

Accelerated Cure Project for MS

April 2019



iConquerMS™ Spotlight – Expanding the MS Research Toolbox

The [MS Minority Research Engagement Partnership Network](#) (MREPN) was [featured](#) on the PCORI website earlier this month.

MS is a neurological disease that impacts the lives of people of all backgrounds, but such diversity is not reflected in those participating in MS research. Participation in research by people of all races and ethnicities is key to ensuring that discoveries, treatments, and prevention strategies are relevant to those populations. As discussed in our [February 2018 newsletter](#), the MREPN is a collaboration designed to identify and address disparities and increase participation by underrepresented communities in MS medical research. In October 2016, a team led by Hollie Schmidt at ACP was awarded a [Eugene Washington PCORI Engagement Award](#) that supported the building of the MREPN. These awards support projects that encourage active integration of patients, caregivers, clinicians, and other healthcare stakeholders as essential participants in patient-centered, [comparative effectiveness research](#) (CER). The MREPN team has made great strides toward this goal. In Hollie's words, "Our engagement award is aimed at understanding why there is a lack of diversity in MS research participation when it comes to racial and ethnic minorities. We've been doing a lot of learning about what the barriers are to participation and also what the facilitators of participation are. We're trying to disseminate that information to researchers and clinicians, as well as to the populations themselves. We are conducting a number of outreach activities. We're also disseminating the [results](#) of a survey we conducted among people with MS and are trying to publish them in a medical journal to reach the medical and research communities. We've also published a couple of toolkits, one for researchers and one for clinicians that help to educate them about the topic of underrepresentation in research and how they can help to



promote diversity in research.” When asked how a Eugene Washington PCORI Engagement Award made the team’s work possible, Hollie states, “We knew that ACP, being a small, independent nonprofit organization, could only do so much on our own. So, PCORI and its award enabled us to bring together stakeholders from different organizations, different advocacy groups, researchers, clinicians, industry representatives, communication specialists and, most importantly, people with MS belonging to minority groups, so we could all tackle this challenge together. I think it made for a much more impactful project and we were able to accomplish much more than any one of us could have done on our own.” In September, the iConquerMS governance and other stakeholders in the MS community gathered at our [Leadership Summit](#) to discuss the future direction of the initiative. A key focus of this meeting was collaborations, such as MREPN, in which partners come together as equals, take fullest advantage of differing ideas to approach the problem at hand and achieve the desired outcome (in this case, diversity in MS research). To keep the momentum going, a Next Steps Committee is working to bring this important work to fruition. This is one of the many ways the ACP/iConquerMS team is working to improve the health and quality of life of people living with MS.

