

# November 2019 Newsletter



## November 2019 Research Spotlight

### EVENTS



### MS Sucks, Singing for a Cure 2019

Stubby Pandav is the lead singer of the popular Chicago band, [Lucky Boys Confusion](#). After having symptoms for many years, he was diagnosed with MS a year ago. The timing of his diagnosis was especially difficult as his wife was three months pregnant with their first child at the time. However, he has been undergoing MS treatment and his last MRI showed no active lesions. He feels very blessed that his disease is now stable and he is feeling good. Stubby would like to raise awareness and funds so MS research can occur and hopefully one day a cure can be found.

The first annual concert “MS Sucks, Singing for a Cure” concert, hosted by Stubhy Pandav and benefitting ACP, will be held at 6PM on Saturday, December 21st, 2019 at The Bottom Lounge in Chicago, IL. The show will feature well-known bands such as Lucky Boy Confusion, The Plain White T's, and many others. The bands performing are donating their time and talent to support Stubhy, ACP, and to bring awareness to MS. Promotional merchandise will be available and there will be a raffle at the concert. Stubhy is directing proceeds to ACP to support our work to accelerate research in MS to improve the health, healthcare, and quality of life for those affected by MS.

If you're interested purchasing tickets to the MS Sucks concert, please click [here](#). Anyone interested in making a donation on Stubhy's behalf can click [here](#). For more information or questions, please contact Lindsey Santiago at [lsantiago@acceleratedcure.org](mailto:lsantiago@acceleratedcure.org) or 781-487-0013.

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## **The MS Research Mythbusting Webinar is now Available Online!**

While MS affects all races and ethnicities, minority populations may bear an unequal burden from the disease, including a higher risk of aggressive disease and disability. However, minority populations are severely underrepresented in scientific research. In fact, recent studies show that African Americans make up more than 13 percent of the U.S. population but only 5 percent of clinical trial participants and Hispanics, who make up 16 percent of the population account for only 1 percent of research participants.

To help raise awareness and address the misconceptions people often have about research participation in MS, the Multiple Sclerosis Association of America (MSAA) and ACP presented a national webinar, MS Research Mythbusting, on Tuesday, October 29, 2019.

MS expert neurologist Mitzi Joi Williams, MD discussed the role research plays in improving the health and well-being of people affected by MS, and the reasons why participation from minority populations is needed to develop treatments for all affected by the disease.

Did you miss MS Research Mythbusting and would you like to see it? Were you able to attend and would you like to see the program again? The webinar is now archived on the MSAA website. Anyone interested in watching it can click [here](#). This program is made possible through educational grants from Genentech and Biogen.

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## RESEARCH OPPORTUNITIES



### **A Study to Understand Exercise Behavior in People with MS**

**Study Title:** Social Cognitive Correlates of Physical Activity in Adults with Multiple Sclerosis in the United States.

**Study Purpose:**

Social cognition focuses on the role that thought processes play in our social interactions. Previous research suggests cognitive processes like social support, self-regulation and motivation significantly impact physical activity in adults in the general population. This study will evaluate various social cognitive factors that may be associated with exercise behavior in people with MS.

**This study involves:**

This study involves completing a questionnaire about your physical activity and health habits. The survey will take 25-40 minutes to finish. If you begin and want to finish later, you are able to save your progress and come back to answer the questions for up to one week. The valuable feedback that you provide will be used to help inform future exercise interventions for people with MS.

**Participating locations:**

The University of Alabama at Birmingham

**Researcher:**

Robert Motl, Ph.D.

**Recruiting:**

Anyone that is 18 years of age or older and has been diagnosed with MS is welcome to participate in this study. We hope that 1000 people across the United States will complete these questionnaires. Participation in this study is completely voluntary.

**Study website:**

If you are interested in participating in this study, please click [here](#), or e-mail Stephanie Silveira at [enrl@uabmc.edu](mailto:enrl@uabmc.edu).

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iConquerMS™

A Research Study  
EVERYONE  
can join!

**Real MS™ (Research Engagement About Life with MS)**

In the summer of 2016, the iConquerMS initiative launched REAL MS, a longitudinal study of MS. REAL MS participants complete questionnaires online twice each year on a

variety of subjects, including health history, diet, exercise and their experience with MS. A seventh round of REAL MS surveys are now available through the iConquerMS portal. Completing these surveys is one of the simplest ways you can accelerate MS research. The information collected will play a pivotal role in helping scientists and clinicians gain a better understanding of the health and quality of life over time for people with MS. REAL MS is just one of the many ways iConquerMS is facilitating research on topics of importance to people affected by the disease. **If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Already a member? Please [log in to your account](#) and complete your open surveys!**

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## NEW RESEARCH RESULTS



### **A new MS Treatment is approved!**

On October 30, 2019, Biogen announced that the U.S. Food and Drug Administration (FDA) approved [Vumerity<sup>TM</sup>](#) (diroximel fumarate), a novel oral therapy for the treatment of relapsing forms of MS. Diroximel fumarate is in the same class as Tecfidera® (dimethyl fumarate), but is believed to cause fewer gastrointestinal side effects, such as diarrhea, nausea, vomiting, and abdominal pain, than Tecfidera. This marks the culmination of a multi-year development program in partnership with [Alkermes](#) (a biopharmaceutical company in Ireland) and with the help of nearly 1,100 subjects participating in the research. With the approval, Biogen intends to make Vumerity available in the United States in the near future.