



Expressions of Gratitude

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Thank you, Thank you, Thank you for attending September's MS Patient Led Community Event at Embassy Suites. Bonnie, Carl, and the Kims would like to introduce this first edition newsletter. Our commitment as researchers and nurses to the group is to provide you with a quarterly newsletter with updates on the progress being made on the patient directed research topics. Within this newsletter we would like to include a blog from Kim Haddock who, if you recall from the conference, is a research nurse diagnosed with MS approximately 3 years ago. We would also love to include a short write-up each quarter written by one of you. The write-up can be on any MS related issue, experience, or example. You can also send us poems, pictures, informative articles, or inspirational quotes. It is important that this group remain patient focused, so please consider providing your input. Simply contact Kim Cooley or Kim Haddock with your questions or ideas.

In addition, feel free to contact us anytime with suggestions on what YOU want or need from this new partnership. We will compile these thoughts and discuss them at our quarterly conferences. See the back of this newsletter for information on upcoming group conferences. We truly desire growth in our relationship with you.

Looking Ahead...

The INI MS Center in Peoria is moving to 200 Pennsylvania Avenue (next to OSF Saint Francis Medical Center) the beginning of February. Located on the ground level of this beautifully remodeled building, you can expect to receive the same individualized MS Care as before and will enjoy many additional perks. This will be a "one stop shop" for MS patients. Onsite labs, EKG, and neuro-ophthalmology (Neurology/Eye) testing will be accessible the same day as your appointment. The INI MS Center is also in the process of refining a MS Comprehensive Visit that will be performed on newly diagnosed and established patients. This service will be extended to existing patients in the future. During this annual MS comprehensive visit, patients and family members or caregivers, will experience time with the provider (MD and Mid-Level Providers), MS certified nurses and physical/occupational therapists, social worker or licensed neurology counselor, dietician, and urology (bladder) clinicians. If the need arises, speech therapists and representatives to assist with wheelchair and orthotic (ankle/foot brace) needs will be available as well. A MS specific neurology exam, called an EDSS, will be performed and patients will also be given the opportunity to complete quality of life questionnaires. A new MS Flowsheet Registry that can integrate with the electronic medical chart is also being implemented. This registry has many benefits, one of which will assist providers and staff with viewing your individualized, complete, MS history in one electronic "view". The INI MS Center is making steps to improve the care they provide and become the best MS Center in the Nation.

Establishment of a MS Patient Led Research Community



***You Spoke and
We Heard!***

You spoke, and we heard. 76 patients and guests attended the PCORI MS Community Event on September 19, 2015. More than 50 patient/guest led MS research topics of importance to you were gathered. Bonnie, Carl, and the Kims have sorted the topics and divided them into the following groups:

*sorted in order of majority per community members account.

- 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)

The researchers and nurses on your patient led community charter are dedicated to creating research studies around these topics. If a topic is already being investigated elsewhere, we hope to provide you with the findings.

Please send your Newsletter Title suggestions to Marie McWhirter by emailing her at mariemcw@uic.edu or call her at 309-671-8454.

We will vote at our gathering on March 1st to determine the Title for this ongoing newsletter.



Suggested Websites:

INI website: <https://www.osfhealthcare.org/services/neurosciences/medical-services/multiple-sclerosis/>

National Multiple Sclerosis Society
www.nationalmssociety.org

Multiple Sclerosis Foundation
www.msfocus.org

www.livinglikeyou.com

<http://positivelivingwithms.com/>

This is an awesome blog by Penelope Conway, a beautiful woman living with MS.

She has been an inspiration to me and has helped me get through tough days over the past year.

