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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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Background

- MS is an autoimmune demyelinating disorder of multifactorial etiology, involving a complex interplay of genetic and environmental factors, and sex^{1,2}
- Current understanding of the impact of **race and ethnicity** on MS pathogenesis, disease course, and treatment response is limited, which may be attributable to the **underrepresentation of minority populations in clinical trials**¹
- Historically, the risk and incidence of MS has been considered higher in Caucasian Americans versus other ethnic groups;¹ however, there is increasing evidence to support an impact of MS in other ethnicities:
 - A cohort study of 2691 Gulf War veterans (male: 66.1%; female: 33.9%) reported MS incidence rates of 12.1 and 9.3 per 100,000 for African Americans and Caucasian Americans, respectively, with African Americans having a 27% higher risk³
 - In a multi-ethnic cohort study (N=496, >9 million person-years of observation), the incidence of MS was higher among African Americans (10.2 per 100,000 person-years) than Caucasian (6.9), Hispanic (2.9), and Asian Americans (1.4)⁴
 - African Americans often have **more severe MS at diagnosis**⁵ and a **more aggressive disease course** versus other racial groups in the US^{1,6}

MS, multiple sclerosis.

1. Khan O, et al. *Neurol Clin Pract*. 2015; 5(2): 132-142; 2. Sawcer S, et al. *Lancet Neurol*; 2014;13(7): 700-709; 3. Wallin MT, et al. *Brain*. 2012;35(6): 1778-1785;

4. Langer-Gould A, et al. *Neurology*. 2013; 80(19): 1734-1739; 5. Cree BA, et al. *Arch Neurol*. 2009; 66(2): 226-233; 6. Kister I, et al. *Neurology*. 2010; 75(3): 217-223.

AAwMS Experience Significant Disparities in Clinical Outcomes and Healthcare Access versus CAwMS

Disparities in Clinical Outcomes

- Greater frequency of multi-site involvement at initial clinical presentation versus CAwMS¹
- Worse EDSS scores at diagnosis (2.9 vs 1.8; $p=0.0002$)²
- Increased incidence of opticospinal MS (16.8% vs 7.9%; $p<0.001$) and transverse myelitis (28% vs 18%; $p=0.001$)¹
- Shorter median time to ambulation with a cane (16 vs 22 years; $p<0.0001$) and wheelchair dependency (30 vs 38 years; $p=0.05$)¹
- Faster atrophy rates of:
 - Grey matter ($-0.9\%/year$ vs $-0.5\%/year$; $p=0.02$)³
 - White matter ($-0.7\%/year$ vs $-0.3\%/year$; $p=0.04$)³
 - Retinal nerve fibre layer ($-1.1\%/year$ vs $-0.8\%/year$; $p=0.02$)³
 - Ganglion cell inner plexiform layer ($-0.7\%/year$ vs $-0.4\%/year$; $p=0.01$)³

Disparities in Healthcare Access

- A greater proportion of AAwMS versus CAwMS have never been cared for by a neurologist specializing in MS or at a MS clinic⁴
- AAwMS are less likely to be provided with equipment, technology and modification services, case management, and nursing services than CAwMS, despite experiencing greater mobility impairment⁵
 - Estimates of predicted Medical expenditures have been shown to be lower for AAwMS (men: \$56,088.17; women: \$56,335.60) than CAwMS (men: \$70,002.33; women: \$59,783.15)⁵

AAwMS, African Americans living with multiple sclerosis; CAwMS, Caucasian Americans living with MS; EDSS, Expanded Disability Status Scale; MS, multiple sclerosis.

1. Cree BA, et al. *Neurology*. 2004; 63(11): 2039-2045; 2. Naismith RT, et al. *Mult Scler*. 2006; 12(6): 775-781; 3. Caldito NG, et al. *Brain*. 2018; 141(11): 3115-3129;

4. Buchanan RJ, et al. *Ethn Dis*. 2010; 20(4): 451-457; 5. Fabius CD, et al. *BMC Health Serv Res*. 2018; 18(1): 773.

National African Americans with Multiple Sclerosis Registry

The NAAMSR
(www.naamsr.org) was
launched on
September 1, 2020

Primary Objectives

1. Expand evidence-based knowledge of MS and its management in African Americans
2. Educate AAwMS and increase their opportunities for clinical trial participation
3. Engage in research beneficial to AAwMS

Registry Design:

- **Target enrollment:** 20,000–30,000 registrants in urban, suburban and rural communities
- Self-identifying AAwMS are being recruited via brochure distribution at healthcare facilities, and print, broadcast, internet, and social media outreach
- Registrants are sent an **extensive questionnaire via email after registering on the NAAMSR website**, and annually thereafter
 - Questionnaire topics include demographic and socioeconomic status, timing of symptom onset and diagnosis, MS pattern, use of DMTs, quality of life, disability status, and access to care

Primary Measures:

- The impact of social determinants of health on access to care, timeliness of diagnosis, DMT initiation, and long-term outcomes
- The potential effect of racial identity on disease pattern and severity
- The relationship between disease severity and medication efficacy

Enrollees
as of
March 18,
2021:
173

Conclusions

- AAwMS may experience increased disease burden and incidence, and worsened long-term outcomes versus CAwMS¹⁻⁴
- The NAAMSR will provide a platform for addressing the critical and urgent health disparities experienced by AAwMS by:
 - Collecting real-world data on demographics, disease course, and access to care and treatment from AAwMS in different regions
 - Advancing health equity for this population through education
 - Engaging in collaborations/partnerships that advance the care and wellbeing of AAwMS

