

## Working toward a solution

The NAAMS Registry was purposefully created to benefit African American people, who have not historically been adequately represented in efforts to improve the lives of people with MS. Too little is known about how MS uniquely affects African Americans, nor is there enough relevant information on MS available to African Americans seeking resources. We hope that participation in this Registry and engagement with the African American community affected by MS will be powerful tools in shaping a solution.

## Our Purpose

The NAAMS Registry was created by a group of African American neurologists who are nationally-recognized experts in MS. Our goal is to improve care for African Americans with MS by increasing patient and healthcare provider knowledge, while improving access to the best care. The Registry also aims to increase opportunity for African Americans interested in being part of clinical trials, so that the therapeutic needs of African Americans with MS are better addressed in research and medication development.

PLACE  
STAMP  
HERE

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[www.naamsr.org](http://www.naamsr.org)

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## National African Americans with Multiple Sclerosis Registry



**NAA**MS REGISTRY

### **What happens once I sign up?**

We will send you surveys once or twice a year to learn about you, your disease, and the treatments or services you use to help manage your disease. A number will be assigned to represent your information, so your name will never be linked to your clinical information. All information you provide will be secured. You will also receive our MS Facts newsletter, which will communicate important information about MS as well as how the registry is being used.

### **Who sees my information?**

Only Registry researchers will see your information, but they will never know your personal identity. Your contact information will only be used to send you follow-up surveys, Registry information, and the newsletter. Your personal information will never be used in reports or given to insurance companies.



### **How is information about me used?**

The information you and other persons with MS provide will only be used for research purposes. The data will be used to learn about and understand what factors may make African American people more likely to develop MS, how their symptoms start and progress, and the effectiveness of MS treatments in African Americans. Individual data will never be used in scientific publications or presentations.



### **Participation is voluntary**

You are not required to answer all survey questions, and you will not receive payment for participating. You may choose to stop your participation at any time. If you decide to stop taking part, please notify us by using the NAAMS Registry contact information. Information that you have already provided will still be included as part of the registry, but no further information about you will be collected. Whether or not you remain a participant, your information will never be disclosed.

### **How do I participate?**

To sign up or learn more about the registry, visit us at:

**[www.naamsr.org](http://www.naamsr.org)**

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