

# LIVING Well

WITH MS

A GUIDE FOR BLACK AMERICANS

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DIAGNOSED IN 2009



Presented by...



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## INTRODUCTION



Multiple sclerosis, or MS, is an unpredictable and chronic disease of the **central nervous system (CNS)** that progresses over time. There has been a steady increase in the prevalence of MS (the number of all people with MS) over the past 50 years, and it is estimated that nearly 1 million people in the United States have MS.

MS is thought to result from interactions between factors such as genetic tendencies, gender, and environment. Another factor is ethnic background, but its role is still uncertain. Historically, it was thought that MS mainly affected white people of northern European ancestry, but recent studies have theorized this may not be the case.

Minority populations are often underrepresented in clinical trials in the United States, and in 2015, researchers noted that of the 60,000 articles written on MS only 113 focused on MS in Black people.

In the last 10 years, there has been growing awareness of MS in people of color, with more research being conducted. Recent studies have shown that Black and Latinx Americans have a higher rate of MS versus their ancestral countries of origin, and the number of new cases of MS is increasing in Black Americans, which may suggest changes in genetics and environment.

With ongoing research, more is being learned about the impact of MS on other ethnic backgrounds.



**DAWNIA**  
DIAGNOSED IN 2006

To help raise awareness of MS in the Black community, the National Multiple Sclerosis Society and Janssen Pharmaceuticals have partnered to provide this guidebook. Its goal is to help educate people with MS and caregivers about how the disease can affect Black Americans and how that differs from how MS affects white Americans.



**ANGELA**  
DIAGNOSED IN 1992

## WHAT IS **MS?**

MS is an autoimmune disease, meaning that the immune system itself becomes misdirected and attacks healthy cells and tissues of the body. In MS, the immune system attacks the central nervous system (CNS), which is made up of the brain, spinal cord, and optic nerves.

Like insulation on an electrical wire, myelin is the fatty covering that surrounds and insulates nerve fibers in the CNS. Inflammation in the CNS caused by MS damages the myelin, the nerve fibers it protects, and the specialized cells that make myelin. Scar tissue (sclerosis) develops in the damaged areas.

When damage occurs in many areas, it is called “multiple sclerosis.” Because of this damage, the flow of information within the brain—and between the brain and body—is interrupted. Damage in the CNS produces a

variety of neurological symptoms that will vary in type and severity among people with MS. These symptoms may include numbness, walking problems, visual impairment, fatigue, and changes in thinking ability.

Researchers are still not sure what causes MS but continue to study the cells of the immune system, genetics, and environmental factors to better understand what may cause the disease.

## WHO GETS MS?

MS is usually diagnosed in young adults and is the most common cause of nontraumatic disability in young adults. MS symptoms typically first appear between ages 20 and 50, with Black Americans more likely to be at the older end of this age range when the disease starts. It is uncommon for MS symptoms to first appear in children younger than 10 or in adults after the age of 60.

Women, regardless of race or ethnicity, are about three times more likely to have MS than men. In one study, the incidence (the number of new cases) of MS was shown to be higher in Black women than in white, Lantinx, or Asian people, but the prevalence (number of all people with MS) remains highest in white people.



**ELLECIA**  
DIAGNOSED IN 2011



## Additional Risk Factors

The cause of MS is not known, but a combination of genetic and environmental factors—some of which you may be able to control—can contribute to the development of MS.

MS is not inherited. However, as with some other diseases, you are at a higher risk of developing MS if one of your parents or siblings have it. Based upon large studies of genes in the human body, variations in certain genes may contribute to the overall risk of developing MS.

Obesity, especially in girls during early childhood and adulthood, may increase the risk of MS later in life.

Additional factors that may increase the risk of developing MS include:



**Smoking:** There is increasing evidence that, in addition to increasing the risk of developing MS, smoking is associated with more severe MS and increased progression. The good news is that stopping smoking can slow the progression of MS.



**Obesity:** Obesity, especially in girls during early childhood and adulthood, may increase the risk of MS later in life.



**Vitamin D:** Vitamin D is sometimes known as the “sunshine vitamin” because it can be made in the skin from exposure to sunlight. Low levels of vitamin D in the blood is a risk factor for developing MS. Since people who live close to the equator are exposed to frequent sunlight year-round, they tend to have higher levels of naturally produced vitamin D. This may help protect them from getting MS and may explain why MS is more common in countries further from the equator.



