

September 2021 Newsletter



MS in African Americans

Historically, the medical community has held to the premise that MS primarily affects Caucasians, particularly those of Northern European descent. However, researchers are uncovering new information about the disease in other racial and ethnic populations that suggests the disease is more common in people of color than originally thought. In addition, there is evidence that MS symptoms, disease course and the efficacy of treatments vary among minority groups.

A [2013 study](#) looked at three years of data from more than 3.5 million members of the Kaiser Permanente Southern California health plan and identified 496 people who were diagnosed with MS during that time. Results suggest that African Americans have a 47 percent higher risk of MS compared with Caucasians, while Hispanics and Asians have a 58 percent and 80 percent lower risk than Caucasians, respectively. Interestingly, the higher risk in African Americans was seen only in women, while the lower risk for Hispanics and Asians was seen in both sexes. These data show that African American women have triple the risk of MS that African American men do. Similarly, [researchers](#) at the Department of Veteran's Affairs Medical Center found that among U.S. military veterans, Black people have the



highest incidence of MS out of all races and ethnicities in the study group. Their data show the incidence of MS in females of all races is three times that of their male counterparts.

There is mounting evidence that MS symptoms tend to be more severe and disease progression is more rapid in African Americans. Studies performed in [2010](#) and [2016](#) found that African Americans with MS have a more severe disease course than Caucasian Americans. [Investigators](#) at the University of Southern California found that Black people with MS are more likely to have disease involving the eyes or spinal cord than white people, both of which predict greater disability. The study team notes this greater tendency toward disability is also related to lower access to healthcare in general, and MS specialists in particular, in Black communities. [Researchers](#) at John's Hopkins School of Medicine suggest that both brain and retinal (eye) atrophy happen faster in African Americans than in Caucasians with MS and suggest that African Americans with MS may benefit from a more aggressive therapeutic approach.

A number of studies suggest that MS disease modifying therapies (DMTs) are less effective in African Americans than Caucasian Americans with MS, although it's important to note



that the evidence is limited in this area due to the [lack of diversity in clinical trials](#) for MS treatments (resulting in a low number of minority participants in these studies). [Researchers](#) at the Medical University of South Carolina found that African Americans with MS have a poorer response to DMTs in general than Caucasian people with MS.

Investigators state that more research is needed to confirm these results. The [EVIDENCE study](#) compared the response to interferon beta-1a treatment (Avonex and Rebif) in 36 African Americans with MS and 616 white people with MS. Results showed the Black participants experienced more exacerbations and were less likely to remain exacerbation free. They also developed more new MS lesions on MRI. Despite the small sample size, African American participants appeared less responsive to treatment than white participants. Researchers state that it is difficult to base these differences solely on response to treatment given the potential difference in MS disease course in African American people with MS. According to an [abstract](#) that was presented at a recent American Academy of Neurology (AAN) meeting, the rate of [B cell recovery](#) differs in Black people and white people with MS taking B cell depletion therapies like rituximab

(Rituxan) or ocrelizumab (Ocrevus). Investigators looked at the medical records of 168 people, of whom 134 had MS (61 identified as Black, 60 identified as white). Six to twelve months after treatment, 76 percent of Black participants had B cells reappear in the blood, compared to 33 percent of white participants. Further study is necessary to determine whether or not this type of treatment wears off more quickly in African Americans with MS.

A [recent study](#) sheds light on the disease experience of Black people with MS. Researchers interviewed 19 African American women about the disease's effect on their lives. Many reported that their MS diagnosis was a surprise to them and their doctors because of the common belief that MS is a "Caucasian disease." For this reason, many participants felt their diagnosis had been delayed while their physicians initially focused on other diseases considered more typical in African American individuals. Results suggest other challenges African Americans with MS face include living with losses related to social and family activities, independence, and employment. Key coping strategies included coming to grips with the diagnosis, working through MS challenges, and pushing forward. Participants also indicated that taking care of themselves and their faith was of great benefit. [The Black MS Experience Summit](#) is a program offered by the National MS Society. This three-day virtual event gives the Black MS community an opportunity to connect with others who understand the distinct experience of life with MS as a Black person. The Summit features leading MS experts who can speak to this experience to offer support, guidance and updates in research.



