

Charting New Horizons

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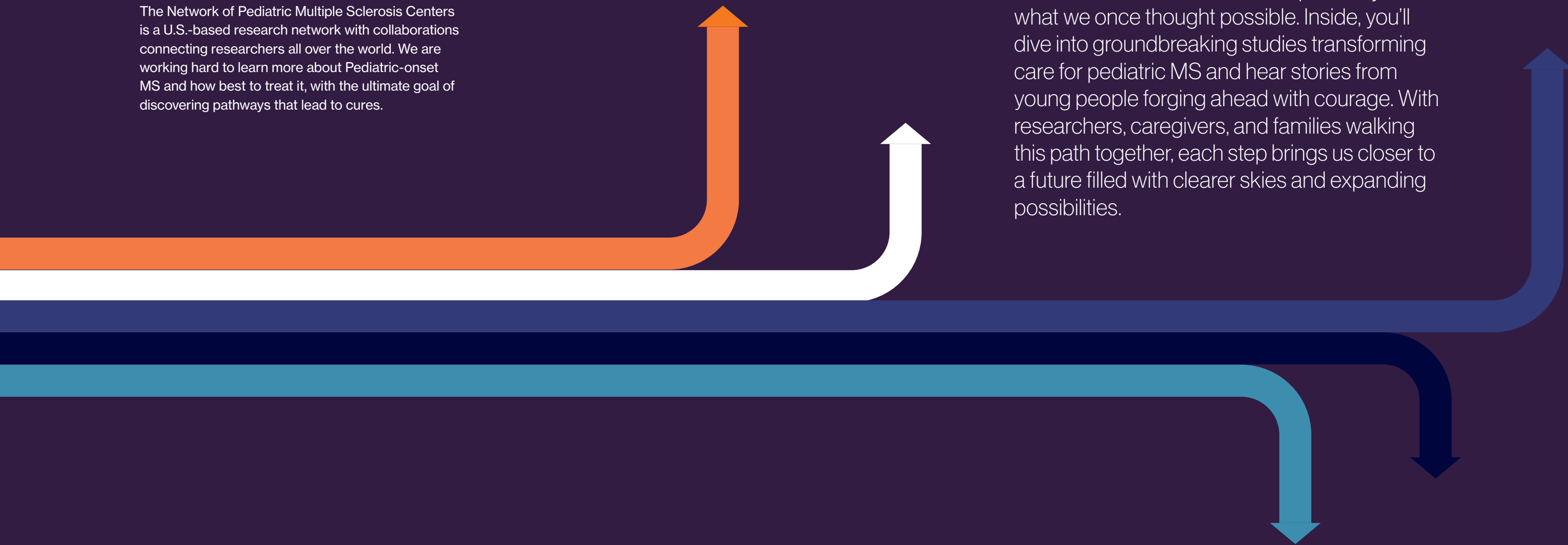
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The Network of Pediatric Multiple Sclerosis Centers is a U.S.-based research network with collaborations connecting researchers all over the world. We are working hard to learn more about Pediatric-onset MS and how best to treat it, with the ultimate goal of discovering pathways that lead to cures.

In this edition, we're charting new horizons in MS research—discoveries that push beyond what we once thought possible. Inside, you'll dive into groundbreaking studies transforming care for pediatric MS and hear stories from young people forging ahead with courage. With researchers, caregivers, and families walking this path together, each step brings us closer to a future filled with clearer skies and expanding possibilities.





Hope Leads the Way.

If you ever find yourself at a Cleveland Guardians game, singing along at a country concert, or loudly cheering for Notre Dame, you might spot someone with a huge smile, a contagious laugh, and an energy that can light up a stadium.

That's Maria Manley—20 years old, from North Benton, Ohio, carving her own path forward and inspiring other young people navigating MS-related conditions.

But Maria's story didn't begin under bright stadium lights.

