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National African American Multiple Sclerosis Registry: Advancing Equitable Care and Outcomes for African Americans with Multiple Sclerosis

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Abstract Text:

Background:

Historically, multiple sclerosis (MS) has been underdiagnosed among African Americans with MS (AAwMS). Recent evidence suggests that AAwMS have a different clinical presentation, increased disease incidence and burden, and worsened long-term outcomes versus Caucasians with MS. Due to the underrepresentation of AAwMS in clinical trials, there are limited data to make informed, generalizable conclusions about the natural history, prognosis, and therapeutic response in this population. The goals of the National African Americans with Multiple Sclerosis Registry (NAAMSR) are to: i) expand evidence-based knowledge of MS and its management in African Americans; ii) educate AAwMS and increase their opportunities for clinical trial participation; and iii) engage in research that will benefit this underserved community.

Objectives:

To raise awareness about the mission, objectives, and design of the newly launched NAAMSR.

Methods:

Self-identifying AAwMS will be recruited via brochure distribution at healthcare facilities and print, broadcast, internet, and social media outreach. Educational outreach to AAwMS will also be prioritized. Participants will be asked to complete an extensive questionnaire on the NAAMSR website (www.naamsr.org) at registration and annually thereafter, providing information on demographic and socioeconomic status, timing of symptom onset and diagnosis, MS pattern, use of disease modifying therapies (DMTs), quality of life, disability status, and access to care. The registry was launched on September 1, 2020 with a target enrollment of 20,000–30,000 registrants in urban, suburban, and rural communities nationwide.

Results:

Among other measures, the registry will facilitate clinical trial recruitment and examine the impact of social determinants of health on access to care, timeliness of diagnosis, DMT initiation, and long-term outcomes; the potential effect of ethnicity on disease pattern and severity; and the relationship between disease severity and medication efficacy.

Conclusions:

The NAAMSR will provide a platform for addressing the critical and urgent health disparities experienced by AAwMS.

Title:

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Would you give CMSC and International Journal of MS Care the first preference to any article that is submitted for publication based on this abstract presentation?:

Yes

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