**Infections:** There have been several viruses thought to contribute to the risk of MS, but the evidence for increased risk of developing MS is strongest in those with previous Epstein-Barr (the virus that causes mononucleosis) infection.

## Factors Not Proven to Cause MS

Since MS is a complex disease without a known cause, there have been many theories about what causes it; many do not have enough evidence to support whether they cause MS. These unproven theories include:

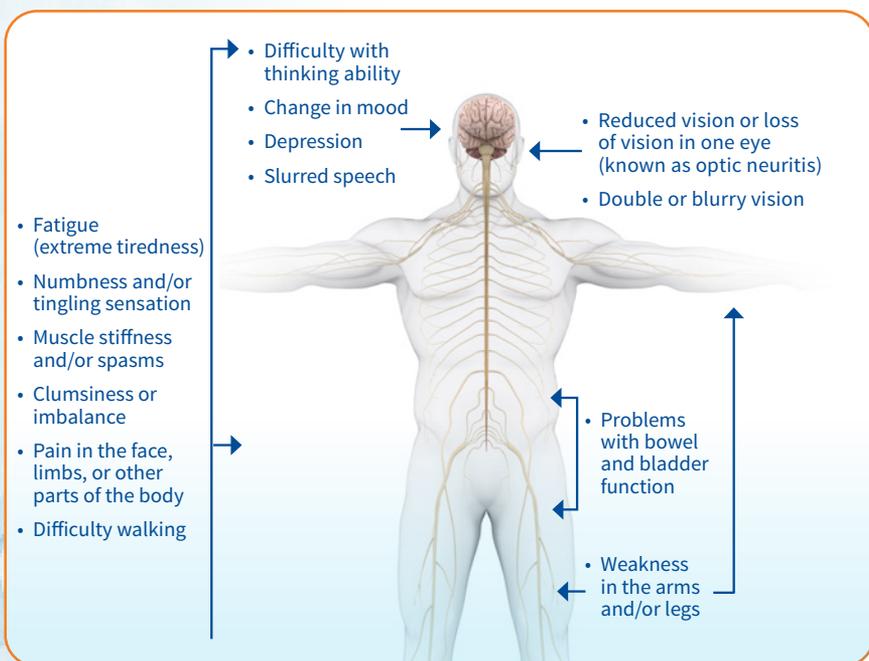
- Exposure to organic (chemical) solvents
- Exposure to heavy metals such as mercury tooth fillings, lead, or manganese
- Exposure to household pets
- Environmental allergies

## SYMPTOMS OF MS

MS

Symptoms of MS vary in type and intensity. Many areas of the body can be affected, and symptoms are often “invisible,” meaning other people can’t see the challenges a person with MS is experiencing.

Below are some of the more common symptoms of MS. Visit [nationalMSSociety.org/symptoms](http://nationalMSSociety.org/symptoms) for more information about these as well as less common symptoms:



It is unlikely for one person with MS experiences all of the above symptoms at the same time! But it is common to experience some of them throughout their life while living with MS.

Symptoms can come and go—also known as relapses and remissions. The term “**relapse**” describes when the disease is actively attacking the nervous system and symptoms occur and/or there is new activity seen on magnetic resonance imaging (MRI). Symptoms “**remit**” (resolve partially or fully) during remission or recovery periods.

## FOCUS ON FATIGUE:

### A Common Symptom

Nearly all people with MS report experiencing extreme fatigue, and in some people, fatigue may even be the first sign of MS, occurring weeks or months before a first attack. MS-related fatigue is often described

as extreme physical or mental exhaustion that is not improved

by bed rest. It can be worsened by heat, and it can also get worse after engaging in physical or mental activity and may interfere with a person's routine physical and mental functioning. In one study, approximately 80% of study subjects with MS had fatigue, and in half of these cases the subjects considered it to be

their most disabling symptom. For those living with MS, this extreme fatigue and exhaustion can increase depression and can have a significant negative impact on quality of life, productivity, and employment.

