

Accelerated Cure Project for MS



Accelerating research towards a cure for multiple sclerosis

Dear Friends,

We hope everyone's summer is off to a great start! This issue of the newsletter focuses on impact — ways that you and others affected by MS can accelerate research.

Read about how you can propel research forward by joining iConquerMS™ and by participating in REAL MS™ surveys, suggesting research topics, contributing your insights to research studies, and much more.

Epidemiologist Dr. Farren Briggs describes a compelling Multiple Sclerosis Journal article — built on patient-reported data — comparing the costs of living with MS in 16 European countries.

The third article details the many ways YOU can accelerate MS research — from joining iConquerMS, to volunteering your time and expertise at ACP, to donating in a variety of ways.

And lastly, we spotlight one of our partners, MS Views and News, a nonprofit founded by Stuart Schlossman in 2009 and dedicated to the global collection and distribution of information concerning MS.

iConquerMS™ -- Research Driven by You!

Have you ever wanted to tell MS researchers what topics you thought they should study? Or wished you had more opportunities to participate in MS research? Or felt that your knowledge as a person with MS could help in designing clinical trials or new products for MS?

If you have, we have an online community for people like you who want to engage in, learn about, and influence MS research. This community is called **iConquerMS™**, and its members participate in many kinds of activities, from joining research studies, to helping design studies and products, to sending in suggestions about the research they'd like to see performed.

We wanted to share a few of the many research activities that have happened recently in iConquerMS. If you're an iConquerMS member, you may have been involved in some of these activities. And if you're not already a member, we hope you'll sign up to contribute your ideas, information and experience going forward! Just go to iConquerMS.org to learn more and enroll.

Suggest a Research Question

As someone living with MS, you know the disease better than anyone — and your ideas about what researchers should explore are very valuable.

We encourage you to submit questions on topics that you care about, and that you think need to be addressed by the research community.

Please include your contact information; we may follow up to help further develop your question. If you prefer to submit an anonymous question, you may omit your name and contact information and delete your email address.

Once submitted, your question will be shared with the Accelerated Cure Project and the iConquerMS™ Research Committee.

Your Name:

Your Email:

Your Phone Number

Your Question: *

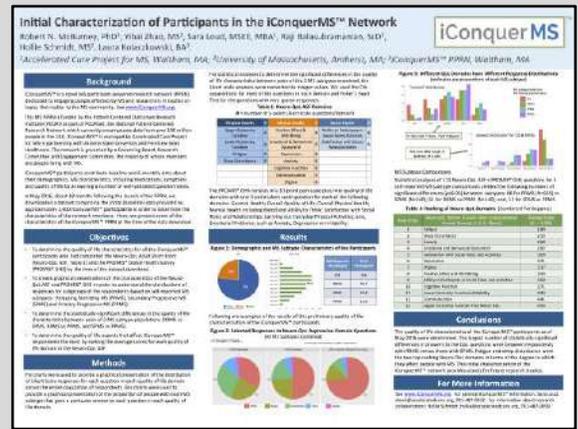
My Research Surveys

New | In Progress | Completed

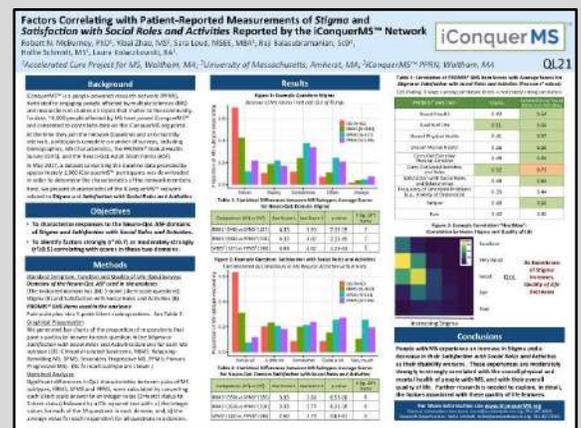
- REAL MS - Demographics >
- REAL MS - MS History >
- REAL MS - Overall Health >
- REAL MS - Quality of Life >
- REAL MS - Other Conditions >
- REAL MS - Physical Activity >
- REAL MS - Demographics - Summer 2016 >
- REAL MS - MS History - Summer 2016 >
- REAL MS - Overall Health - Summer 2016 >