Multiple Sclerosis Association of America
www.mymsaa.org

www.multiplesclerosis.net

www.mslifelines.com

Patient to Patient: Being the Best YOU in 2016

I am not a person who believes in making New Year's Resolutions because I learned many years ago that by making those, I generally was setting myself up for failure. To be honest, I think it is important for us as human beings to consider our lives on a daily basis, rather than just once a year, when considering how to make positive changes to better ourselves. I am certain we can all improve in one way or another. Some of us want to improve our physical self, possibly by losing weight or working to strengthen a certain body part. Some of us want to improve our spiritual self, possibly by attending worship service more often, reading our Bible daily, or praying more regularly. Some of us want to improve our emotional self, possibly by finally admitting to our depression or anxiety and accepting help, trying to worry less about those things that are out of our control, taking our medications as prescribed, or seeking out a professional counselor to talk through our difficulties. Some of us want to improve our cognitive health or enhance our knowledge, possibly by working word puzzles, reading more often, socializing with others more, watching the news more frequently, or maybe simply by keeping a calendar or learning to write daily reminder lists. Some of us may want to improve our social health, possibly by volunteering in our community, making it a priority to call a friend once a week, or go out with your significant other once a month. Some of us may want to improve our nutrition by eating less processed foods; eating more fruits and vegetables, eating more salmon, or eating fast food less often. I am sure I can go on and on about how we could all improve ourselves during the year ahead.

Regardless of living our lives with Multiple Sclerosis, we truly are no different than anyone else in the world, when it comes to choosing to make positive changes in ourselves. Multiple Sclerosis might present some unique challenges in attaining our goals and changing for the better, but it certainly should not prevent us from trying to do so. Take a moment to reflect on your daily life, count your many blessings, see your many strengths, acknowledge your faults (*it's okay, we all have them ;)*), and consider how you could make any simple change to help you become a better YOU in 2016. These changes can be as many or as few as you want. There is absolutely nothing stopping you, other than yourself, in becoming the absolute Best YOU! You might have to dig deep within yourself or talk with your family members and friends to get some suggestions on how you can make your quality of life a bit brighter and better this year, but I challenge you to at least pick one area in your life to focus on. A positive attitude and belief in oneself can carry you great distances. Make this a year for YOU and realize MS cannot defeat you unless you choose to defeat yourself.

Writing this brief article, and hopefully more in the future, is one way I am planning to better myself this year. Now that I am 3 years out from my official MS diagnosis, I am beyond the initial shock and devastation. I have discovered a happy mix of prescribed medications, over the counter supplements, nutrition tricks, and even a bit of essential oils to help me feel good most days. I am more positive and realistic about the possibilities I still have for a happy and rewarding life, regardless of my diagnosis. I have decided it is time for me to use my strengths, knowledge, and abilities to better support others within the MS community, be a stronger advocate for MS patients and the future care available to us, and be more active in my fundraising efforts to raise money for MS research. I hope some of you will choose to continue partnering with me this year by remaining active participants in our Patient Led Multiple Sclerosis Community. Please realize our head, hands and hearts working together can achieve so much more than one of us alone.

On page 2 there are a few resources I would like to share with you all that I have found helpful and uplifting in my daily life as a person **LIVING** with Multiple Sclerosis. Best wishes to each of you as you try to achieve the best possible YOU in 2016.

The preference of the majority of members is to meet quarterly. We are planning our next meeting for March 1st from 5:30 - 7:00 PM. We will meet in the Ghandi Conference room located on the first floor of the Milestone Building at OSF Saint Francis Medical Center. Valet parking will be available. Simply pull up to the front circle of the Building where the Valet parking sign is located. The Ghandi room is located just past the main lobby across from the chapel in the small hallway. We will gather together at this time to further discuss our next steps in the Patient Led Research Project. We will soon be submitting the application for a PCORI Tier 2 award which would provide funding for us to move forward with one of our patient suggested research questions. We will also have a speaker from the community, Brooke Bisping, Registered dietician, to provide a brief educational session on clean eating and how good nutrition can possibly lessen some multiple sclerosis symptoms. Please plan on joining us.

Let's keep this Patient Led Community Group going.



MS Carnivale Fundraiser—February 25, 2016

Par-A-Dice Hotel - East Peoria, IL

Tickets \$125/person (dinner included)

<https://www.osfhealthcarefoundation.org/page.aspx?pid=1223>

Questions? Please call 309-566-5666.

May 10, 2016

JUMP SIMULATION CENTER @ OSF Saint Francis

Speaker: Richard Davidson

Presentation on Benefits of Mindfulness

If you were unable to attend our September 2015 Conference or would like to review the topics covered at that event, you can go to the following website to view video from that day.

http://peoria.medicine.uic.edu/research/center_for_research/training/

