## MS in Underserved Communities: Where Do We Go From Here?



One of the many reasons I entered the field of neurology and did extra training focused on multiple sclerosis was because I knew I would be on the cutting edge of medical discovery.

I have been fortunate to see numerous advances, from improved understanding of the disease and updated imaging techniques to the expansion of treatment options from a handful to more than 20 for those living with MS. Although I have seen many people now able to manage their MS more effectively with less disability, there is still more work that needs to be done. There are still groups of people who do not have equal access to diagnosis, specialty care and treatment options, including participation in research trials.

Just as our understanding of MS has progressed over time, so has our understanding of MS in ethnically minoritized groups. I focused on this work early in my career because, although I learned of MS as a disease in young white women, the population I served in Georgia was largely Black and African American.

We <u>now have research suggesting</u> that the risk of MS in Black and Hispanic individuals is much higher than we previously thought, and that outcomes may be worse in some members of these populations.

When we think about communities and people groups that are underserved, certainly ethnically minoritized groups come to mind. But there are many who need additional

attention and resources, including those with low socioeconomic status, rural populations, older populations and members of the LGBTQ+ population, to name a few. Underserved communities may experience decreased access to care, leading to more severe outcomes over time.

What I'm extremely excited about is the work focused on better understanding MS in minoritized groups. This includes efforts to empower individuals to advocate for themselves, understand why there are disparate outcomes and increase diversity in clinical trials. I have participated in many work groups, steering committees and other initiatives focused on MS in Black and Hispanic populations, and there is a great deal of amazing work going on in this space.

In the area of patient advocacy, organizations like the National Multiple Sclerosis Society have created focused programming, including the <u>Black MS Experience Summit</u>, to educate and empower the community. I have participated and spoken at multiple in-person and virtual programs on topics ranging from current research on minoritized groups with MS to the importance of diversity in trials and how to improve health equity.

We have also seen the rise of dynamic patient advocates who are sharing their stories and empowering others to take control of their health, such as Tyler Campbell, Damian Washington and Victoria Reese – the Founder of We Are III, an organization focused on the needs of Black women with MS.

In the area of research, I have worked with dynamic thought leaders, such as Dr. Annette Okai and Dr. Lilyana Amezcua, to publish research focused on Black and Hispanic Individuals with MS, as well as create frameworks to improve health equity.

This work includes creating a diversity, equity and inclusion statement for the Society and becoming chair of the Diversity and Inclusion Committee for the Consortium of MS Centers. Additionally, we worked together with many others to develop the protocol for the first clinical trial focused on Black and Hispanic individuals with MS, the CHIMES Trial. I was also instrumental in the creation of the National African American MS Registry (NAAMSR).

Finally, the work of my colleagues has inspired me to do work with my own non-profit organization, the Joi Life Foundation. I have a podcast called <u>Brain Chat with the Nerdy Neurologist</u> and discuss many topics, including wellness practices, symptom management and diversity in research. We do round-table discussions with MS specialists and patient advocates, with the goal of empowering people to receive the best care possible.

Improving access to care for diverse populations within the MS community requires multiple approaches that address socioeconomic, cultural, geographic and disability-related barriers.

By promoting cultural competence, leveraging technology, expanding outreach efforts and fostering community partnerships, we can work toward achieving health equity and ensuring

that all individuals with MS receive the support and care they need to live their best lives.

Together, we can bridge the gap and create a more inclusive and accessible healthcare system for everyone affected by MS.

Editor's Note: April is National Minority Health Month. You can get involved by <u>participating in a clinical trial</u> and learn more about the healthcare barriers that people of color face by reading the article "<u>Obstacles to Access</u>."