It started in a hospital room when she was just 16. Two days after giving birth to her daughter, everything changed. She experienced hours of seizures, was placed into a medically induced coma, and woke up unable to move. Somewhere during those frightening hours, doctors discovered what was happening: Myelin Oligodendrocyte Glycoprotein Antibody-Associated Disease (MOGAD), a rare autoimmune disease that affects the brain, spinal cord, or optic nerves. It's not the



“ I focus on staying strong for my daughter and my family.”

same as MS, but it shares some similarities—and it hit Maria hard.

But here's the part that makes her story truly shine: Maria didn't stay down for long.

Piece by piece, step by step, she rebuilt her strength. She learned to move again. She learned to mother a newborn while healing from something most adults would find overwhelming. And she learned what it meant to be surrounded by people—doctors, nurses, family—who refused to let her face the storm alone.

Now, she's turning that experience into something extraordinary. Maria is working toward her Bachelor's in Nursing, determined to one day walk into a hospital as an RN, greet a scared patient, and say: “I've been where you are. And you're not alone.”

She still loves country music, sports, and mac and cheese. She still cheers louder than anyone at Cleveland games. But her dreams have grown even bigger.

Maria hopes research will keep unlocking answers—why MOGAD and MS happen, how we can treat them faster, and how to give every young patient the best chance at recovery. Research, she says, is how we keep charting new horizons.

And Maria? She's already leading the way.

“You would never know that I was paralyzed just three years ago.”



What It Means to Move Forward Together: Inside the NPMSC Research Network



Imagine standing at the edge of a vast landscape—one too big for any single person, family, doctor, or clinic to understand alone. Pediatric MS can feel like that sometimes: complex, unpredictable, and different for every child and teen who faces it. But when people join together, share what they know, and look ahead with purpose, that landscape becomes easier to navigate.

That’s exactly why the Network of Pediatric Multiple Sclerosis Centers (NPMSC) exists.

The NPMSC began in 2006 as just six centers, all committed to improving the lives of young people with MS and other demyelinating diseases. Families needed clearer answers. Clinicians needed better tools. Researchers needed larger, united data to spark discovery. And so these centers teamed up—not as separate hospitals, but as one community with a shared mission.

By 2010, the NPMSC had become an official research network, with the University of Utah’s Data Coordinating & Analysis Center (DCAC) stepping in to help bring everyone’s efforts together. That collaboration led to the creation of one of the world’s most comprehensive resources for pediatric MS research: the PeMSDD registry, now filled with information from over 3,000

children and teens. Each data point represents a real experience, a real challenge, a real step forward in understanding the disease.

Today, the NPMSC includes leading pediatric MS centers across the country—clinicians, scientists, nurses, coordinators, data teams, and families—working as one. These centers collect information in the same way, follow the same research protocols, and meet regularly to ask big questions: How do we stop MS? How do we restore function? How do we end the disease for good?

Together, we push forward the discoveries that can’t happen at one site alone. Insights grow clearer. Patterns emerge. Treatments become safer and more effective. And every study, every survey, every shared effort moves us closer to a future where pediatric MS is better understood—and one day, cured.

That’s what a research network truly is: people in different places, united by a mission larger than any individual center, working side by side to light the path forward for young people living with MS. And with each year, each partnership, each new horizon reached, the NPMSC continues to make that path brighter for families everywhere.

“Thousands of families have contributed to discoveries that help kids everywhere.” - Charlie Casper, PhD, University of Utah Data Coordinating Center

The NPMSC includes Clinical Centers, a Data Coordinating & Analysis Center, and a Community of Collaborators:

Center for Pediatric-Onset Demyelinating Disease
Children’s of Alabama & University of Alabama at Birmingham
Principal Investigators: Jayne Ness, MD, PhD; Yolanda Wheeler, PhD

Pediatric Neuro-Immunology and MS Program
University of California San Francisco & Benioff Children’s Hospitals
Principal Investigator: Emmanuelle Waubant, MD, PhD