**“I stopped being able to do things socially with my friends because this thing just wiped me out.”**

**AZURE, DIAGNOSED IN 2009**

Since fatigue severity—and how often it occurs—is subjective, researchers

have developed standardized questionnaires for patients to report their symptoms of fatigue. While there are several fatigue scales used across different diseases, including MS, the Fatigue Symptom and Impact Questionnaire-Relapsing Multiple Sclerosis (FSIQ-RMS), is an MS-specific, 20-item patient-reported outcome

measure that healthcare providers use to assess fatigue in people with MS. Questionnaires like this are important tools for measuring fatigue, as researchers have learned that the level of MS-related fatigue is not always related to the severity of the disease. One study found that even those with very mild MS had as much fatigue as those with more severe MS.

Although studies are ongoing, currently no MS treatments have been approved by the US Food and Drug Administration (FDA) to specifically treat MS-related fatigue. However, there are ways to potentially manage it. People with MS should talk with their healthcare team to



first make sure their fatigue is related to MS and not caused by something else, such as other medical conditions or side effects of other drugs. Sleep assessment, developing a regular exercise program, and optimal management of other symptoms like depression and pain may help improve overall energy levels and lessen the impact of MS-related fatigue.

## HOW IS MS DIAGNOSED?

An early diagnosis of MS is important for limiting the damage to the nervous system, but there is no single test to reliably confirm MS. Symptoms of MS can be similar to other diseases, and diagnosis may take time. The use of published diagnostic guidelines has helped providers make an accurate and more timely diagnosis.

Diagnosis begins with a review of medical history that includes current symptoms, any previous symptoms, medications, allergies, other medical issues or surgeries, and so on. This is generally followed by thorough physical and neurological exams. Based upon the history and exam, numerous diagnostic tests including blood tests, MRI of the brain and spinal cord, and analysis of spinal fluid may be recommended.



## TYPES OF

## MS

There are four basic types or courses of MS: clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), secondary progressive MS (SPMS), and primary progressive MS (PPMS). The type of MS is important as it will help determine the optimal management strategies.

### What Is Radiologically Isolated Syndrome (RIS)?

RIS is not considered a course of MS; however, it is used to classify those with abnormalities on MRI of the brain and/or spinal cord that appear similar to lesions seen in MS. The abnormalities can't be explained by another diagnosis, as the person will not have a history of any past or current neurological symptoms or abnormalities. The person may have had an MRI due to other symptoms, such as headache.

Some individuals with RIS may eventually develop symptoms and then be diagnosed with MS; however, not everyone with RIS will develop MS. Although there is no specific treatment for RIS, MRIs and neurological symptoms will be monitored to quickly identify any changes in case the diagnosis is MS. This will allow for early treatment. Ongoing studies in RIS may help to provide more guidance for monitoring and treatment.

## **Clinically Isolated Syndrome (CIS)**

CIS describes the first episode of a symptom or symptoms that lasts more than 24 hours and is suggestive of MS. While the history, exam, and tests may point to an MS diagnosis, there is not enough evidence to confirm an MS diagnosis. Additional symptoms or new evidence on the MRI or other tests may be needed to confirm MS.

## **Relapsing-Remitting MS (RRMS)**

RRMS is the most common form of MS, occurring in about 85% of people who are diagnosed at disease onset. In RRMS, people experience neurological symptoms (relapses) that evolve over days to weeks, persist for several weeks or more, and then settle down (remit). Symptoms may include vision change, numbness, mobility problems, or any of the other symptoms associated with MS noted above.

Sometimes relapses remit with symptoms disappearing completely, but people may be left with residual and persistent symptoms. People having new MRI activity or new relapses are considered to have active RRMS, and those who have experienced an increase in disability are considered to be experiencing worsening RRMS.

**WILLIAM**  
DIAGNOSED IN 2011

**CIS** AT A GLANCE

- CIS usually occurs in young adults and may affect the optic nerves (nerves of the eye), brain stem, or spinal cord.
- About 65% to 80% of people who have CIS and an abnormal MRI scan will develop MS.
- Only 8% to 25% of people with CIS and a normal MRI scan will progress to MS.



## Secondary Progressive MS (SPMS)

Some of those individuals who started with a relapsing course will go on to develop SPMS, where relapses become less and less prominent or evident but what appears to emerge is a slow, ongoing worsening of neurological function, which has been referred to as progression. In SPMS, neurologic function can worsen over time, with or without relapses. Acute relapses may still occur but with less frequency. There is more of a decline in function over time that is not associated with relapses.

