# Health Ming nitor

Explore your treatment options

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"MS changed me for the better!"

# **Multiple Sclerosis**

Coming to terms with relapsing MS wasn't easy for Samantha Payne. Three years later, she's got energy to spare, greater confidence and a bright outlook—and a biologic medication has made it all possible.

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# Keep looking ahead!

Multiple sclerosis (MS) has long been known as a "White person's disease," yet Black people aren't immune—in fact they're getting the disease in greater numbers than ever. To protect yourself, know the signs and report them early. The sooner you're diagnosed, the more effective your treatment. —BY TONYA RUSSELL



arryl W. is determined to keep his focus on the future these days—and he credits the ability to do so with a disease-modifying therapy that is helping him maintain his mobility and independence. Yet just a few years ago, he wasn't sure he would ever get relief from the strange symptoms bothering him.

"The signs would come and go, one day it was fatigue, the next I'd have tingling in my legs and trouble with my vision," he recalls.

At the time, Darryl didn't have insurance, and every time he went to urgent care, he never saw the same doctor twice. It wasn't until he finally opened up about his concerns to his daughter, who works as an ER nurse, that anyone was able to put it all together.

After some time making appointments to meet with the right doctors and request the proper tests, Darryl was finally diagnosed with MS and started on the medication that has put the disease into remission.



"I'm so grateful my daughter recognized what was going on—MS can be tricky to diagnose in even the best circumstances. And now that I'm on a treatment that works, I feel like my old self again!"

If you are a Black person with MS, know that–like Darryl–you, too, can do the things you love and be optimistic about the future. Start by reading this guide to learn more about the disease, how it affects Black people in particular, the treatment options available to you and the strategies that can help you make the most of every day!

## Understanding the basics

MS is a chronic autoimmune condition that causes your body to attack myelin, the protective sheath that surrounds the brain's nerve cells, as well as the nerve itself. When myelin breaks down, messages between the brain, spinal cord and other parts of the body get delayed. That slowed communication leads to a range of complications that can affect the way you think (trouble remembering information, for example) and the way you move and feel (e.g., you may lose your balance or experience numbness).

#### How does MS manifest in Black patients?

Until recently, doctors thought MS was a White person's disease, with most cases tied to European ancestry. But current statistics tell another story: Not only are diagnoses on the rise among the Black community, but rates of the disease among Black women don't lag far behind those of White women. Three in 1,000 Black people are diagnosed with MS compared with 3.75 in 1,000 White people. Unfortunately, the misconception can still cause the disease to be missed in Black people.

In truth, despite the fact that MS symptoms among White and Black people are essentially the same, they often are not detected in Black people until they are more pronounced or chronic– and the disease more advanced. That's why it's important to alert your doctor immediately if you notice any of the following. The sooner you get help, the lower your chances of MS causing you to become disabled:

- Sudden, painful vision loss or color changes, often in one eye
- Problems with balance, walking and coordination
- Trouble with memory, attention and understanding information
- Extreme fatigueMuscle stiffnessNumbness, tingling
- or pain

  Slurred speech
- Bladder and bowel
   problems

#### How is it diagnosed?

MS is usually diagnosed by blood tests and spinal taps that can check for antibodies related to myelin damage. And an MRI to look for lesions–i.e., myelin damage on the brain and spine–is crucial to diagnosis. Although most people are diagnosed between the ages of 20 and 40, Black patients are often diagnosed at later ages. For one, false beliefs about MS being a "White person's disease" can stand in the way of a timely diagnosis. For another, some Black people may not have easy access to a neurologist who can run tests. Consider that in 2021, 12.7% of Black workers were uninsured compared to 7.5% of White workers, according to CDC reports. Black adults are also less likely to have paid time off (PTO) or paid sick leave, so it's harder for them to even get to a doctor.

And while MS appears to be more prevalent in the Northeast and Midwest than in the South or West, those numbers may actually be a reflection of people living in "care deserts"—places with fewer options for proper diagnostics and treatment.

#### Who gets it?

An estimated 947,000 Americans have MS. Race is often missing from patient data, but it is estimated that 3 out of every I,000 Black people develop MS. While the disease affects people of all ages, most are diagnosed between ages 20 and 40, with women about three times more likely than men to develop the condition.

#### What are the types?

About 85% of those diagnosed have relapsing remitting multiple sclerosis (RRMS)–that's when periods of no disease activity (remission) alternate with flare-ups (i.e., a relapse or exacerbation). Two other common forms of MS are primary-progressive MS (PPMS), which is marked by a steady worsening of symptoms without any relapses, and secondary-progressive MS

#### MS AT A GLANCE



THE NUMBER OF BLACK AMERICANS DIAGNOSED WITH MS.

20-40 THE TYPICAL AGE RANGE FOR DIAGNOSIS.

**3X** HOW MUCH MORE LIKELY WOMEN ARE TO DEVELOP MS THAN MEN. (SPMS), where symptoms gradually start as relapsing remitting MS (RRMS), then become progressive, and relapses may or may not occur.

#### How is it treated?

Taken regularly, disease modifying therapies (DMTs) help reduce MS relapses and thus potentially help to slow progression of the disease. Nearly 20 different DMTs are FDA-approved for the long-term treatment of MS. They are available in pill form and by injection and infusion; most of them work by modifying the immune system to prevent it from attacking myelin, the protective coating around nerves.