Mass General Brigham Pediatric MS Center
Massachusetts General Hospital for Children
Principal Investigator: Tanuja Chitnis, MD

Pediatric Multiple Sclerosis and Related Disorders Program
Boston Children’s Hospital
Principal Investigators: Leslie Benson, MD; Rebecca MacRae, MD

The Pediatric MS Center
Mayo Clinic
Principal Investigators: Jan-Mendelt Tillema, MD; Moses Rodriguez, MD

Pediatric MS Center
Hassenfeld Children’s Hospital at NYU Langone
Principal Investigators: Lauren Krupp, MD; Kim O’Neill, MD

The Blue Bird Circle Clinical Research Center
Texas Children’s Hospital at Baylor College of Medicine
Principal Investigators: Timothy Lotze, MD; Nikita Shukla, MD

Neuroimmunology Clinic for Children
Children’s Hospital Colorado,
University of Colorado Anschutz Medical Campus
Principal Investigator: Teri Schreiner, MD, MPH

Pediatric MS & Demyelinating Diseases Center
Washington University Medicine
Principal Investigator: Soe Mar, MD

Mellen Center for Multiple Sclerosis
Cleveland Clinic Neurological Institute
Principal Investigators: Mary Rensel, MD; Aaron Abrams, MD

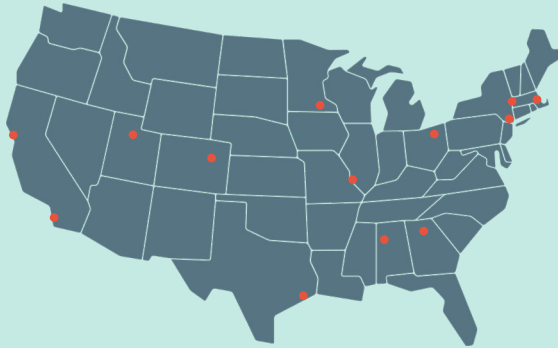
Pediatric Multiple Sclerosis Center
University of California San Diego & Rady Children’s Hospital
Principal Investigator: Jennifer Graves, MD

Pediatric Neuroimmunology and Multiple Sclerosis Center
Children’s Healthcare of Atlanta and Emory University
Principal Investigator: Grace Gombolay, MD

Data Coordinating & Analysis Center
University of Utah Data Coordinating Center
Principal Investigators: Charlie Casper, PhD; John Rose, MD

What is a research network anyway?

- A research network is a group of clinics and scientists who work together instead of working alone.
- It helps researchers gather more information, faster.
- It improves care by making sure kids everywhere get high-quality, consistent treatment.
- It lets families contribute to discoveries that benefit others.
- It speeds up progress toward better treatments and, one day, a cure.



Redefining the Journey.

“This diagnosis wasn’t an ending. It was just a shift in direction.”



When Bridget Breland McCrary looks back, she can still picture herself at 14 with her new school notebooks, big dreams, and absolutely no idea that life was about to change course.

One week she was racing through her classes, and the next she found herself unable to keep up with note-taking. Within just three days, she heard the words multiple sclerosis (MS) for the first time. To a teenager who knew nothing about MS, it felt like the world had tilted off its axis.

But every explorer charting a new horizon needs a good crew, and Bridget had hers: her mom and aunt, steady as lighthouses in those first frightening days. With their support, she slowly discovered something important—this diagnosis wasn’t an ending. It was a shift in direction.

And wow, did she navigate it well.

Today, Bridget is 30, living in Centreville, Alabama, and thriving as both a pharmacist and a mom to two little girls. Her path into healthcare began the moment MS entered her life. She once imagined becoming a nurse, but as she learned more about her condition, her curiosity tugged her toward pharmacology. Years later, she holds not one but two bachelor’s degrees—chemistry (with a biology minor) and pharmacy studies—plus a PharmD. Talk about plotting a remarkable course.