REAL MS: REAL MS™, aka Research Engagement about Life with MS, is the flagship research project of iConquerMS. REAL MS is what is called a prospective survey: we collect information from our members when they join iConquerMS, and then ask for updated information every 6 months thereafter. We've conducted two updates so far and are starting to build a detailed picture of our members' health and quality of life over time. With data from over 2,200 iConquerMS members in hand, we've begun analyzing the responses to learn about life with MS and are sharing our findings at conferences:

- For the American Committee on Treatment and Research in MS (ACTRIMS) meeting in February, we showed the general characteristics of our members and highlighted the effects of MS that appear to affect people the most, such as fatigue and sleep disturbance. (Download this poster [here](#).)



- In May for the Consortium of MS Centers (CMSC) meeting, we presented insights about our members' perception of stigma and their satisfaction with their social roles and activities. (Download this poster [here](#).)

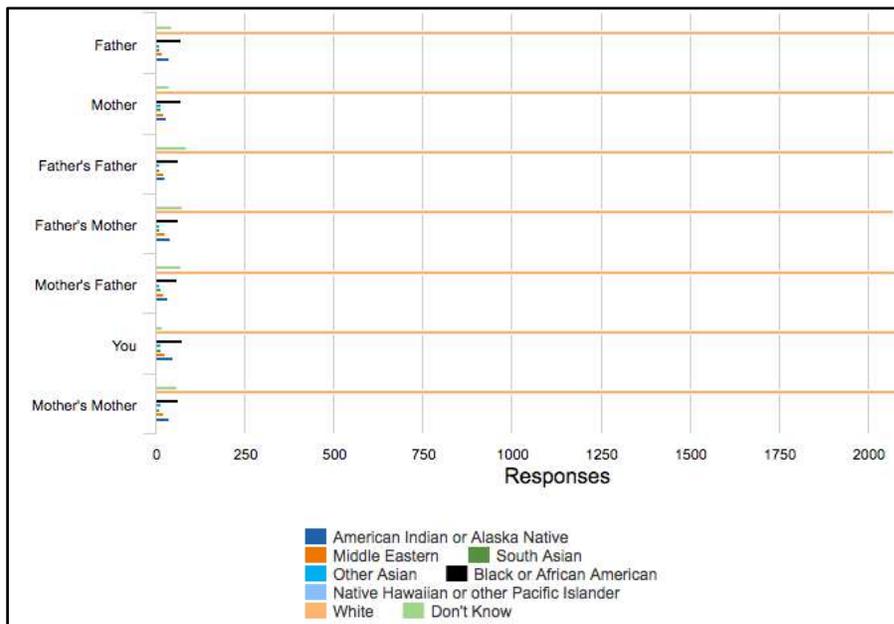


Later this summer we'll be releasing the 3rd round of surveys, which will include improvements and new topics and questions suggested by our members. We look forward to a great response and the ability to answer many more questions about life with MS, thanks to the help of the iConquerMS community!

Other Studies: Last year, iConquerMS members were invited to be part of a study led by Dr. Deborah Miller of the Cleveland Clinic on the topic of **insurance coverage and concerns**. This May, Dr. Miller and her colleagues presented two posters at the CMSC meeting with a variety of findings. For instance, most of the study participants reporting having health insurance, but over half of them were concerned about losing this insurance if their employment situation changed. Also, fewer than half of the participants had disability or long-term care insurance that would provide support if they became disabled. You can see the abstracts for these posters [here](#) and [here](#).

The study team is now working on additional analyses and publications, and the National MS Society will be using the results in its public policy and educational efforts.

In May, ACP invited iConquerMS members and others to take a survey on **research participation and perceptions** among people with MS. We noticed that racial and ethnic minority groups were not fully represented in iConquerMS or the ACP Repository, or in clinical trials and studies performed elsewhere.



So we applied for funding from the Patient-Centered Outcomes Research Institute to study the reasons behind this imbalance. This survey will help us understand which factors are most important to focus on in research-related outreach efforts. We'll share the findings of the survey and will ask for ideas for follow-up activities that might help encourage research participation in a wider group of people.