The American Academy of Neurology issued guidelines recommending that for most people, it can be better to start treatment with a DMT as soon as

S dendrites

cell body

axon

mvelin sheath

possible-even if symptoms are mild-because early treatment can help slow the disease process and may help keep your condition stable. There are also treatments available to help speed recovery if your MS relapses.

#### Lifestyle strategies

Adopting healthy behaviors not only boosts your overall health, it may also slow the progression of your MS. If you need help making changes in your life, reach out to your family and friends for support.

• *Eat nutritious meals*. There's no "MS diet," but research suggests a diet low in saturated fat and supplemented with omega-3 fats (such as from fatty fish like salmon) and omega-6 fats (from sunflower or safflower oil) may have benefits for people with MS.

How MS affects

nerve cells

In MS, the nerve cell's

myelin sheath is damaged

(demyelinated), which

prevents signals from traveling

easily along the nerve. Once

the myelin is damaged,

inflammatory cells attack

the nerve itself, leading to

permanent damage.

- *Exercise*. Activity that suits your capabilities can boost your mood, strength, cardiovascular fitness and even bladder and bowel function.
- Manage your stress. Your MS symptoms may worsen during times of stress. Eliminating or minimizing your stressors and reaching out to family and friends for support can lift your spirits and make your days more pleasant.
- *Stay cool.* Getting overheated-whether from exercising, hot outdoor temperatures or taking a steamy bath-makes it harder for damaged nerves to transmit electrical impulses, leading to temporary worsening of MS symptoms, aka "pseudorelapses."
- *Get enough rest.* Adequate quality sleep can help safe-guard your mood, cognitive abilities and physical well-be-ing, helping you to avoid spasticity, pain and balance problems.

Here's the good news: The more motivated you are to work with your healthcare team and try the lifestyle strategies and other treatments as prescribed, the better your odds of living your best life with MS. The critical piece? Opening up about your symptoms. With so many treatment options available-from disease modifying therapies (DMTs) to treatments for relapses and therapies for symptom relieffinding what works for you is usually a matter of trial and error. Let your care team know what you're coping with, so they can help you find relief or adjust your treatment as needed.



# Who's on your healthcare team?

These are the healthcare professionals who will support you through your MS journey.



Primary care provider (PCP): an internist or family physician who manages and coordinates your overall care. Your PCP may have referred you to a neurologist for your MS care.

**Neurologist:** a physician who specializes in diseases involving the nervous system and who will create a treatment plan for you.

**Nurse:** a medical professional who can answer questions, provide guidance and help you follow through with your treatment and self-care. Some nurses are MS-certified and have received advanced training in MS care.

**Neuropsychologist:** a physician who will develop a care plan to address the cognitive effects of MS and boost your mental functioning.

#### **Physiatrist:** a physician who can develop a care plan to address the physical effects of MS and boost your functional abilities.

#### **Physical therapist (PT):**

a licensed healthcare professional who can help you manage your MS symptoms through movement and exercise.

#### Occupational therapist

**(OT):** a licensed healthcare professional who can make recommendations to help you function your best while at home, work or out-and-about.

## Speech-language pathologist (SLP):

a licensed healthcare professional who can assess, diagnose and treat many types of communication and swallowing problems.

**Dietitian:** a licensed nutrition professional

who can help you eat well to feel your best.



# "MS CHANGED ME FOR THE BETTER!"

Coming to terms with relapsing MS wasn't easy for Samantha Payne. Three years later, she's got energy to spare for her new grandson, Chance, greater confidence and a bright outlook—and a biologic medication has made it all possible. –BY TONYA RUSSELL

Samantha Payne, 42, of Chicago is energy in motion. After all, the hair salon owner, mother and grandmother can't afford to slow down. To balance out all the activity, she's a wellness enthusiast who's devoted to her daily asanas and until recently, believed the only medicine she'd ever need came on a plate—fruits, vegetables, legumes, whole grains, lean proteins. So even when she started "not feeling like herself," she stuck to her ways and soldiered through.

"For seven years, I felt off," she recalls. "I'd have recurrent UTIs, and I'd wake up with tingling in my feet. But what really sent me to seek answers was a pain in my neck and shoulder that wouldn't go away." In late 2020, she saw her doctor about the discomfort, who ordered various tests, including X-rays. When they turned up inconclusive, she took a shot at physical therapy. When that didn't work, she turned to a chiropractor. But nothing helped.

#### "I hoped I could heal my MS holistically"

Finally in May 2021, about six months after that first doctor visit, she learned the reason for her unrelenting symptoms: An MRI showed brain lesions—Samantha had multiple sclerosis. Next, a difficult decision: Was she ready to start taking medication or would she lean further into her holistic lifestyle?

"I just didn't know enough about MS to start taking medication. I wanted to do my research first," says Samantha, who admits that the diagnosis also got her down. For about a year, she tried an elimination diet, thinking maybe hitting on the right combo of foods would help. But when her symptoms persisted—including the unbearable neck and shoulder pain and stiffness—despite her best efforts, she decided to get a second opinion.