Bridget still loves all the things she enjoyed before—DIY crafts, hanging out with friends and family, and Mexican food (always)—but she’s learned to adapt, pacing herself and keeping cool when she needs to. She explains that MS doesn’t define her; it’s simply one part of her story. Her message to others newly diagnosed? It’s going to be okay. Find people who listen, support you, and help you learn. And don’t be afraid to overshare with your doctor—more information is always better than not enough.

She’s participated in MS research before and hopes that future discoveries continue to expand treatment options, improve comfort, and, of course, steer us toward a cure. Because every bit of research—every question asked, every answer found—helps young people with MS navigate their own uncharted waters. Bridget’s journey reminds us that while MS may alter the map, it doesn’t take away the horizon. And hers is wide, bright, and full of possibility.



“I refuse to let MS define me—it may be part of my life, but it doesn’t determine what I’m capable of.”

Movement on the Research Front.

Want to know what our
researchers have been up to?
Here's the scoop...



More Than a Retreat: A Lifeline for Families Living with MS

The Center for Pediatric Onset Demyelinating Disease (CPODD) was established at the University of Alabama at Birmingham in 2006 to provide clinical expertise and treatment for children and families across a seven-state southeastern region. Over time, CPODD identified a significant unmet need: children living with multiple sclerosis (MS) rarely had opportunities to connect with peers who shared their diagnosis, and parents and siblings lacked spaces to share experiences with other affected families.

In response, CPODD launched an annual Family Retreat in 2008 for families of children with MS, expanding in 2010 to include families affected by neuromyelitis optica (NMO), who face similar challenges. The retreat is a four-day, theme-driven event designed to foster connection, education, and community. Families build relationships through structured activities and informal time together, where meaningful conversations and peer support naturally occur.

The retreat includes expert-led workshops covering topics such as symptom management, treatment options, ongoing research, complementary therapies, coping strategies, school interventions, and overall wellness. Recreation and enjoyment are also central to the experience, with activities including swimming,

canoeing, sports, arts and crafts, team-building exercises, movie nights, campfires, and dance parties.

The retreat is held at Children's Harbor on Lake Martin in Eclectic, Alabama. Attendance is free for families, including lodging, meals, and activities, though families are responsible for travel. (If travel is an issue, families can apply for assistance.) Facilities are provided as in-kind donations, and program costs are supported through grants and charitable contributions. The retreat event is offered to patients who have been seen at CPODD or the MS center at Children's Health Care of Atlanta and is made possible by dedicated staff and volunteers.

In 2024, CPODD partnered with Children's Healthcare of Atlanta's pediatric MS center to expand collaborative efforts. In 2025, the program celebrated its 15th retreat. Since its inception, 93 families from seven states have participated, with more than 55% attending two or more times. The time at the retreat may be limited but the connections last a lifetime.

Four days
of learning,
laughter, and
lakeside fun:
From expert-
led workshops
to campfires
and dance
parties, this
retreat is
ALL about
connection.

Real science in progress!

Long-Term Outcomes Study

We're excited to share a new project that looks at what life is like for kids and teens who have multiple sclerosis (MS) as they grow up and how their treatments may shape their well-being over many years. This study isn't about trying new medicines—it's about listening and learning from real experiences of young people living with MS and their families. Specifically, we want to better understand the challenges that they face and the long-term safety and benefits of Disease Modifying Therapies (DMTs), even 5-10 years after diagnosis.

Children and teens with MS who have been part of the Pediatric MS Network, along

with their families, will be invited to complete multiple surveys about their current daily lives. By collecting this information, we hope to answer the following questions: How does MS affect quality of life years after diagnosis? Do DMTs continue to help young people stay healthy and active over time? The answers will guide doctors and families in making the best choices for care and support.

Your voices matter, and together we can build a clearer picture of life with MS—today and in the future!