**In some cases, Black people may experience a faster transition from RRMS to SPMS.**

Factors that are associated with rapid disease progression include more frequent brain stem or spinal cord lesions and a greater decline in neurologic function during the first five years after diagnosis. SPMS can be classified as active or not active, with progression or without progression. Each person's experience will be unique, with periods of worsening, relapses, or stability; however, disability gradually increases, with or without changes on an MRI or any additional relapses.

## Primary Progressive MS (PPMS)

PPMS is characterized by progressive worsening. About 10% to 15% of people with MS are initially diagnosed with PPMS, where neurologic function starts to decline from the first onset of symptoms. The average age of onset of PPMS is 40 years of age, about 10 years later than RRMS. As with other forms of MS, PPMS affects each person differently.



**DAMIAN**  
DIAGNOSED IN 2015

## TREATMENT OF MS

Managing MS involves both medications and lifestyle behavior strategies. Decisions about management are often made in a shared decision model, where the goals and values of the person with the disease and the knowledge of the healthcare provider are considered equally when making treatment decisions.

Participating in the decision process requires that the individual be well informed about the disease and the various treatment and management strategies.

Managing MS over time often requires multiple professionals who work collaboratively. Everyone involved in the care of a person with MS—including the patient—should work together on potential solutions.

Although there is currently no cure for MS, management of MS falls into three categories, depending on the type of MS, disease stage, and disease activity:

## 1

## Disease-modifying treatment (DMT)

- DMTs target the immune system in order to limit new inflammation and damage in the CNS.
- DMTs are prescribed to limit new relapses, limit additional disease activity, and delay the progression of disability.
- It is recommended that a DMT be started soon after a confirmed MS diagnosis and be continued unless there is breakthrough MS activity, intolerable side effects, or intolerable risks associated with the treatment.
- There are more than 20 different DMTs. Some are self-injected, some are taken by mouth, and some are given as an infusion into a vein in the arm (through an IV).
- An exploratory analysis suggested that Black people may not respond as well to certain DMTs, such as interferons. The benefits of DMTs may differ between Black Americans and white Americans.



2

## Treatment for managing relapses

- Most relapses will resolve over time without treatment.
- Relapses are sometimes treated with intravenous (IV) and oral corticosteroids (medications that reduce inflammation) to speed recovery; however, they do not have any long-term benefit. Several studies have found high-dose oral steroids to work just as well as IV steroids and are often used.
- Intramuscular adrenocorticotrophic hormone (ACTH) can be effective but is not used as often due to its high cost.
- **Plasmapheresis** is sometimes used as an alternative treatment for severe relapses when steroids have not been effective.
- Intravenous immunoglobulin (IVIG) is not typically used as a first option for treating relapses but may be helpful in certain circumstances. It is usually reserved as an alternative after other treatments have failed or when previous treatments were not well tolerated.
  - IVIG may be considered for pregnant women because steroids should be avoided during pregnancy.
  - IVIG is sometimes used to treat relapses that aren't helped by corticosteroids.

3

## Treatment of symptoms

- Symptoms vary in type and intensity. Management requires correct assessment of the symptom cause and can include medication and/or lifestyle modifications.



## HEALTH AND WELLNESS STRATEGIES

From meditation and acupuncture to diet, supplements, and exercise, complementary and alternative medicine (CAM) is increasing in popularity. Interventions used in combination with conventional medicine are termed “complementary,” while those used instead of conventional medicine are called “alternative.”

Although research is limited on how safe and effective these treatments are for MS, many people with MS use CAM treatments—often in combination with prescribed medications—in hopes of controlling their MS or treating their symptoms. Surveys found that at least one-third of people with MS have tried one or more CAM treatments. Research is ongoing, but

several complementary and alternative interventions are known to provide some benefit. For example, exercise can help to reduce fatigue and improve mood, strength, and bladder and bowel function. Stretching can increase mobility and reduce stiffness.

Studies suggest acupuncture may help with a variety of symptoms, including gait, fatigue, and pain. MS-related fatigue can be made worse by MS-related depression. People with MS suffering from depression may benefit from cognitive behavioral therapy. Some stress management strategies may also be helpful in dealing with MS.