#### "Medication made the difference"

Samantha saw a neurologist who not only confirmed her first doctor's diagnosis but recommended an injectable biologic she would give herself each month. Time was of the essence, he stressed, since effective treatment sooner rather than later would be her best bet for stalling the disease's progression and fending off relapses. He believed this treatment, a biologic that targets an immune-system glitch underlying MS, could make a difference.

While it wasn't what Samantha wanted to hear, she *did* want a path

"I thought my diagnosis was the end, but it turned out to be a new beginning!" to relief from the symptoms that were threatening to slow her down, so she agreed to give it a try. "Before I started, I was sent a test syringe that teaches you how to use it-it's preloaded so it was pretty simple," says Samantha, who has been on the treatment ever since. Fortunately, she says that other than a "little tiredness" the day after her injections, she doesn't experience any side effects. And while some people say they notice a period where they feel poorly before their next dose, Samantha sails through the month just fine.

#### "I feel like I'm really thriving!"

"My diagnosis has changed me for the better!" says Samantha, who says she seldom feels held back by her MS these days. And with her symptoms under control, she's able to focus on the things that really matter to her. "I'm really conscious about my stress levels. I try to exercise more, meditate more and practice more yoga-different things to keep my mind and body in alignment."

While the shift from diagno-sis to treatment was daunting,

Samantha is at peace and feels blessed she's able to celebrate milestones, like the birth of her brand-new grandson, Chance. "I told God that if I have to do this, I want to be able to help people. I asked that he let my life be a beacon of light for other people to have some hope.

"Ithought my diagnosis was the end, but it turned out to be a new beginning," continues Samantha. "Here it is, three years later and besides some occasional aches and pains, I feel like I'm really thriving. For that I'm grateful."



## **RECENTLY DIAGNOSED?** HOW TO NAVIGATE YOUR NEW NORMAL

Here, Samantha shares the tips that helped her adjust to her diagnosis. Maybe they can help you, too.

#### Join support groups.

Samantha is a part of the We Are ILL community, which connects Black women diagnosed with MS. In the past, MS has been thought of as a "White woman's disease," and the community is helping to raise awareness. "Having a good support group is important. I have my husband and my friends who do support me. But they don't necessarily always understand what I'm going through, because I can look fine but not *feel* fine."

#### Find a qualified therapist.

Samantha was in therapy prior to her diagnosis but she became more consistent after. "I definitely needed that weekly relationship with my therapist. Being able to talk things through was important for managing my stress." She says that a therapist who's well-versed in your diagnosis or even chronic illness can help you to develop coping skills.

#### Open up to loved ones.

Samantha had no idea that two women in her family were diagnosed with MS, and she believes it would've helped her get over her fear of going on medication. "I'm pretty vocal, and I talk about MS on my Facebook page, and I've had a few family members reach out to me and say that they have MS too, but nobody knows. They've kept it a secret. It would've helped and prepared me to know and have an understanding."

#### Have an outlet.

A new diagnosis is daunting, but according to Samantha, "Having an outlet can help manage your stress. That can include some activities you find really fun. For me, that's meditation and yoga. I love breathing—being intentional about the way that I breathe, then holding it. It just really relaxes me."

#### YOU & YOUR CARE TEAM

# Is it an MS attack?

It's not always easy to tell when you're having an MS attack. After all, they can be unpredictable, vary from person to person and from episode to episode. Tracking your symptoms can prompt you to get immediate care, which can help reduce inflammation, speed recovery from an attack and minimize disability.

#### Take note of your symptoms

Fill in the worksheet below—but report a suspected MS attack ASAP to your doctor.

| Date that your new<br>or worsening<br>symptom(s) began: | How long did<br>the symptom(s) last<br>(e.g., hours, days): | Describe the symptom(s):        | Questions/<br>comments for<br>your doctor: |
|---|---|---------------------------------|--|
| 7/28/2024   | 2 days  | Left leg suddenly<br>went numb. | Is this an MS attack?<br>What can I do?    |
|   |   |                                 |  |
|   |   |                                 |  |
|   |   |                                 |  |
|   |   |                                 |  |
|   |   |                                 |  |

#### It may be an MS attack if your symptoms...

□ are either new or are old MS symptoms that have worsened

- □ have lasted for at least 24 hours (and often days to weeks)
- □ are occurring at least 30 days after your last attack

□ cannot be explained by anything else (for example, a fever, illness or overexertion)

Make copies to keep

handy!

# WITH KESIMPTA FOR RMS, CAN EI TIME MY WAY."

-ZENOVIA W. Entrepreneur, Wellness Coach, **Started KESIMPTA in 2022** 

Here's why KESIMPTA® was Zenovia's first choice when it was time to start a new treatment:

Easy and simple to use pen\*—Take it yourself in less than 1 minute a month<sup>+</sup> at home or on the go

— Plus —

**Proven safety profile**<sup>1</sup>—Plus an ongoing safety study ✓ Powerful results<sup>™</sup>—For reducing relapses, active lesions, and slowing disability progression

Zenovia W. has taken KESIMPTA and has been compensated for her time. RMS, relapsing multiple sclerosis.

