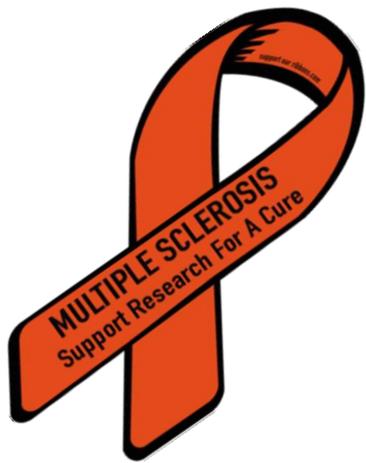
REVIEW FROM SEPTEMBER 2015 EVENT

- Attended by 76 patients and guests.
- More than 50 questions were posed by those in attendance.

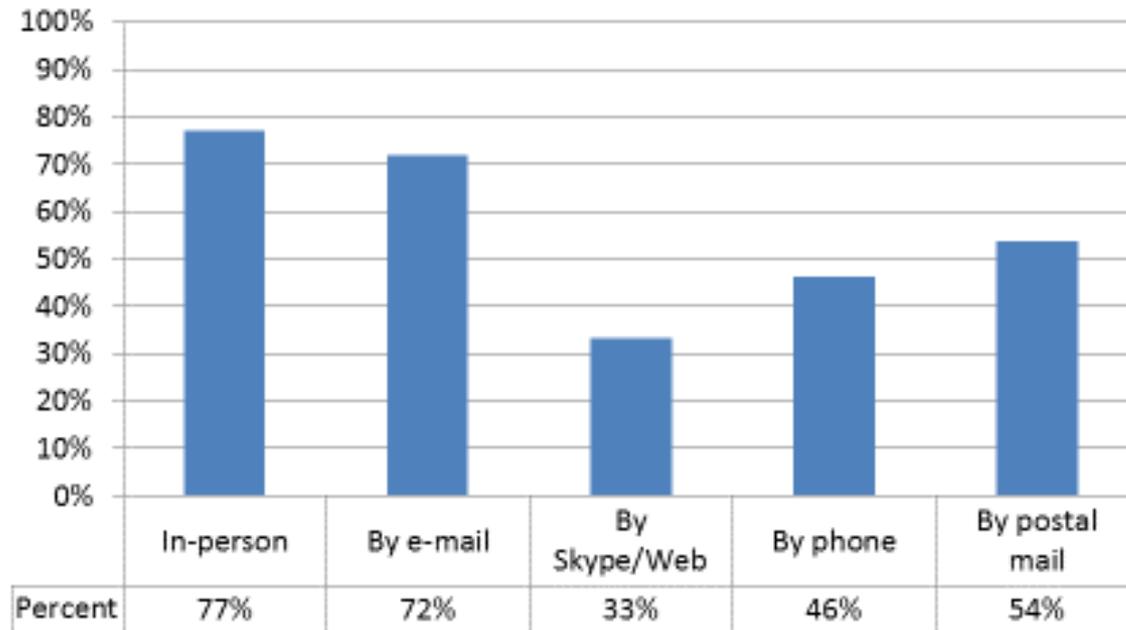
Categories of Questions:

- Alternative Therapies (17)
- MS Treatments (7)
- Genetics (Biomarkers) (6)
- MS Symptoms & Symptom management (6)
- Relationship of MS to other diseases—such as ALS, Chron's, RA, Autism (5)
- MRI scans (3)
- Progressive MS (1)
- Physician Level Awareness (1)





Best way to meet?



PCORI TIER 1 PROJECT WRAP-UP

TIER 1 Project Purpose: We envision a dynamic, diverse, patient-led group that is driving the research agenda based on what is important to them. In addition to reaching more people living with multiple sclerosis, we need to include representatives from the Greater Illinois Chapter of the National Multiple Sclerosis Society, researchers at Bradley University and University of Illinois Urbana Champaign, and interested care providers from UnityPoint neurology (a local competitor to INI).

The Tier I recruitment strategy and communications plan was very effective at reaching patients and moderately effective at reaching researchers and healthcare providers. Attempts to broaden our partnership by engaging researchers from Bradley University and practitioners from the UnityPoint Methodist system were not successful. However, our work on the Tier I project was very successful at engaging patients and family members, as well as healthcare providers from the OSF healthcare system. Patients are providing content for the seasonal newsletter; for example, Kim Haddock's blog. Our partnership also expanded to include researchers at University of Illinois Urbana-Champaign with expertise on exercise and MS.