It's important to note that a wide variety of environmental, genetic and social factors may all contribute to the onset of MS and worsen outcomes. For example, a [2019 study](#) found that MS is 38 percent more prevalent in the Northeast than in the South. One reason for this is that people who live in cold northern climates are less likely to expose their skin to sunlight (which enables the natural production of vitamin D) and vitamin D deficiency is a risk factor for MS. Interestingly, the [MS Sunshine Study](#) supports the conclusion that sun exposure reduces the risk of MS in African Americans and Hispanics, however results suggest this effect is independent of

vitamin D levels. According to investigators, higher blood levels of vitamin D were associated with a lower risk of MS in white people only. The [genetics of MS](#) are also complex, with as many as 200 different genes involved. To complicate things further, there is [evidence](#) that the genetic makeup of nearly all African Americans reflects a mixture of ethnic groups. For example, due to the history of slavery in the United States, Black Americans often have Northern European ancestors. They may also have Native American or Asian forebears. Differences in the use and receipt of health services, cultural beliefs, and distrust of the medical profession may also contribute to worse outcomes.

Regardless of race, it's important for anyone at risk of developing MS to recognize its symptoms and seek diagnosis and treatment early, when it's most effective. [Read on](#) to learn more about the work that the [MS Minority Research Engagement Partnership Network](#) is doing to increase diversity in MS research so its findings apply to and benefit people of all ethnic and racial backgrounds. Through efforts like this, everyone living with the disease can receive the best care!



MS Research That Benefits Everyone

People of all genders, ages, races and ethnicities require medical treatment. Medical research helps us learn what treatments work best for which people. It's important for participants in clinical trials to "look like" the patients who may end up taking the treatments.



When research involves a group of people who are too much alike, the findings may not apply to or benefit everyone. Minority populations are severely underrepresented in MS research and clinical trials. A [2015 review](#) showed that out of nearly 60,000 published articles about MS, only 113 (0.2%) focused on African American and 23 (0.04%) focused on Hispanic American people with MS. This could partly be due to [past injustices](#) that have led people in these communities to have less trust in clinical research than they otherwise might have. The end result is researchers and clinicians don't have a good understanding of how MS affects minorities, and which treatments work best in these populations.



The [MS Minority Research Engagement Partnership Network](#) (MREPN) is a group, founded and led by the Accelerated Cure Project (ACP), that is dedicated to increasing diversity in MS research so that people of all ethnic and racial backgrounds can receive the best care. The Network consists of a wide range of stakeholders involved in overcoming MS and health disparities, including advocacy partners, clinicians and researchers, industry representatives, minority health organizations, community organizers, business leaders, educators, faith institutions, and people with MS belonging to minority communities (both African American and Hispanic American). The MREPN [website](#) is a rich resource for anyone interested in participating in research. It contains helpful information on [what to expect as a research participant](#), [how research participants' rights are protected](#) and a [listing of MS studies](#) looking for participants. Also included is an [MS Minority Health Hub](#) which contains useful information, such as articles, reports and news about MS in minority communities.

In an effort to understand why the disparity in MS research exists, the MREPN designed and implemented a survey about research experiences and opinions. Over 2,500 people with MS from diverse backgrounds completed the survey. [Results](#) showed minority groups have specific concerns regarding mistrust, receiving poor-quality care, unemployment, health insurance, and legal status. Across all groups, the biggest concern about participating in research is not being fully informed

about the study. African Americans are more concerned about being taken advantage of by the research team and about having their personal information released without approval. These findings shed light on the concerns that investigators must address in order to recruit a diverse population of subjects in their studies.