\*Real-world 30-question survey of 105 US patients (aged ≥18) diagnosed with RMS for 1+ years, who took KESIMPTA with the Sensoready® Pen within previous 12 months. On a scale of 1-5, 89.5% of patients rated it a 4 or 5 (5 being most positive) on overall ease of use and ease of monthly dosing schedule. Questionnaire not validated.

<sup>†</sup>Typical administration time when ready to inject. Once monthly after 3 weekly starter doses. <sup>‡</sup>In 2 studies vs teriflunomide.

#### Indication

#### What is KESIMPTA (ofatumumab) injection?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including clinically isolated syndrome (CIS), relapsing-remitting disease, and active secondary progressive disease.

It is not known if KESIMPTA is safe or effective in children.

#### Important Safety Information

#### Who should not take KESIMPTA?

Do NOT take KESIMPTA if you:

have an active hepatitis B virus (HBV) infection.

have had an allergic reaction to ofatumumab or life-threatening injection-related reaction to KESIMPTA.

## **U**NOVARTIS

**Novartis Pharmaceuticals Corporation** East Hanover, New Jersey 07936-1080

5/24



(ofatumumab)<sup>20 mg</sup>

Important Safety Information (cont)

#### What is the most important information I should know about **KESIMPTA**?

KESIMPTA can cause serious side effects such as: • Infections. Serious infections, which can be

- life-threatening or cause death, can happen during treatment with KESIMPTA. If you have an active infection, your health care provider (HCP) should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections. Tell your HCP right away if vou have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.
- **HBV reactivation.** If you have ever had HBV infection, it may become active again during or after treatment with KESIMPTA (reactivation). If this happens, it may cause serious liver problems including liver failure or death. Before starting KESIMPTA, your HCP will do a blood test to check for HBV. They will also continue to monitor you during and after treatment with KESIMPTA for HBV. Tell your HCP right away if you get worsening tiredness or yellowing of your skin or the white part of your eves.
- Progressive Multifocal Leukoencephalopathy (PML). PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your HCP right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory, which may lead to confusion and personality changes.
- Weakened immune system. KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

#### Before you take KESIMPTA, tell your HCP about all your medical conditions, including if you:

- Have or think you have an infection including HBV or PML
- Have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- Have had a recent vaccination or are scheduled to receive any vaccinations.
- You should receive any required 'live' or 'liveattenuated' vaccines at least 4 weeks before vou start treatment with KESIMPTA. You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your HCP tells you that your immune system is no longer weakened.
- Whenever possible, you should receive any 'nonlive' vaccines at least 2 weeks before you start treatment with KESIMPTA.
- Talk to your HCP about vaccinations for your baby if you used KESIMPTA during your pregnancy.
- Are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception)

during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your HCP about what birth control method is right for you during this time.

 Are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your HCP about the best way to feed your baby if vou take KESIMPTA.

#### Tell your HCP about all the medicines you take,

including prescription and over-the-counter medicines, vitamins, and herbal supplements.

#### How should I use **KESIMPTA**?

See the detailed Instructions for Use that comes with **KESIMPTA** for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready pens or prefilled syringes.

- Use KESIMPTA exactly as your HCP tells you to use it.
- Your HCP will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender. bruised, red, scaly or hard. Avoid areas with moles, scars, or stretch marks.

#### KESIMPTA may cause serious side effects including:

- Injection-related reactions. Injection-related reactions are a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. There are two kinds of reactions:
- at or near the injection site: redness of the skin, swelling, itching and pain. Talk with your health care provider if you have any of these signs or symptoms.
- that may happen when certain substances are released in your body: fever, headache, pain in the muscles, chills, tiredness, rash, hives, trouble breathing, swelling of the face, eyelids, lips, mouth, tongue and throat, and feeling faint, or chest tightness. Contact your HCP right away if you experience any of these signs and symptoms. especially if they become worse or you have new severe signs of reactions after subsequent injections. It could be a sign of an allergic reaction, which can be serious.
- **Low immunoglobulins**. KESIMPTA may cause a decrease in some types of antibodies. Your HCP will do blood tests to check your blood immunoglobulin levels.

#### The most common side effects of KESIMPTA include:

• Upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache. Headache.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/ medwatch, or call 1-800-FDA-1088.

Please see accompanying Consumer Brief Summary on the following page.

🐼 Kesimpta

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment.

To learn more about KESIMPTA (ofatumumab) injections, talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, call 1-888-669-6682 or visit www.kesimpta.com.

## What is the most important information I should know about KESIMPTA?

#### KESIMPTA can cause serious side effects, including:

**Infections.** Serious infections, which can be life-threatening or cause death, can happen during treatment with KESIMPTA. If you have an active infection, your health care provider should delay your treatment with KESIMPTA until your infection is gone. KESIMPTA taken before or after other medicines that weaken the immune system may increase your risk of getting infections.

Tell your health care provider right away if you have any infections or get any symptoms including painful and frequent urination, nasal congestion, runny nose, sore throat, fever, chills, cough, or body aches.