Coming up next: a study to learn about the most valuable characteristics of **MS medicines** for people with MS. Lots of conversations are taking place among health care leaders, politicians, and organizations about the price and value of drugs. But the voice of people living with MS hasn't been included as much as it should be. Working with Dr. Surachat Ngorsuraches from South Dakota State University, we'll be sending a group of iConquerMS members a survey that asks them to compare and choose between pairs of hypothetical MS therapies. The results of this study will contribute to efforts to ensure that people can get access to their therapy of choice.

Research Input Opportunities: People with MS are experts about living with and managing the disease, and each individual with MS has a unique and valuable set of insights. Researchers are increasingly recognizing how useful those insights could be when planning their studies, and are coming to iConquerMS for help connecting with this expertise.

Recently we helped a biotech company invite people with MS to a one-day **patient advisory board**. They were designing a clinical trial for a new MS drug and wanted to make sure it was designed and communicated as effectively as possible. The input from our members will help ensure that the trial can be completed successfully.

We also helped a team of engineering students from Arizona State University who were developing an **auto-injector support device** and needed input on their design. Many iConquerMS members viewed the team's video online and provided constructive feedback. The students have all graduated, but one of them is pursuing further development of the device and hopes to bring it to market!

Over the next few weeks, we'll be inviting iConquerMS members to talk with the founders of a start-up company. They're developing products to support people with MS and their doctors in making healthcare decisions, and want to know more about the **experience of being an MS patient**. One-on-one interviews will help them create products that meet the needs of people with MS.

Do you want to share your expertise as a person with MS? Join [iConquerMS](#), and be sure to complete your REAL MS surveys so we can match you up with the right opportunities!

The Cost and Burden of MS in Europe 2015: A Patient-Reported Outcomes Approach

By Farren Briggs PhD, ScM

Commentary on access to and cost of healthcare is currently the center of most Capitol Hill conversations. These conversations touch every American, and understanding the healthcare cost relevant to subgroups of individuals is necessary for fruitful discussions. In the US, the direct healthcare cost for a person with MS (PwMS) is \$39,000; but when lost wages are considered, the annual cost rises to \$69,000¹. Of course the annual cost of healthcare varies by disability level¹: \$30,000 for those with mild disability and upwards of \$100,000 for those with severe disability². Other considerations include drugs used – in 2011, for PwMS using disease modifying therapies (DMTs) to manage their MS, 75% of their total MS healthcare costs was for DMT monotherapy². Healthcare costs change over time, due to changes in the rate of disability accrual, therapeutic options, and clinical care; therefore it is important to update estimates across multiple populations to appropriately inform policy and to allow easier comparisons across health systems and countries.



This month the *Multiple Sclerosis Journal* (MSJ) dedicated an entire issue to updating the information on the annual costs incurred by persons with MS (PwMS) in Europe¹. What is unique about this issue is it presents MS-related healthcare costs across 16 countries, in 16 articles, allowing direct comparisons of costs across these European nations. The authors undertook a non-traditional ‘bottom-up’ approach to evaluating the costs related to MS, by directly asking PwMS about their health and healthcare utilization, versus a ‘top-down’ approach of extracting information from registries and administrative data (i.e. healthcare billing). A total of 16,808 PwMS were recruited from national MS societies in 16 countries, including: Austria, Belgium, Denmark, Czech Republic, France, Germany, Hungary, Italy, the Netherlands, Poland, Portugal, Russia, Spain, Sweden, Switzerland and the United Kingdom. something that would be extremely challenging from a ‘top-down’ approach.

Participants completed a detailed questionnaire that included questions on MS-related resource consumption, employment, MS symptoms and disease activity, and health-related quality of life. This ‘bottom-up’ approach allowed for assessing costs related to symptomatology and disease activity—something that would be extremely challenging from a ‘top-down’ approach.

