



Multiple Sclerosis Patient Perspectives



UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE AT PEORIA

COMING SOON:

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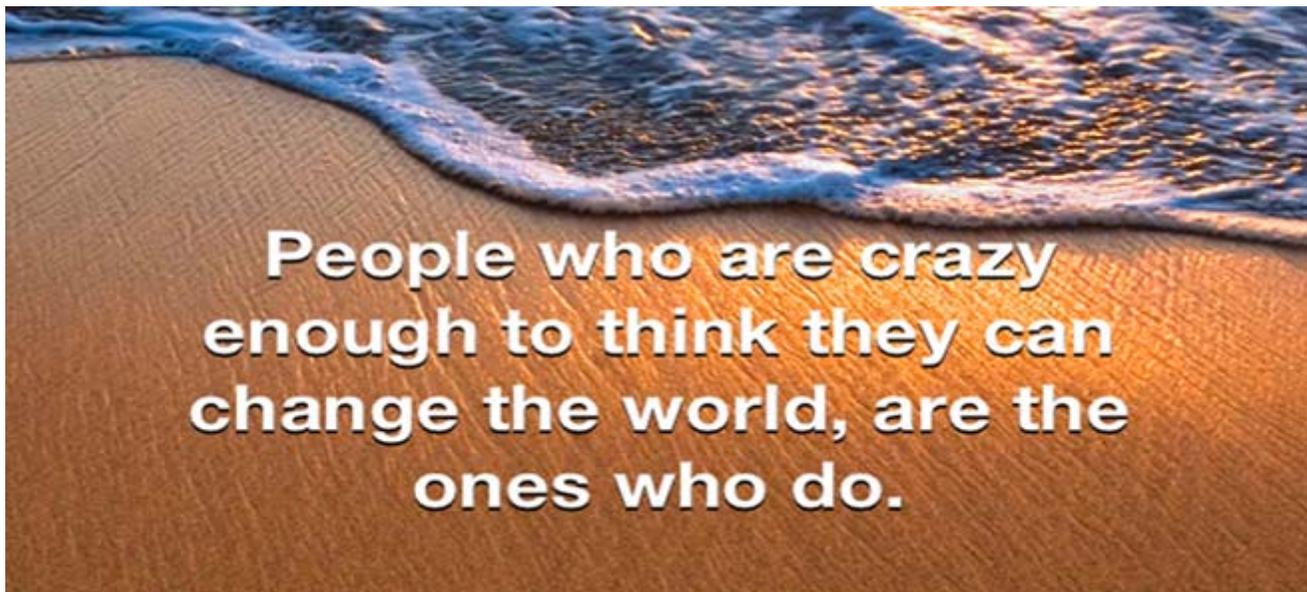
2016 Patient-Led MS Research Community Tier 2 AWARD —Meeting #1

Date: Saturday, October 1, 2016
Time: 10 AM — NOON
Location: Jump Trading Simulation & Education Center
Conference Rooms A& B
1306 N. Berkeley Avenue
Peoria, Illinois 61603

Wheel Chair Accessible Building & Valet parking is available.
Light snacks will be provided.

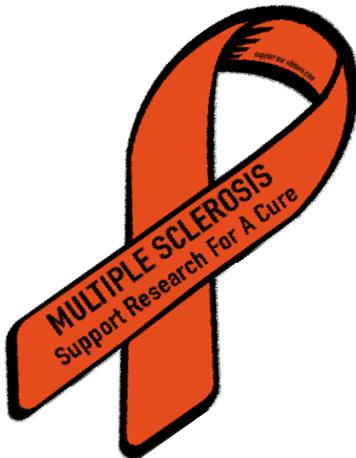
Please RSVP to Kimberly Haddock by Wednesday, September 14th

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**People who are crazy
enough to think they can
change the world, are the
ones who do.**

Establishment of a MS Patient Led Research Community



PROJECT UPDATE:

We are underway with the continuation of building our patient community and we would like to thank each of you for your contributions up to this point. We are in the process of planning our first patient meeting for this year, to be held October 1, 2016. We also have been busy sorting through the many responses to the survey you all should have recently received via email or postal mail. If you did not receive a survey and would like one, please contact Marie McWhirter at 309-671-8454. Based on the feedback we have received, below is a summary of our survey results:

Type of Patient contribution to the group?