Members of the MREPN used survey results to develop three toolkits for the key stakeholders in the research process, aimed at boosting enrollment of minorities in MS research studies. The [Community Partner Toolkit](#) is designed to increase awareness about the importance of diversity in MS research and to give people from all racial and ethnic backgrounds the confidence and knowledge to explore available study opportunities. The [Health Care Professionals Toolkit](#) provides insight for healthcare providers into the reservations their patients may have about research participation and guidance on how to address them. This resource also contains information about current MS research opportunities. The [Research Professionals Toolkit](#) helps researchers better understand what is currently known about MS in different racial and ethnic minorities, sheds light on the perceptions and concerns people in different minority groups may have about research, and helps investigators reach out to these communities and work with them in ways that are culturally appropriate, effective, and mutually beneficial.



For those interested in participating in MS research, there are a number of studies that are currently looking for participants with MS from minority communities.

MS Research Opportunities for People of Color

[iConquerMS](#) is open to anyone who wants to help shape and accelerate MS research. In order to diversify its membership, the initiative has appointed a RIDE Council (Research, Inclusion, Diversity and Equity) that will come together with people in the MS community who belong to underrepresented groups, invite them to join the network, and brainstorm ideas on how to better serve their community.

The [North American Research Committee on MS](#) (NARCOMS) is a global registry of more than 38,000 people with MS that is focused on MS research, treatment, and patient education. It has supported past research analyses on MS in African Americans and Hispanics/Latinos.

The [National African Americans with MS Registry](#) is working to accurately estimate the number of Black people diagnosed with MS in the United States and their geographic distribution. With the data, researchers can identify any barriers to accessing quality healthcare in minority communities and develop strategies needed to undo any inequities that may exist.

The [Multiple Sclerosis Genetic Susceptibility Project](#) is a multi-center research study dedicated to better understanding the role of genetics in the development and progression of MS. The project includes an [African American Study](#) that is recruiting Black people on an ongoing basis to shed light on hereditary factors that may affect the course of the disease in this population.

[Investigators](#) in California, Florida and Puerto Rico are inviting Hispanics/Latinos diagnosed with MS within the last two years to participate in a study about the impact of genetics and culture on disease severity.

The [Alliance for Research in Hispanic Multiple Sclerosis](#) is recruiting Hispanic Americans for a study about factors that affect MS risk and experience.

The [CHIMES study](#) is underway to better understand how Ocrelizumab (Ocrevus) helps Black/African American and Hispanic/Latino people with MS. This study is designed to bridge participation gaps in previous clinical trials for this treatment.



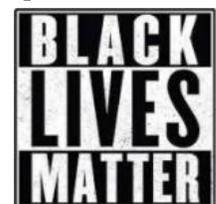
Events of the past year have unexpectedly shed light on the racial disparities that exist in research and society, in general. A [recent study](#) shows that the COVID-19 pandemic has impacted communities of color more severely.

This has led to a sense of urgency surrounding enrolling minorities in vaccine clinical trials. Community leaders are emphasizing the necessity of

diversity and inclusion in research and how important it is for minorities to participate in studies.

The murder of [George Floyd](#) and the Black Lives Matter movement has significantly increased awareness of racial injustices and inequities in all dimensions of life, including the disparities that

exist in MS research. There's growing recognition of the conditions in minority communities that not only affect an individual's access to healthcare, but also their ability to participate in research. As a result, researchers are starting to think more about what they are doing that is limiting who can participate clinical trials.



ACP founded the MREPN in October 2016 and has led the initiative since its inception. In light of the current climate, the network is taking stock of where things stand and brainstorming to determine the most effective way to have the most impact in the future. Members are pondering such important questions as can the MREPN communicate a sense of urgency about overcoming inequities in MS research? Can the group promote transparency and accountability? Can the network be more effective at disseminating successful approaches and best practices? Can the initiative exert some influence on decision makers toward this end? The MREPN is digging deep into these questions as they develop strategies and solutions to promote research participation among racial and ethnic minority groups. This will ensure that MS research findings apply to and benefit people of all racial backgrounds and all individuals living with MS can receive the best care possible. Are you a researcher looking for insights into how to diversify your research? Are you a healthcare provider looking for resources to use to engage your patients of color in conversation about research participation? Are you a person affected by MS who wants to learn more? Please email us at msminorityresearch@acceleratedcure.org. We welcome new perspectives and are happy to answer any questions you might have!