Many people with MS take supplements that can be purchased over the counter

in the hope of helping to manage symptoms. Studies have shown a connection between vitamin D and MS, but it is best to speak with your healthcare professional before taking any supplement. Eating a healthy diet rich in fruits and vegetables is a great way to ensure you are getting proper nutrition.

Always keep your healthcare professional informed about any type of CAM intervention you would like to try, and make sure you are aware of any risks associated with using CAM.

Being informed through credible resources is the best way to make CAM work for you. Visit [nationalMSSociety.org/alternative](https://www.nationalmssociety.org/alternative) to learn more about CAM.



**Research is ongoing,  
but several  
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alternative interventions  
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MS

## IS DIFFERENT FOR BLACK AMERICANS

Most people are not aware that there are distinct differences in how MS affects Black Americans versus white Americans. Numerous studies have found that Black Americans are at a high risk for disability, so early treatment intervention is even more critical.

Black people with MS may be more likely to have:

- transverse myelitis (inflammation of the spinal cord), which impacts the walking ability
- the need to use a cane sooner than white Americans
- more visual symptoms
- more frequent relapses and poorer recovery
- more balance and coordination problems
- faster transition from RRMS to SPMS
- a rapidly disabling course of the disease
- visual symptoms with thinning, or **atrophy**, of the inner retinas of the eyes, the structures responsible for vision
- faster progression of tissue loss, or atrophy, of the CNS

Since Black people with MS are at such a high risk for disability, starting treatment early with an MS disease-modifying therapy is often recommended.

However, studies suggest that Black people may respond differently than white people to some treatments, so it is important to work closely with your healthcare team to find the best treatment to help you manage your MS.

It is not well understood whether immunological, socioeconomic, genetic, or environmental factors contribute to the more aggressive progression of MS in Black Americans, which also illustrates the need for ongoing research.

You can help make a difference in MS by participating in research. The MS Genetics Group is collecting blood samples from African Americans with and without MS: [nationalMSsociety.org/recruiting-genetics](https://nationalMSsociety.org/recruiting-genetics)

You can learn more about making a difference in MS through research at the MS Minority Engagement Research Network: [acceleratedcure.org/ms-minority-research-network](https://acceleratedcure.org/ms-minority-research-network)

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“MS is a very, very quiet fight, because it is an invisible disability.”

AZURE  
DIAGNOSED IN 2009

## LIVING YOUR BEST LIFE WITH

MS

MS is unpredictable and often disabling. However, there are steps you can take to help you feel more in control and that you are doing everything you can to improve your outcomes. A healthy lifestyle is important for everyone but even more important for people with MS.

### Exercise

Exercise can improve fitness, endurance, and strength—as well as decrease fatigue and improve your mood! The National MS Society recommends appropriate exercise and physical activity for every person with MS. It is important to talk with your healthcare provider to learn what types of exercise work for you. Yoga and swimming or exercising in water are gentle ways to improve flexibility. But exercise doesn't have to be a sport. Any kind of movement—gardening, walking the dog, taking the stairs instead of an elevator—can help provide benefits. Learn more by visiting the National MS Society website: [nationalmssociety.org/healthy](https://www.nationalmssociety.org/healthy)



**MICHELLE**  
DIAGNOSED IN 2001



## Diet

There isn't a specific MS diet, but what you eat can affect your energy, digestion, and overall health and immune system. Information on specific diets such as paleo, Mediterranean, gluten-free, and others can be found on the National MS Society website.

## Support

Dealing with a chronic disease can be lonely, but the power of connection can do amazing things in the face of challenges like MS! Build a strong “web” of support that includes your doctor and healthcare team, family and friends, and faith leaders. Consider participating in a clinical study or peer support group where you can meet others facing the same challenges.

You can also take charge of your MS by contacting an MS Navigator (1-800-344-4867), who can provide expert advice to help you connect to resources and programs in your community, as well as healthcare professionals experienced with MS. MS Navigators can also help you:

- **identify strategies for appropriate treatment or symptom management**
- **understand insurance benefits**
- **meet workplace challenges**
- **find support when MS progresses**

Visit [nationalMSSociety.org/resources-support](https://www.nationalmssociety.org/resources-support) for more information about MS Navigators and other helpful resources.