19/30 (63%) plan to provide feedback/opinions through email or letters

25/30 (83%) plan to attend at least 1 patient meeting in-person this year

15/30 (50%) plan to attend at least 1 patient meeting via phone or computer

9/30 (30%) plan to contribute to one of the newsletters

Who plans to bring a friend or caretaker to our community events?

9/30 (30%) provided contact information for an interested Caretaker/Friend

Which of the Suggested Research Ideas are you most interested in?

I have ranked the responses below:

- 1. Cognitive Therapy Research**
- 2. Treadmill Exercise vs. Aquatic Therapy Research**
- 3. Dietary/ Nutrition Research**
- 4. Probiotic supplementation Research**

We also received several other patient suggestions for the direction we should focus our future research. All ideas will be presented and discussed with the group on October 1st.

In general, Saturday is the day when most of you said you would be available for our meetings, however, it was an even split between morning and afternoon/evening times.

Patient to Patient: Incontinence Journey—provided by Michelle Mayer

Now, this is something a “lady” doesn’t want to talk about, but you all are a great audience for this; so, listen up while I tell you about my incontinence journey:

I was totally bereft a few years ago over this issue, as you might be now...and I know the issue didn't happen overnight...at least it didn't for me.

Before I tell you my tale, I want to jump forward and say that the Botox injections to the bladder procedure my urologist does has been a life changing experience, and I couldn't be more grateful; so don't despair....

I've been experiencing problems since I was in my 30's, but it started out as urinary retention problems that would lead to incontinence from an overfilled bladder. Once I learned how to self-cath, (and I fought it for a few years...silly girl that I was), I experienced such freedom! I no longer had to make sure I knew where the bathroom was the minute I visited somewhere new.

Well, in my 40's, I began to have more issues with incontinence, even though I always made sure my bladder was empty; Poise had a good customer in me. In my early 50's, it became the ruling force in my life: I wouldn't go anywhere without a Depends, I had to change my sheets frequently in the dead of night, even though I'd been to the bathroom an hour before...and of course, I had incontinence underpads on every chair I used. I got myself a covered bathroom waste basket, and that helped a lot with the odor until I could get to the dumpster, but I was so sad.

My urologist wanted me to try an InterStim device that would be implanted and would keep the sphincter from letting loose at will, but then his partner pointed out it's not a good choice for MS patients as we have to have periodic MRIs; the device would interfere.

About a year after that, my urologist’s nurse told me I should consider Botox as they had just approved it for neurogenic incontinence. I was willing to try just about anything, so we started the testing. It turned out that I was having such bladder spasms that my bladder was only holding about 90 cc's before it would expel the urine....that's why I was always wet! My kidney ultrasound was good, so the doctor did a cysto to have a look-see into the bladder, and afterwards told me I was a good candidate. The procedure was scheduled.

It was such an easy procedure! I was put under, and the doctor put about 15 injections of Botox into my bladder. I went home with a foley catheter overnight that I was to remove in the morning. I was scared to do it, but turns out it's super easy! Here's the tough part, though...the bladder is now totally paralyzed, so the patient has to use a self-cath 4 or 5 times a day to empty the bladder. Now, I was used to using disposable cath's already, so it was no problem. A little painful for a day or two for my tender urinary tract, but oh, so worth it.

The procedure has great results for anywhere from 3 to 10 months. I had my second procedure in December 2013; I was good for about 10 months, I was one of the lucky ones. I never even dribble anymore! Of course, you know it's time to do it again when you *do* start to dribble. There is a limit, I understand, as to how many injections you can have over your lifetime; but I figure that by the time I've had my quota, they will come up with something different!

Anyway, that's my incontinence journey. I know the Botox procedure is not for everybody, but as I write this, I hope that your doctor will find as good a solution for you.



WINGSHOOTERS FALL WARM-UP for MULTIPLE SCLEROSIS

Date: Friday, August 12, 2016 (Rain Date Saturday, August 13)

10 AM—4:30 PM at Oak Ridge Sportsman's Club

1301 Weishaupt Road, Mackinaw, Illinois

ALL funds raised go towards the MS Clinic Fund to support MS patients and families in Central Illinois.