A publication earlier this year summarized the results for the 16 countries, and noted many similarities and differences between these countries⁴. For example, perceived quality of life (as measured by EQ-5D) decreased with disease severity (as measured by the Expanded Disability Status Scale [EDSS]) across all countries (Figure 1). However, there were dramatic differences in the annual costs by EDSS (Figure 2). For mild to moderate disability (EDSS<5), healthcare costs were under ≤50,000€ EUR across all countries, but for EDSS>5, healthcare cost varied greatly. In 2015, for a PwMS with severe disease (EDSS=9; PwMS is bed-ridden but can communicate and eat) the annual cost of care in: Portugal=35,000€; Spain=50,000€; Italy=80,000€; Switzerland=100,000€; and Sweden=135,000€ (1€ was worth approximately \$1.10 USD in 2015). These differences in cost relate to the cost of living in each country, but more importantly these costs are influenced by healthcare systems organization, the availability of services, and the ease of access to these services to PwMS. Also, 95% and 70% of participants reported fatigue and cognitive difficulties as major issues irrespective of disease severity and country of origin, which argues for more focus on management of these areas of MS in Europe. The overall goal of the special MSJ issue and these evaluations is to contribute to more effective approaches to disease management to result in better outcomes for PwMS.

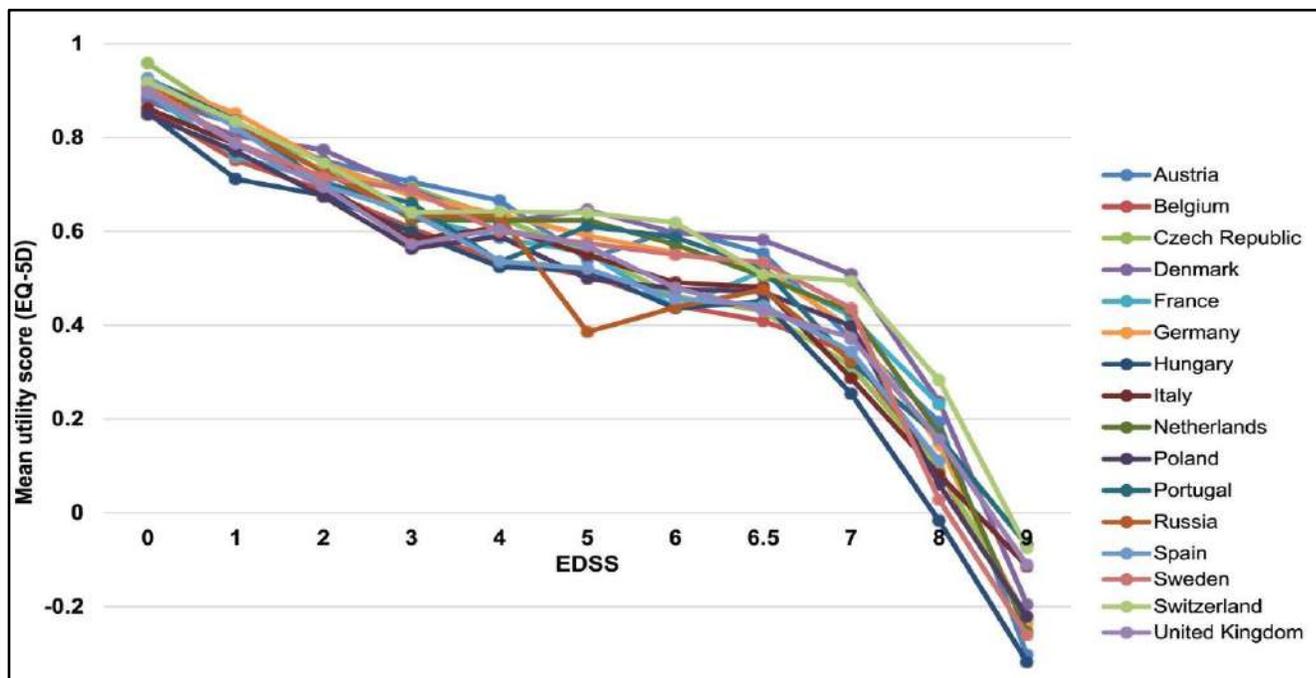
1. <https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Documents/Health-Policy-Fact-Sheet-2-Costs.pdf>

2. <http://www.ajmc.com/journals/supplement/2016/cost-effectiveness-multiple-sclerosis/cost-effectiveness-multiple-sclerosis-economic-burden>