September 2021 Research Spotlight

RESEARCH OPPORTUNITIES



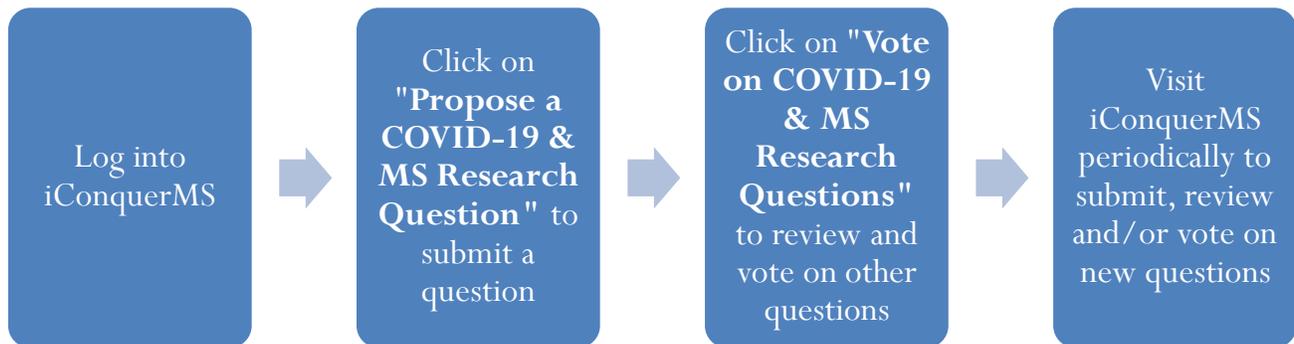
Learn more or get started at iConquerMS.org

Power MS Research With Your Questions and Priorities!

iConquerMS is leading the movement to include the patient perspective in every step of MS research. Now, network members can play a larger role than ever before in initiating and collaborating with researchers on studies that will expand knowledge in areas that matter most to people affected by MS.

iConquerMS members have always been able to submit research questions to the initiative. It's now possible to comment and vote on questions submitted by the community through the newly launched [Our Questions Have Power](#) program. Questions that are high priority for the iConquerMS community will be shared with researchers, who will work in collaboration with the iConquerMS community to develop them into research studies.

Participation is easy!



If you are not already a member, please consider [joining](#) iConquerMS, the only people-powered research network for MS. Add your voice to those working together to improve MS care and bring us closer to a cure!

September 2021 iConquerMS Spotlight

A New Survey on the use of Alternative Medicine is now available!

Researchers from Gryphon Scientific and the Veterans Health Administration are conducting a new research study about the use of **complementary and alternative medicine (CAM)** by people with MS. CAM includes visits to providers such as acupuncturists, practices you can do on your own such as yoga, and products such as herbal therapies that are not typically part of conventional healthcare. The study team is interested in knowing how different types of CAM are being used, how much it costs, whether people with MS consider it to be helpful, and whether it's being incorporated into overall MS care along with conventional medical care.



Who can participate?

iConquerMS members who have been diagnosed with MS, whether or not they use any form of CAM.

What does the study involve?

The study involves completing an on-line survey on the iConquerMS web site. It will take around 15-30 minutes to complete.

Who is funding the study?

The study funder is the National Multiple Sclerosis Society.

How can I take the survey?

Log into your account at www.iConquerMS.org and click the button that says "View and Complete my Research Surveys." You'll see a survey named "Use of Complementary and Alternative Medicine in MS." Click on the survey name to get started.

Study participants will be entered into a **drawing for an Amazon Gift Card**. We will be awarding two \$100 gift cards and thirty \$10 gift cards.

Thank you for helping us learn about the use of CAM by people with MS! Not yet a member of iConquerMS? Please [join](#) today and start powering MS research with your insights and experiences!