HOW WILL WE NARROW DOWN OUR IDEAS?

50 Ideas have been narrowed down by the Researchers into 4 possible areas of patient suggested research interest.



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We have already made some progress in moving the brainstormed research ideas toward CER questions, but a great deal of work remains. We plan to have the community prioritize the CER questions and other research themes; then we will use the prioritized list to guide our research efforts. For topics that have already been investigated elsewhere, we will work to spread awareness of the findings (e.g., highlighting in a newsletter, bringing in a guest speaker). We will identify a researcher to lead development of each CER question and develop a collaboration with other researchers and interested patients on the topic. We will ask for community volunteers to be more involved with developing research study designs from individual CER questions and report back to the group at routine intervals. As previously discussed, it is important for us to communicate using multiple methods (in-person, mail, e-mail, phone, web) to reduce barriers to participation. It is essential that our Patient Led Multiple Sclerosis Research Community is, in all aspects, patient-led, and we are making progress towards that goal. For example, our January newsletter featured a blog by Kim Haddock, and other patients have been invited to share their writings for future newsletters.



WHAT QUESTIONS/IDEAS WILL MOVE FORWARD?

CER IDEA	Health Topic	Population at risk for health topic	Relevance of the idea to your partnership
Treadmill exercise vs. Aquatic exercise	Multiple Sclerosis improving Quality of life (mobility)	Patients diagnosed with Relapsing Remitting and Secondary Progressive MS	Patients suggested more research on symptom management and improving quality of life through avenues other than pharmaceuticals. Researchers with expertise in exercise and MS have joined the partnership.
Probiotic supplement vs. daily yogurt vs. nothing	Multiple Sclerosis Improving Quality of life (diet/nutrition)	Patients diagnosed with any form of MS	Patients expressed deep interest in the gut biome and how it relates to multiple sclerosis symptoms and progression. Planned addition of a nutritionist to the INI care team may facilitate conducting such a study.
Computer based Cognitive therapy vs. Cognitive behavioral therapy sessions	Multiple Sclerosis Improving Quality of life (maintenance/improvement of cognition)	Patients diagnosed with any form of MS (possible focus on Primary and Secondary Progressive forms of the disease)	Patients have concern for the cognitive deficits present and how to maintain or improve their levels of cognition. Matches with researcher interest in telemedicine applications and training patients in chronic disease self-management.
Comparison of different diets (Paleo diet vs. American Heart Association recommended diet vs. usual diet)	Multiple Sclerosis Improving Quality of life (diet/nutrition)	Patients diagnosed with Relapsing Remitting MS	Patients interested in knowing if diet really impacts MS symptoms and progression and if so, which diets are best to decrease progression. Planned addition of a nutritionist to the INI care team may facilitate conducting such a study.



WHAT ARE THE NEXT STEPS?

PCORI PROJECT CONTINUATION – TIER 2

- Project Team Charter Completed
- TIER 2 Application has been submitted. Hopeful of receiving award for up to \$25,000 for continued development of this research committee and future project.
- Continue to communicate through our Newsletter Quarterly – next issue May 2016.
- Continue to provide opportunities for patient-led group to meet for project development discussions and M.S. educational events at least quarterly. The next event will be held May 10th – 6:30-8:30 PM at the Jump Trading Simulation and Education Center: Well-being is a Skill by Richard Davidson.
- Select a concrete idea and develop the formal CER question for our Tier 3 research application/project.

OTHER M.S. PROJECTS IN DEVELOPMENT

- MS Flowsheet Project is currently being implemented in the MS Clinic to improve care and the quality of Physician Engagement.
- MS Flowsheet Paper was recently published in the online Journal, Austin Journal of Multiple Sclerosis & Neuroimmunology. Kudos to Kim Cooley, Carl Asche, and Bonnie Paris.
- Grant application submitted to the NMSS for a large research project looking at the benefits of Mindfulness training provided via telehealth to MS Patients.
- Comprehensive M.S. Exam is being rolled out to improve patient care within our local M.S. Clinic.
- M.S. Clinic has moved to a nicer facility – Now located at 200 Pennsylvania Avenue.



OPINIONS & QUESTIONS

- Which CER idea do you like best?
- How do each of you wish to continue making a contribution to this committee?
 - ❖ Attend future meetings
 - ❖ Write blog/article for newsletter
 - ❖ Recruit other patients and community partners
 - ❖ Participate in future research project(s)