- Hepatitis B virus (HBV) reactivation. Before starting treatment with KESIMPTA, your health care provider will do blood tests to check for HBV. If you have ever had HBV infection, the HBV may become active again during or after treatment with KESIMPTA. Hepatitis B virus becoming active again (called reactivation) may cause serious liver problems including liver failure or death. You should not receive KESIMPTA if you have active hepatitis B liver disease. Your health care provider will monitor you for HBV infection during and after you stop using KESIMPTA. Tell your health care provider right away if you get worsening tiredness or yellowing of your skin or white part of your eyes during treatment with KESIMPTA.
- Progressive Multifocal Leukoencephalopathy (PML). PML may happen with KESIMPTA. PML is a rare, serious brain infection caused by a virus that may get worse over days or weeks. PML can result in death or severe disability. Tell your health care provider right away if you have any new or worsening neurologic signs or symptoms. These may include weakness on one side of your body, loss of coordination in arms and legs, vision problems, changes in thinking and memory which may lead to confusion and personality changes.
- Weakened immune system. KESIMPTA taken before or after other medicines that weaken the immune system could increase your risk of getting infections.

#### What is **KESIMPTA**?

KESIMPTA is a prescription medicine used to treat adults with relapsing forms of multiple sclerosis (MS) including:

- clinically isolated syndrome
- relapsing-remitting disease
- active secondary progressive disease

#### It is not known if KESIMPTA is safe or effective in children.

#### Do not use KESIMPTA if you:

- have active hepatitis B virus infection.
- have had an allergic reaction to ofatumumab or lifethreatening injection-related reaction to KESIMPTA.

# Before using KESIMPTA, tell your health care provider about all of your medical conditions, including if you:

- have or think you have an infection, including HBV or PML. See "What is the most important information I should know about KESIMPTA?"
- have ever taken, currently take, or plan to take medicines that affect your immune system. These medicines could increase your risk of getting an infection.
- have had a recent vaccination or are scheduled to receive any vaccinations.
- You should receive any required 'live' or 'liveattenuated' vaccines at least 4 weeks before you start treatment with KESIMPTA. You should not receive 'live' or 'live-attenuated' vaccines while you are being treated with KESIMPTA and until your health care provider tells you that your immune system is no longer weakened.
- Whenever possible, you should receive any 'non-live' vaccines at least 2 weeks before you start treatment with KESIMPTA.
- Talk to your health care provider about vaccinations for your baby if you used KESIMPTA during your pregnancy.
- are pregnant, think that you might be pregnant, or plan to become pregnant. It is not known if KESIMPTA will harm your unborn baby. Females who can become pregnant should use birth control (contraception) during treatment with KESIMPTA and for 6 months after your last treatment. Talk with your health care provider about what birth control method is right for you during this time.
- Pregnancy Registry: There is a registry for women who become pregnant during treatment with KESIMPTA. If you become pregnant while taking KESIMPTA, tell your health care provider right away. Talk to your health care provider about registering with the MotherToBaby Pregnancy Study in Multiple Sclerosis. The purpose of the registry is to collect information about your health and your baby's health. For more information or to register, contact MotherToBaby by calling 1-877-311-8972, by sending an email to MotherToBaby@health.ucsd.edu, or go to www. mothertobaby.org/join-study.
- are breastfeeding or plan to breastfeed. It is not known if KESIMPTA passes into your breast milk. Talk to your health care provider about the best way to feed your baby if you take KESIMPTA.

Tell your health care provider about all the medicines you take, including prescription and over-the-counter

#### medicines, vitamins, and herbal supplements.

Know the medicines you take. Keep a list of them to show your health care provider and pharmacist when you get a new medicine.

#### How should I use KESIMPTA?

See the detailed Instructions for Use that comes with KESIMPTA for information about how to prepare and inject a dose of KESIMPTA and how to properly throw away (dispose of) used KESIMPTA Sensoready® pens or prefilled syringes.

- Use KESIMPTA exactly as your health care provider tells you to use it.
- KESIMPTA is given as an injection under your skin (subcutaneous injection), in your thigh or stomach-area (abdomen) by you or a caregiver. A caregiver may also give you an injection of KESIMPTA in your upper outer arm.
- Your health care provider will show you how to prepare and inject KESIMPTA the right way before you use it for the first time.
- **Do not** inject into areas where the skin is tender, bruised, red, scaly or hard. Avoid areas with moles, scars or stretch marks.
- The initial dosing is 20 mg of KESIMPTA given by subcutaneous injection at Weeks 0, 1, and 2. There is no injection at Week 3. Starting at Week 4 and then every month, the recommended dose is 20 mg of KESIMPTA administered by subcutaneous injection.

If you miss an injection of KESIMPTA at Week 0, 1, or 2, talk to your health care provider. If you miss a monthly injection, give it as soon as possible without waiting until the next scheduled dose. After that, give your KESIMPTA injections a month apart.

#### What are the possible side effects of KESIMPTA?

KESIMPTA may cause serious side effects, including:

See "What is the most important information I should know about KESIMPTA?"

- **Injection-related reactions.** Injection-related reactions are a common side effect of KESIMPTA. Injecting KESIMPTA can cause injection-related reactions that can happen within 24 hours (1 day) following the first injections and with later injections. There are two kinds of reactions:
- **at or near the injection site:** redness of the skin, swelling, itching and pain. Talk with your health care provider if you have any of these signs or symptoms.
- **that may happen when certain substances are released in your body:** fever, headache, pain in the muscles, chills, tiredness, rash, hives, trouble breathing, swelling of the face, eyelids, lips, mouth, tongue and throat, and feeling faint, or chest tightness. Contact your health care provider right away if you experience any of these signs or symptoms, especially if they

become worse or you have new severe signs of reactions after subsequent injections. It could be a sign of an allergic reaction, which can be serious.

