



Welcome to the REAL MS Report!

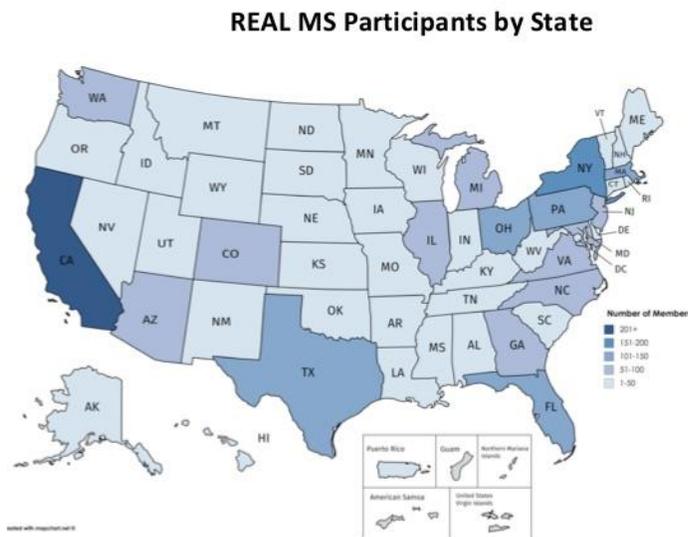
REAL MS – or Real Engagement About Life with MS -- is the ongoing iConquerMS study about the effects of MS on health and quality of life, and the steps that people with MS are taking to help manage those effects.

This study started in 2014 when the iConquerMS website was launched. In 2016 we began asking participants to provide updated information twice a year so that we could track changes over time. As a result we have a wealth of data that can be explored by researchers to answer a variety of questions. Because it's an ongoing study, this data will only grow more powerful over time.

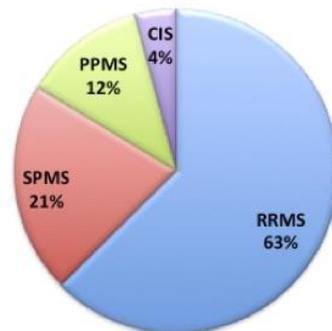
We want to share some of the interesting things we're learning through the REAL MS study with you. And we want to thank everyone who has participated in REAL MS so far! Your data holds the key to new breakthroughs in MS.

Who's participating in REAL MS?

To date, 2,814 iConquerMS members have participated in REAL MS. Most (2,389) are from the US, representing each of the 50 states as well as Puerto Rico and the District of Columbia. Seven states are the homes to over 100 participants each: California, New York, Massachusetts, Ohio, Florida, Texas, and Pennsylvania.



REAL MS Participants by Type of MS



Looking beyond the US, we also have 106 participants from Canada, 69 from the UK, and 27 from Australia (the home country of our co-Principal Investigator, Robert McBurney). We also have members from **50 other countries** including Norway, Turkey, Ghana, Kuwait, India and Brazil, to name a few!

Summer 2018 REAL MS is coming soon!

Keep an eye on your inbox for our invitation to take the new REAL MS Summer 2018 surveys. We'd especially like everyone to complete the very quick one-question Patient-Determined Disease Steps survey. The few minutes it takes to answer our surveys every six months will help uncover important new findings about MS. Thanks in advance for taking part!

How are REAL MS members managing their MS?

In each set of REAL MS surveys, we ask our participants about the disease-modifying therapies (DMTs) they're currently taking or used to take. Here are the DMTs that were most commonly being used by our members as reported in the Winter 2018 survey:

- Among our members with **relapsing-remitting MS**, 19% were on Copaxone or its generic version Glatopa; 16% were on Ocrevus or the earlier, similar drug Rituxan; another 16% were on Tecfidera; 14% were on one of the interferon beta drugs; and 12% were on Gilenya.
- For our members with **secondary progressive MS**, 32% were taking Ocrevus or Rituxan, and 11% were taking Tysabri.
- And 48% of our members with **primary progressive MS** reported that they were currently on Ocrevus or Rituxan. (Ocrevus is the only FDA-approved drug available today for PPMS.)

Reasons reported by REAL MS members for stopping past therapies:

My doctor recommended stopping the drug	25%
My MS got worse	22%
I didn't like the side effects	18%
I wanted to try another drug	8%
I had safety concerns	4%
I didn't like how the drug is taken	3%
Insurance issues	3%
Pregnancy reasons	1%
The drug was too expensive	1%
Other	15%

Wellness and diet strategies used by REAL MS participants

In addition to the available MS drugs, REAL MS participants are also trying a number of diets, vitamins and minerals, supplements, and wellness activities to manage their MS and improve other aspects of their health. In 2017 we began asking our participants which options they have used in the past 6 months, and whether they felt these options were helpful.

Here are some highlights from the data shared by 1,050 participants so far:

- The most frequently used option overall is **Vitamin D**, which was used by 858 people.
- Several wellness activities were deemed helpful by **80%** or more of those people engaging in them. These include **massage** (88%), **yoga** (86%), **chiropractic treatment** (86%), **exercise therapy** (Feldenkrais, Pilates, etc.) (85%), and **meditation** (84%).
- The most commonly tried supplements included **probiotics** (328 people), **fish oil** (324) and **biotin** (273). **Marijuana/cannabis** had been used by 194 people.
- Not as many people reported trying a special diet, but the most often reported were **organic foods** (160 people), **gluten-free** (157), **low-sugar** (154), and **anti-inflammatory** (152).

(Keep in mind that something that helps one person may be harmful to another. It's always a good idea to check with your doctor before trying any new diets, supplements, or wellness activities.)

Your research questions are influencing REAL MS!

We've received hundreds of thoughtful and interesting research questions from iConquerMS members through our surveys, email, and web site. Many of these indicate valuable topics that can be explored through REAL MS. We also look at the feedback that our REAL MS members send in along with their survey responses. Here are some of the ways we've improved REAL MS thanks to your helpful input!



- We added the Wellness & Diet surveys because of the number of research questions that our members submitted on this topic.
- We've modified questions and instructions over time when people have told us that the wording is confusing. This isn't always possible – such as when the survey was developed by other researchers and can't be changed – but we do our best to respond.
- We added a list of activities to our Physical Activity survey because of member interest.
- And we've added symptoms like MS hug and restless legs syndrome to our MS symptoms list based on your input.

Bringing REAL MS to the research community

Starting in 2015, we've been sharing information about REAL MS with the research community at scientific conferences. These include the annual meetings of the American Committee on Treatment and Research in MS (ACTRIMS) and the Consortium of MS Centers (CMSC). Our posters have covered topics such as stigma, social roles and activities, differences between relapsing and progressive forms of MS, and general characteristics of our cohort. You can see our posters at <https://www.iconquerms.org/materials-and-documents> if you're interested in learning more.

Curious about your past REAL MS responses?

You can look up your previous survey responses anytime you like! Here's how:

- (1) Log into your account at iConquerMS.org
- (2) Click on any Completed survey in the My Research Surveys list. You'll see a list of your completed surveys.
- (3) Then just find the survey you're interested in in the list, click on its name, and click on any of the individual pages to see your responses.

We hope you've enjoyed this report!

Please let us know what you'd like to see us cover in future reports by sending an email to info@iConquerMS.org. And feel free to forward this to anyone who might be interested in participating in REAL MS!