3. http://journals.sagepub.com/toc/msja/23/2_suppl

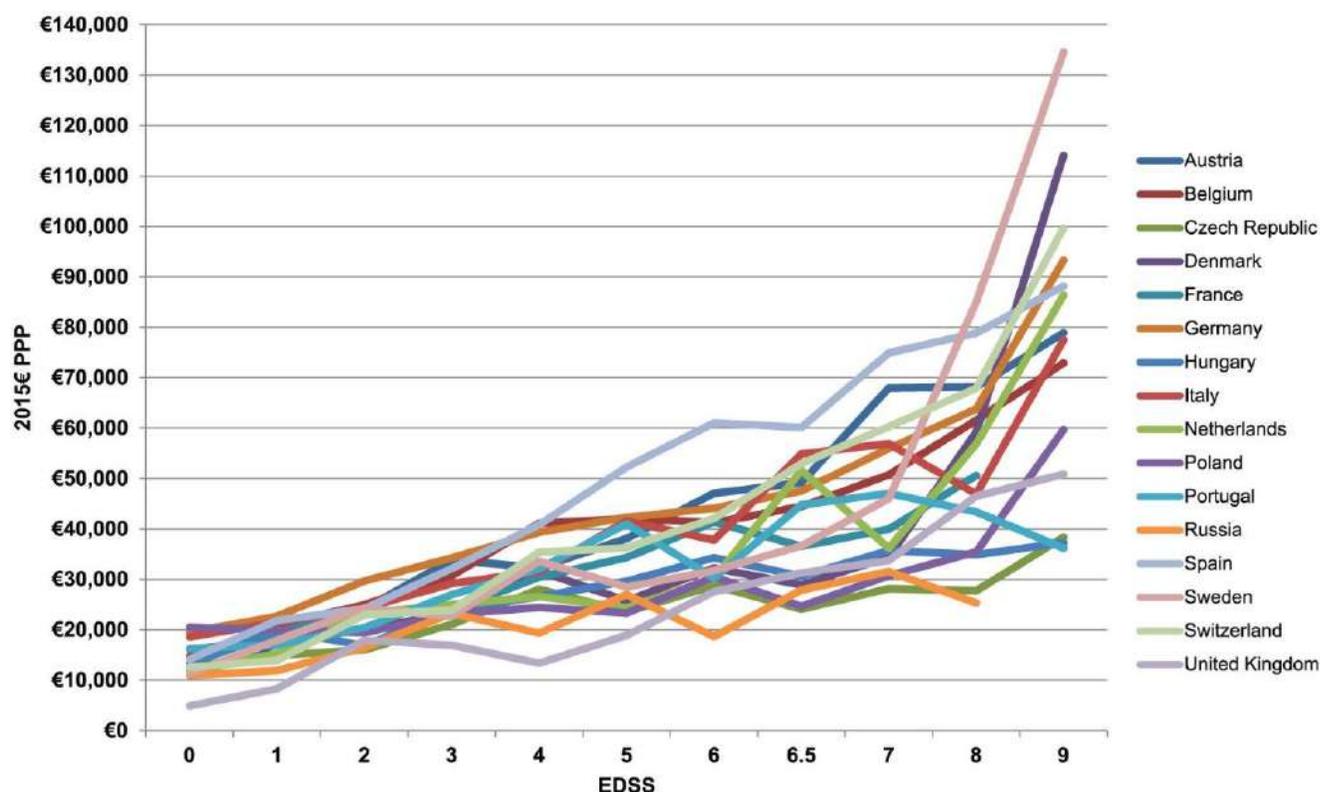
4. <http://journals.sagepub.com/doi/10.1177/1352458517694432>

Figure 1: Relationship between disease severity and health-related quality of life in 16



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Figure 2: Mean annual cost (EUR €) per PwMS by MS severity (EDSS) in 2015 (1 EUR ~



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Make an Impact and Accelerate MS Research

As a person affected by MS, either as someone living with the disease, caring for someone with it, and/or working in a related field, you may be wondering how you can accelerate research in MS.

Below we've listed some of the ways we've thought of and perhaps you have some ideas of your own!

Email us at info@acceleratedcure.org or give us a call at 781-487-0032 to get started.