• Low immunoglobulins. KESIMPTA may cause a decrease in some types of antibodies. Your health care provider will do blood tests to check your blood immunoglobulin levels.

#### The most common side effects of KESIMPTA include:

- upper respiratory tract infection, with symptoms such as sore throat and runny nose, and headache. (See "What is the most important information I should know about KESIMPTA?")
- headache.

These are not all the possible side effects of KESIMPTA. Call your doctor for medical advice about side effects.

You may report side effects to FDA at 1-800-FDA-1088.

#### How should I store KESIMPTA?

- Store KESIMPTA in a refrigerator between 36°F to 46°F (2°C to 8°C).
- Keep KESIMPTA in the original carton until ready for use to protect from light.
- If needed, KESIMPTA may be stored for up to 7 days at room temperature, up to 86°F (30°C).
- Write the date taken out of the refrigerator in the space provided on the carton.
- If stored below 86°F (30°C), unused KESIMPTA may be returned to the refrigerator and must be used within the next 7 days. If this KESIMPTA is not used within those 7 days, then discard the medicine.
- Do not freeze KESIMPTA.
- Do not shake KESIMPTA.

## Keep KESIMPTA and all medicines out of the reach of children.

# General information about the safe and effective use of KESIMPTA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use KESIMPTA for a condition for which it was not prescribed. Do not give KESIMPTA to other people, even if they have the same symptoms that you have. It may harm them.

You can ask your pharmacist or health care provider for information about KESIMPTA that is written for health professionals.

#### What are the ingredients in KESIMPTA?

Active ingredient: ofatumumab

**Inactive ingredients: Sensoready pen and prefilled syringe:** arginine, disodium edetate, polysorbate 80, sodium acetate trihydrate, sodium chloride, and Water for Injection. Hydrochloric acid may be added. YOU & YOUR CARE TEAM

# How is MS affecting you?

Living with MS can be challenging, but the right treatment can make all the difference. Fill out the assessment below and take it to your next doctor visit, so you and your care team can make sure your treatment plan is the best it can be.

Not at Very much MS interferes with my ability to... A little Somewhat A lot Work Exercise and do other physical activities Get a good night's sleep (including trouble falling asleep and staying asleep) Concentrate throughout the day because I'm tired Engage in relationships with family and friends Eat properly and/or pick certain foods Go out in public without feeling embarrassed Pick out and wear the clothing I like Figure out things, like my bills or finding directions Meet new people Be in a good mood/feel calm and confident Be myself around others

Have a healthy sex life

| Do these statements apply to you?             | Never | Rarely | Sometimes | Often | Always |
|---|-------|--------|-----------|-------|--------|
| I feel sad or blue.                           |       |        |           |       |        |
| l feel nervous, edgy or anxious.              |       |        |           |       |        |
| I feel like everyone is looking at me.        |       |        |           |       |        |
| I say no to activities I'd like to do or try. |       |        |           |       |        |



# "MS hold us back? *No way!*"

Jamison and Ashley were blindsided by their MS diagnoses. But learning about the disease, getting the right healthcare and giving themselves grace are helping them thrive despite it. -BY TONYA RUSSELL

### "KEEP A POSITIVE MINDSET"

**JAMISON SHARP** CHARLOTTE, NC Jamison Sharp, 38, of Charlotte, NC, loves travel and adventure and is known as the life of the party. However, in October 2022, odd symptoms threatened his fun-loving ways: Waking up for his job as a forklift operator one weekday, he noticed some tingling in his legs. It didn't quite hurt, so he went to work anyway, and that weekend he and his girlfriend, Jasmine, made their way to the South Carolina state fair in Columbia. "Even with the tingling in my legs, we rode on all of the janky rides," recalls Jamison. "We were getting jerked all over the place. I even drove all the way back home."

But by Monday, there was no ignoring the problem. "I explained to the guys at work that I had tingling in my legs and that I thought it was from the forklift or moving around the pallets. Everyone looked at me like I should have been dead on the floor—they thought the symptoms sounded like I was having a heart attack."

His coworkers urged him to head to the ER, where doctors were able to get to the root of the problem: While his heart was fine, an MRI revealed that he was actually in the early stages of MS.

Jamison gave himself a little time to grieve–and then swore MS wouldn't get in the way of his active life. After starting treatment with a biologic medication and using the strategies below, today there's no stopping him from working, riding coasters and planning his next getaway.

Continued on next page ►

#### Add bliss to your life.

"About five years ago, on New Year's Eve, I started waking up at 7:58 AM. At 8 AM is when Sydney welcomes in the new year, and I happily sit and watch all the fireworks and whatnot, and I just reflect on the time in life I have been given and on how to make myself better." Since his MS diagnosis, the yearly celebration has served as a reminder of his journey. He says, "I'm just thankful to still be here and still be able to enjoy life. I made a promise to myself to be better for myself and Jasmine as well."