10th Annual Main Street Tee-Off Against MS

Date: Saturday, August 13, 2016

Location: Laurel Greens

Start Time: Shot Gun Start at 9AM

Cost: \$60 per person or \$240 per Team

Includes Cart and Steak Dinner with all the Fixin's

Additional Fun: Scavenger Hunt and Crazy Outfit Contest

Come out for a Fun day of golf, family & friends!

All Proceeds will go directly to The Central Illinois MS Clinic Fund

NMSS: 10th Annual Regional Research Symposium

Date: Saturday, August 27, 2016

Time: 9:00 AM - 12:30 PM

Location: Embassy Suites Hotel and Riverfront Conference Center
100 Conference Center Drive
East Peoria, IL 61611

Register to attend by calling 1-800-344-4867.

2016 WALK MS (Peoria)

Get your team registered and start raising money for the National Multiple Sclerosis Society. Hope to see you all at the walk.

Date: September 11, 2016

**Location: Junction City, 5901 N Prospect Rd
Peoria, IL 61614**

Event Manager: Walk MS Team Email: walkmsillinois@nmss.org Phone: 855-372-1331

GET INVOLVED—MS Fundraisers bring in money to increase the Research efforts towards finding a cure for us all.

Recipe Suggestion: Provided by Brooke Bisping, RD , LDN

Tropical Summer Salad

Serves 4 (about 1 cup each)

All you need:

- 3 to 5 tsp fish sauce, to taste
- 1 tsp freshly grated lime zest, plus more for garnish
- 2 tbsp lime juice
- 1 tbsp canola oil
- 2 tsp light brown sugar
- 1 tsp rice vinegar
- 1/4 tsp crushed red pepper
- 1 medium English cucumber, cut into 3/4-inch dice
- 1 avocado, peeled, pitted and cut into 3/4-inch dice
- 1 mango, peeled, pitted and cut into 3/4-inch dice
- 1/4 cup chopped fresh cilantro



All you do:

Whisk fish sauce to taste, lime zest, lime juice, oil, brown sugar, vinegar and crushed red pepper in a large bowl until combined. Add cucumber, avocado, mango and cilantro; gently toss to coat. Serve garnished with lime zest, if desired.

Make Ahead Tip: Cover and refrigerate for up to 1 hour.

Tip: To dice a mango, slice both ends off the mango, revealing the long, slender seed inside. Set the fruit upright on a work surface and remove the skin with a sharp knife. With the seed perpendicular to you, slice the fruit from both sides of the seed, yielding two large pieces. Turn the seed parallel to you and slice the two smaller pieces of fruit from each side. Cut the fruit into the desired shape.

Nutrition Facts per serving: 169 calories, 11g fat, 1g saturated fat, 0mg cholesterol, 302mg sodium, 19g carbohydrates, 5g fiber, 3g protein.

Daily values: 15% vitamin A, 45% vitamin C, 2% iron.

Source: adapted from Eating Well, Inc.

Sounds so Yum, Yum, YUMMY!

Enjoy.



Together We Can Make A Difference!

- Do you have leadership gifts?
- Are you a stickler for detail?
- Do you have good people skills?
- Are you a great helper?
- Are you creative?

If you answered yes to all or any of these gifts, we **WANT** you to consider becoming more involved by taking on a more significant role in this community. Our group needs leaders, helpers, and organizers. Honestly, you do not want us boring Researchers and Nurses leading this MS Community Group for the next 10 + years.

We want you...the patients, caregivers, friends/family, etc. to take the lead. Imagine how awesome this group could become if you...the ones living with MS and those impacted the most ...are pushing this group forward. You can be in control of what is discussed, what questions are being researched, and what topics you want to learn about. The sky is the limit. Please consider joining one of these leadership positions in the coming months so **YOU** can take this MS Community Group to its fullest potential alongside your fellow friends and community members. Roles we are seeking to fill include the following: Chairman, Assistant Chairman, Secretary, Newsletter Coordinator, Community Outreach Representative.

If you are interested in one of these positions, please contact Marie McWhirter at (309) 671—8454 or via email at mariemcw@uic.edu and she will include your name on the ballot .We will all have a chance to vote at the meeting on October 1st.



"You can do what I cannot do. I can do what you cannot do. Together we can do great things."
- Mother Teresa