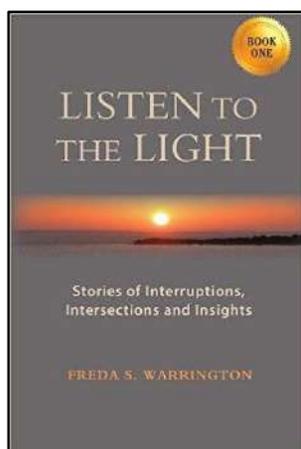
- Join our people-powered research network, [iConquerMS™](#) to securely contribute your health information and to drive, shape, and accelerate MS research by sharing your experiences and insights. We welcome all to join -- those with and without a diagnosis of MS.
- Let others know about ACP and iConquerMS by sharing this newsletter via email, Twitter or Facebook. Encourage friends and family to join [iConquerMS](#) and to [sign up](#) to receive their own copy of the ACP newsletter.
- Share your expertise and time by volunteering with ACP. We have many (many!) opportunities for you to make a meaningful contribution to our work. Live nearby? Join us in the Waltham office if you'd like. Live elsewhere? Most activities can be done remotely. Volunteering your time is a truly wonderful way to advance and accelerate MS research. Email Sara at scloud@acceleratedcure.org or call 781-487-0032.
- [Donate to ACP](#). Your donation has a substantial impact on our ability to accelerate research through our programs. Want to contribute on a regular basis? Join our Accelerators program by making your donation a recurring one. And if you're employed, please ask your company if they match employee donations!
- Have a birthday, wedding or other big celebration coming up? Ask for donations to ACP in lieu of gifts to really make an impact. Contact Lindsey at lsantiago@acceleratedcure.org or 781-487-0013 to learn more. [Donating in honor or memory of a loved one](#) is also a wonderful way to give and to honor a special person.

- Donate to ACP when you buy or sell. Both Amazon (<https://smile.amazon.com/>) and Ebay (<http://charity.ebay.com/>) have giving programs that can direct funds to us.



- Give to ACP through the United Way. Use our contribution code United Way Restricted Contribution Code of M337457

- Host a fundraising event for ACP. Our [last newsletter](#) covered this topic and has generated some terrific ideas. Perhaps you have one, too?



Longtime ACP supporter and friend, Freda Warrington has written a wonderful book, and part of the proceeds from the [sale of the book](#) will benefit ACP.



Patrick & Erin kayaking the Essex River Race & raising over **\$6,000** for ACP!!!

Partner Spotlight -- MS Views and News

What happens when a successful businessman, with a passion for sales, education, and collaboration is diagnosed with MS? The first thing that happens, at least if you are Stuart Schlossman, is that you volunteer countless hours with your local MS organization. Then, upon realizing there is an unmet need to be filled, you start your own MS nonprofit,



[MS Views and News](#) (originally called Stu's Views and MS News). MS Views and News (MSVN), a registered 501(c)(3) nonprofit since 2009, is dedicated to the global collection and distribution of information concerning Multiple Sclerosis (MS). Through partnering relationships, MSVN provides education, advocacy and service to empower and enhance the quality of life of the MS community.

The information and education provided by MSVN flows through a variety of channels to best reach as many people affected by MS as possible. Through [free live educational seminars](#), first held exclusively in Florida but now throughout the USA, MSVN educates attendees on a variety of topics of importance to people affected by MS, including symptom management, communications (with health professionals and others), and connecting with others. Extensive educational information is also found on the [website](#), shared through the [bi-monthly e-newsletter](#), and on Facebook, Twitter, and [YouTube](#). A wonderful addition to the offerings of MSVN is the [MS Social Work Navigator Program](#).

The service is free of charge to the MS community and can connect callers to MS support groups, drug assistance programs, financial resources, education, information, counseling, transportation and much more. Call (888) 871-1664 to connect.

Visit [MSVN's website](#) to take advantage of the many educational resources offered and sign-up for the newsletter while you are there! Looking for a live event? Check them out and register [here](#). And why not attend the Neurological Aspects of MS, annual symposium? This all day event held December 2nd includes 5 speakers, a resource room, and for those not in the South Florida area, a chance to attend “virtually” via live-stream. Topics on the agenda include Pain and MS, available disease-modifying therapies, an integrative approach to MS, and Sex and MS, with ample opportunity for questions and answers throughout the day.

ACP is a proud partner of MS Views and News (MSVN) and appreciates all they do to educate and support those affected by Multiple Sclerosis. Want to see ACP CEO, Robert McBurney and MSVN CEO, Stuart Schlossman in action? Check out this [video](#) from [MS World](#).



*Stuart Schlossman
President of MSVN*

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