#### Move more.

"Walking is of overall importance to me. My brother Reggie likes to joke with me, saying, 'You know the family that makes everyone get together and ride bikes for several miles? That's you, except you make everyone go walk with you.' Walking is definitely number one for me."

#### Keep going.

"I try to keep a positive mindset because no matter what life throws at you, you have to keep going. You can't just fall or falter at every little thing that happens. You know, the saying goes, 'don't cry over spilled milk'? My thing is *alright, well that was spilled, and you can cry, but then clean it up.*"





Ashley Ratcliff's journey started off with her foot dragging. According to the 39-year-old San Diego native, "I started having numbness and tingling in my foot that quickly progressed to me not being able to lift it." Her podiatrist did an X-ray and thought it was a pinched nerve. He referred her to a chiropractor, who proceeded to misdiagnose the problem as a herniated disc.

After three months of physical therapy, her therapist thought Ashley should get a second opinion. "I saw a neurologist who could tell immediately just from the way I walked that I did not have a herniated disc," says Ashley. "So he ordered an MRI that found brain lesions, which indicated a demyelinating disease." (That's any disease that damages myelin, the protective sheath around nerves in the brain, eyes and spine.) Suspicious that Ashley had MS, the

neurosurgeon sent her for a spinal tap, which confirmed the diagnosis.

After exploring her treatment options, Ashley chose to try an injectable biologic to help delay the progression of her disease and protect her from relapses. And as soon as she heard about We Are ILL, an organization led by and for Black women with MS, she joined. She also prioritized physical activity. "Ultimately, that's what's going to preserve your well-being," says Ashley. "I'm grateful my MS is stable enough for me to challenge myself while working with a personal trainer." Here, Ashley shares more of the tips that are keeping her on top of MS:

#### Join support groups.

"I feel like a turning point in my journey was finding my tribe. There's nothing that indicates to the outside world that I'm chronically ill, and there are struggles that you face in your day-to-day as someone living with this that no one can really relate to. Finding support groups or communities of like-minded people like We Are ILL was a game changer." Most important, it reinforced that life wasn't over for her: "It gave me hope and made everything feel less scary. It made me realize that I have a full life ahead of me, and I can still achieve my goals and dreams."

#### Educate others.

It took Ashley six months to get her diagnosis, and she's hoping to inspire other Black women to stand up for their health to avoid a similar delay. "Now I can share my journey and help make it so other people know how to advocate for themselves with doctors," she says. "It helps me remind people to be an active participant in their healthcare because honestly, when I was healthy, I didn't think about these things. I assumed the doctor knows best."

#### Put mental health first.

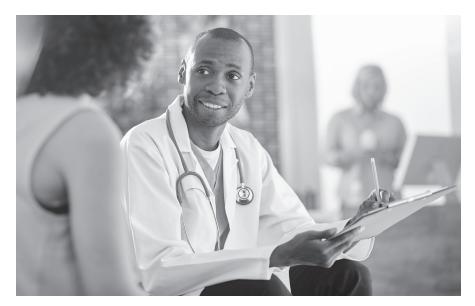
Ashley says that when she became depressed in the aftermath of the diagnosis, she sought the help of a counselor. "It helped to actually speak to a trained professional who has the tools and resources to help you understand and process your diagnosis." Outside her sessions, she has learned to turn off her people-pleasing impulses and

listen to her body. "Fatigue is the number one symptom for MS patients. It was really hard for me to grasp since I'm the person who is reliable. But stress can exacerbate your condition so you have to learn to listen to your body and exercise boundaries. Don't be embarrassed to say no."

#### Health m Monitor

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Feeling isolated As a woman of color with MS, I sometimes feel extremely lonely. No one looks like me or shares my experience at my local support group, and I don't know anyone else in my community with this condition. Are there any places you can recommend where I can reach out and connect with other Black people living with this disease?



Answers to your top questions about *multiple sclerosis* 

A: MS can be extremely isolating, and it can be even harder for people of color to connect with other people battling the disease. But know that you are not alone. While MS used to be known as a disease that only affected White people, we now know that is not the case. There are many people who look like you in the same situation. Online communities and resources now offer a great way to connect and meet others and learn more about how MS affects people of color. The National MS Society has an online support group for mem-

nity each month. There is a Women of Color with MS support group on Facebook with more than 4,000 members. Weareillmatic. *com* is an online hub for Black women with MS to connect with each other. I also recommend the podcast "Brain Chat with the Nerdy Neurologist" by Dr. Mitzi Joi Williams, a neurologist who offers great info and community for Black people living with MS.