## Family and Support Partners

When a person is living with MS, it affects their whole family in some way. In addition to healthcare providers, partners, family, and friends can be an important web of support for a person with a chronic illness like MS. Since MS affects each person differently and can be unpredictable, the kind of support needed may change from one day to the next.

There are many ways the family and community can help support a person with MS, from help with managing treatments and hands-on care at home to just being emotionally supportive. A care partner at home providing daily assistance can become physically and emotionally exhausted, so it's important for them to reach out when they need help too.

People with MS are encouraged to share their diagnosis and challenges with loved ones. The more they can learn about MS, the more they can be of support to not only the person living with the disease but also their care partner and immediate family.

Visit [nationalMSSociety.org/relationships](https://nationalMSSociety.org/relationships) for more information about the importance of your relationships with family and community when living with MS.

**“When  
spider webs  
unite, they can  
tie up a lion.”**

—African Proverb





## GLOSSARY

**Atrophy** Decrease in size or wasting away of a body part or tissue

**Central nervous system (CNS)** The brain, spinal cord, and vision nerves

**Disease-modifying treatment (DMT)** A kind of medication that works to change the course of a disease

**Plasmapheresis** A method of removing blood plasma from the body by withdrawing blood, separating it into plasma and cells, and transfusing the cells back into the bloodstream; it is performed especially to remove antibodies in treating autoimmune conditions

**Relapse** The occurrence of new symptoms or the worsening of old symptoms; relapse symptoms last at least 24 hours and are separated from the previous relapse by at least 30 days; it must also occur in the absence of infection or other cause

**Remit** When symptoms go away for a while or go “into remission”

## RESOURCES

For information and resources specific to Black Americans, visit [nationalMSSociety.org/African-American-Resources](https://nationalMSSociety.org/African-American-Resources)

Read about MS fatigue on the More to MS™ website: [MoretoMS.com](https://MoretoMS.com)

Learn more about CAM at the National Center for Complementary and Integrative Health (NCCIH): [nccih.nih.gov](https://nccih.nih.gov)

MS Navigator: [nationalMSSociety.org/navigator](https://nationalMSSociety.org/navigator)

Treatments: [nationalMSSociety.org/treating-ms](https://nationalMSSociety.org/treating-ms)

Health and wellness: [nationalMSSociety.org/wellness](https://nationalMSSociety.org/wellness)

## DISCLAIMER

This guidebook is intended for informational purposes only, with the understanding that no one should rely upon this information as the basis for medical decisions. Anyone requiring medical or other health care should consult a medical or healthcare professional. Any actions based on the information provided are entirely the responsibility of the user and of any medical or other healthcare professionals who are involved in such actions.

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Most photos in this guidebook depict people identified as living with MS. However, some photos are stock images, acquired for illustrative purposes. The unidentified people in those photos are models.



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### More to MS™

Learn more about the impact of MS fatigue at [MoretoMS.com](http://MoretoMS.com)

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**National Multiple Sclerosis Society**  
[nationalMSSociety.org](http://nationalMSSociety.org) | 1-800-344-4867



The National Multiple Sclerosis Society exists because there are people with MS. Our vision is a world free of MS. Everything we do is focused so that people affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost, and end MS forever. Since its founding by Sylvia Lawry in March 1946, the Society has invested more than \$1 billion to advance MS research and is recognized as the catalyst for all major advancements in MS.

We are more than an organization. We are a movement. United in our collective power to do something about MS now and end this disease forever. The gathering place for people with MS, their family and loved ones, healthcare providers, volunteers, donors, fundraisers, advocates, community leaders, and all those that seek a world free of MS. A place to connect and take action. In order to change the world, we mobilize all possible human and financial resources to achieve results.

Being Black and living with MS brings unique challenges and experiences. From scientific and clinical differences in the disease itself to stark inequities in the healthcare system and beyond. The first national, virtual Black MS Experience Summit took place in September 2020 and offered an opportunity to connect with others who understand the distinct experience of life with MS as a Black person. Learn more at [nationalMSSociety.org/BlackMSExperience](http://nationalMSSociety.org/BlackMSExperience)



Black MS *Experience*  
Summit

Scan this QR code to watch the companion documentary, featuring AZURE ANTOINETTE sharing her experience with MS.

Or access the video online at:  
[nationalMSSociety.org/BlackMSExperience](http://nationalMSSociety.org/BlackMSExperience)

