

December 2019 Newsletter



Forging Ahead to New Innovations in 2020

People living with MS are the heart and soul of [iConquerMS](#). A primary objective of this participant-powered initiative is to enable all people living with MS to participate in research. Network members can not only contribute data about their MS experience, but also steer the direction of research by contributing their ideas for topics to be studied and questions to be answered. Ideally, tens of thousands of people from all parts of the country, from all backgrounds and ethnic groups, and of all ages and stages of living with MS will participate. This diversity will create a rich, interactive resource for MS research.



As we discussed in our [February 2018 newsletter](#), diversity and inclusion are key to ensuring medical research benefits all. Minorities are under-represented in MS research, in large part due to a history of injustice in clinical trials resulting in a sentiment of mistrust among these populations. In addition, studies often have age restrictions that limit participation of people with MS under the age of 18 and over the age of 60. As a result, these important data are missing. One area ACP

will focus on in the coming year will be increasing the representativeness in research in a variety of dimensions including race, ethnicity, age, ability, and others. These efforts are critical to ensuring that participation in research is available to all and reflects the needs and priorities of diverse populations. In 2016, ACP received a [Eugene Washington PCORI Engagement Award](#) to support development of the [MS Minority Research Engagement Partnership Network](#) (MREPN). To date, this collaboration has generated new information and tools for [patients and care partners](#), [health care professionals](#), and [researchers](#) to facilitate the participation of ethnic and racial minorities in MS research and research generally.

In May, ACP and [UsAgainstAlzheimer's](#) received Genentech's first-ever [Advancing Health Equity in Neuroscience Award](#). This award, also focused on diversity, inclusion and equity in research, allows each organization to identify themes and common priorities among patients and caregivers of color and how they relate to interactions with healthcare providers, care practices and participation in research. In the coming year, these findings will be used to create educational materials that address the key needs and concerns of individuals living with, or caring for, someone living with MS.

In 2019, building on the work of the MREPN, ACP and the Multiple Sclerosis Association of America (MSAA) joined together to create and conduct a series of "[Research Myth Busting](#)" educational events designed to educate and inform people with MS and care partners on topics related to participation in research. The goal of this program was to address the misconceptions ("myths") associated with participation in, regulations around, and goals of research. The desired outcome is people living with MS and their care partners (particularly those from underserved populations) would be more likely to participate in research as a result of an improved understanding of the role research plays in improving the health and quality-of-life of people affected by MS. ACP will work to cultivate the seeds sown by this educational program in the coming year. Wish you could have participated in one of the Mythbusting events? Watch the [Research Mythbusting](#) video instead!



In 2020, the ACP team will continue its work to expand the role of MS care partners in research and innovation. As critical partners to those living with MS and keen observers of



the daily burden of the disease and the most important unmet needs, caregivers can provide a unique view into understanding the needs and issues of people living with MS. The recognition of the importance of care partner observations in research and care is growing, and ACP will be

expanding many of its initiatives to include these important perspectives. Additionally, the important topic of the health, well-being, and quality of life of care partners is finally receiving its due attention and becoming more of a focus of research and care. ACP is enthusiastically developing programs which will contribute to improved health, healthcare, and outcomes for all affected by MS – those living with the disease and those who care for them.

In 2019, ACP hosted three small gatherings, called Research Studios, in collaboration with healthcare providers in Atlanta, Denver, and Worcester. The purpose of the Studios was to bring together people of color living with the disease to share their stories about being diagnosed with and living with MS, in order to identify their key questions about MS as a basis for future research. Throughout the Studios common themes have emerged including a deep desire for participants to know what caused their MS, how to achieve faster diagnoses for those still undiagnosed, what wellness activities could improve their quality of life, and how the disease can be cured. In 2020 and beyond, ACP will continue to drive forward research collaborations on topics of the greatest importance and priority to those living with the disease.



In the New Year, ACP will continue to support MS researchers with the open access resources they need to accelerate their studies. This includes ready access to samples and accompanying data from the ACP Repository, offering the capabilities to collect biosamples in the future, and engaging researchers to access the people and data of iConquerMS to advance their research. One key component of iConquerMS, [REAL MS](#) (Research Engagement About Life with MS), is an ongoing study of MS that was launched three years ago. Study participants periodically complete questionnaires about their MS experience through the iConquerMS portal. These data are a growing and powerful resource for MS research, providing investigators and clinicians with real-life information on what living with MS is like. Researchers are also able to engage meaningfully with iConquerMS

participants through in-person and virtual interactions to benefit from their expertise and insights.

In 2020 and beyond, the [iConquerMS portal](#) will continue to be used for data collection and communication with research participants in a number of other studies. One such study is [STEP for MS](#)



(Supervised versus Telerehab Exercise Program for People with Multiple Sclerosis). The purpose of this research is to see if an at-home exercise program can help improve mobility and quality of life for people with MS. [Healthy Mind Healthy You](#) is another study looking at how to use mindfulness to cope with the stress of living with or caring for someone with a disease. This could help people with more than 100 different medical conditions, including MS. In the near future, iConquerMS will also play an instrumental role in a research collaboration with [Dr. Mitchell Wallin](#) focused on MS telehealth services. The study team will design, implement and conduct a survey of iConquerMS participants on the awareness of, use of, and experiences with telehealth. ACP will also provide input to assist with data analysis and results dissemination. The project will provide a more complete picture of how telehealth can best move forward in both the government-sponsored and private health insurance environments within the United States.

In the past year, iConquerMS has facilitated research studies on topics of interest to people with MS, such as those listed above. In 2020 we will continue our efforts to go a step further by enabling research on a specific topic proposed by the network's members. Through a two-year engagement award from PCORI to enable Participant-Driven Research (PDR), iConquerMS will focus on establishing a comprehensive process for advancing research topics suggested by its participants into funded research studies that impact the health, healthcare and quality of life of people affected by MS. This process will cover activities from collecting and prioritizing research topics suggested by people affected by MS to engaging researchers and other stakeholders for the purposes of ultimately advancing those topics into co-created and funded research studies.



From the initial funding application for the creation of iConquerMS to today, ACP has engaged a broad set of stakeholders in the conception, design, and conduct of iConquerMS. Today, the network benefits from the input of people living with MS, support partners, clinicians, researchers, MS advocacy organizations and healthcare companies. Our plan to add PDR capabilities to iConquerMS in the coming year and beyond will be strengthened by this existing community of highly engaged stakeholders. The iConquerMS community will also be of great importance as we strengthen our dissemination capabilities as they represent several influential channels for dissemination activities. We look forward to an exciting and productive New Year! Stay tuned!