INFUSION FATIGUE Q: I've been living with MS for a while, and my treatment seems to be working, but it's given by IV infusion. bers of the Black commu-Sometimes it's really difficult

my schedule and secure rides to receive them. Are there any other options I can try? A: Yes, there are! The landscape of MS treatment has expanded exponentially over the past few years. There are more oral medications now that are safer and with fewer side effects than the ones previously offered. But keep in mindif your current medication is preventing relapses, it is risky to switch to something new. Talk about these concerns with your neurologist to see if an oral medication would be a good option for you. Even if your doctor recommends you continue with your current infusion that is working well, we can set up patients with home infusions. I often work with a home health service who sends a nurse to patients' homes. This is usually covered by insurance and makes infusions much more manageable and convenient!

to fit those appointments in

#### **OUR EXPERT:** Jessica Baity, MD,

board-certified neurologist, Thibodaux Regional Health System, LSU New Orleans School of Medicine

# Reap the mind and body benefits of meditation

You know meditation can help you feel calmer and more grounded-and that's important, since major negative stressful events seem to raise the risk for new or enlarging lesions in people with MS, according to a study in Psychology Medicine. What's more, there's another benefit you may not know about: People who meditate have more brain tissue-in particular, more gray matter volume, says a study in NeuroReport. Why that matters: Brain tissue deteriorates faster in people who have MS, so whatever you can do to build or retain it makes sense-especially since loss of gray matter is a strong predictor of long-term physical disability and cognitive problems in people with MS. Ready to show your mind and body some love?

#### **TRY THIS SIMPLE MEDITATION**

Find a quiet place to sit and close your eyes, then...

- Tune into your current state. Become aware of your surroundings and notice thoughts as they come up. Acknowledge feelings, then let them pass.
- Focus on your breath.

For 60 seconds, notice the pattern of your breathing from your lungs to your stomach.

- · Concentrate on your whole body. Expand your awareness into what you're feeling physically.
- Expand into your environment. Notice what's in your immediate surroundings, such as sounds. Be present in the moment.

**Once done**, open your eyes slowly and try to bring that mindfulness with you for the rest of the day.



TAKE CHARGE

# DO YOU HAVE MS AND DEPRESSION?

Getting help for the mood disorder may help improve your MS symptoms. **It's normal to grieve the loss of certain abilities** when you have multiple sclerosis, and to feel sad when fatigue, spasticity or any of the other symptoms of the disease mean you can't do the things you want. But what's the line between "normal sadness" and depression? It can be tricky to tell, especially since some signs of depression—such as fatigue, cognitive difficulties, and insomnia or excessive sleepiness—are similar to MS symptoms.

"Depression occurs in up to 50% of patients with MS during their lifetime," says neurologist Sylvia Klineova, MD, MS, a professor at the Icahn School of Medicine at Mount Sinai, NYC. Contributing factors related to MS may include unemployment, lack of social support and physical impairment, adds Dr. Klineova.

If you think you may be depressed, it's important to get evaluated by a mental health professional who has experience working with people with MS. Seeking a proper diagnosis and, if you need it, getting treated—whether through talk therapy, medication or both—can help improve your mood and sleep, reduce your physical discomfort and improve your ability to cope with MS.

Fill out the assessment below and review it with your healthcare provider, so you can be sure that your treatment plan is the best it can be.

#### IN THE PAST MONTH, I HAVE FELT:



#### IN THE PAST MONTH, I HAVE:

|   | Never | Sometimes | Often | Constantly |
|---|-------|-----------|-------|------------|
| Had no appetite/<br>skipped meals                                   |       |           |       |            |
| Binged (overate)  |       |           |       |            |
| Slept more than usual   |       |           |       |            |
| Lost sleep or had difficulty sleeping                               |       |           |       |            |
| Declined social invitations   |       |           |       |            |
| Cried more than usual   |       |           |       |            |
| Stopped doing things<br>I once enjoyed                              |       |           |       |            |
| Stopped caring about<br>my appearance (my<br>clothes, grooming)     |       |           |       |            |
| Argued with others more than usual                                  |       |           |       |            |
| Had trouble making decisions  |       |           |       |            |
| Had more aches<br>(headache,<br>stomachache or<br>other) than usual |       |           |       |            |

# FEND OFF DEPRESSION

Depression can make it more difficult to follow your treatment plan and also make you less likely to follow through on healthy behaviors.

#### WHAT YOU CAN DO

- Open up to your healthcare team. They can assess whether you need to be treated for depression and/or if your treatment plan should be adjusted.
- Get a handle on your treatment plan. You may feel overwhelmed by all it takes to manage MS. Work with someone on your care team who can help you get through things. It can help just knowing someone's in your corner!
- Share your feelings. Consider expressing your emotions in a journal, with a trusted friend or, if you're okay with going public, in a blog, as well as with a licensed therapist. The important thing is you put words to your emotions and face them.

#### **ANSWER YES OR NO:**

I generally feel like my mood is suffering. □ yes □ no If "yes," describe when you first noticed a change in your mood:

No one understands what I'm feeling. □ yes □ no I don't feel like life is going to get better. □ yes □ no



# Health Monitor Monitor Living Questions to ask at today's visit



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Which treatment do you recommend and why?

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If I'm having trouble taking daily medication, are there any long-term options I can try?

How will I know if I'm responding to this treatment?

D

Ø

What can I do on my own to avoid MS flares and feel my best?

Can you recommend a support group for people of color, either near my home or online?

#### On treatment and need help covering the cost?

Ask your healthcare provider about patient assistance programs or call the manufacturer of the treatment you have been prescribed. Many pharmaceutical companies offer copay assistance programs that can make treatment more affordable.



Scan this QR code for a free digital copy or home delivery

What are the risks, benefits and side effects of this treatment?

Ø

Health Monitor Living / Multiple Sclerosis