Care in MS Study

The Childhood Adversity Research Effort in Multiple Sclerosis or the CARE.in.MS Study aims to demonstrate the link between childhood adversity and MS outcomes, age of MS onset, and MS severity. The study will also hope to identify the specific social and environmental factors that will become areas of focus for future studies. Enrollment into the Aim I Focus Group portion of the study took place at three participating sites beginning in May 2025 and concluding in July 2025. The cross-sectional portion of the study or Aim II began in enrollment October 2025. Participating subjects are asked to complete a total of 14 surveys that ask about

individual and socioeconomic childhood experiences, complete a blood draw, and complete a clinical brain MRI scan. A total of seven Network of Pediatric Multiple Sclerosis Centers will participate in Aim II with a goal of enrolling 300 subjects, 150 of which will have a diagnosis of Pediatric-Onset Multiple Sclerosis and 150 with a diagnosis of Adult-Onset Multiple Sclerosis. 30 participants who were enrolled in Aim II of the study will then be approached for participation in the Aim III one-on-one interview portion of the study. Enrollment will continue through 2029.



(L-R Dr. Nakita Shukla, MD, Dr. Kelsey Poisson, MD, Dr. Aaron Abrams, MD and Dr. Yolanda Wheeler, PhD)

Pediatric MS Symposium

The U.S. Network of Pediatric MS Centers hosted its first-ever pediatric MS symposium at the 2025 Annual Meeting of the Consortium of MS Centers in Phoenix, Arizona. This groundbreaking session underscored the importance of specialized care for children and teens living with MS.

Led by Dr. Yolanda Wheeler from the University of Alabama at Birmingham, the symposium featured experts addressing key challenges in diagnosis, treatment, and support. Topics included how pediatric MS differs from adult MS, rare conditions that mimic MS, and barriers families face in accessing therapies. Speakers emphasized the need for age-specific expertise and collaborative care involving patients, families, and providers.

The event concluded with interactive case discussions, fostering shared learning and highlighting the commitment to improving outcomes for young people with MS.

Family Caregiving Study

“Our goal is to ensure that every child with MS receives the care they need when they need it.”

- Huong Meeks, PhD

Regular clinic visits and MRI scans are essential for clinicians to understand how Multiple Sclerosis (MS) is progressing and to choose the best treatments. But we also know that life with MS can bring many challenges- social, emotional, and financial- that make it hard for children with MS and their families to keep up with routine care.

With support from the University of Utah Family Caregiving Collaborative, we are conducting the first U.S. multi-center study to look at how often children with MS in the Pediatric MS Network can attend clinic visits and get their recommended MRI scans. We also explore the hardships families caring for children with MS face after the MS diagnosis.

Caring for a child with MS works best when patients, families, and the care team can stay connected and supported. Through this study, we hope to be able to better understand the factors



that make it difficult to keep up with routine care, and to identify what kinds of support might help families overcome these challenges. Our goal is to ensure that every child with MS receives the care they need when they need it.

Important Network Publications & Abstracts from 2025.

Real-World Effectiveness of Switching to Oral or Infusion Versus Injectable Disease-Modifying Therapy in Pediatric Multiple Sclerosis

Published in *Annals of Neurology*, November 2025

If you've ever wondered, "What happens if I switch from injections to pills or infusions?"—we wanted to find out too. So, we studied 212 kids and teens with MS who changed their treatment before age 18. Some stayed with injections, others switched to oral medications, and some moved to infusion therapies. Here's what we discovered:

Switching to oral or infusion treatments worked much better than switching to another injectable. Kids who switched to pills had about 60% fewer relapses, and those who switched to infusions had about 80% fewer relapses compared to staying on injections. Infusion therapies also delayed new MRI activity longer than other options. The most effective treatments were natalizumab and anti-CD20 therapies (like rituximab or ocrelizumab).

Why this matters:

Our research shows that higher-efficacy treatments can make a big difference in controlling MS activity early on. These findings help doctors and families understand real-world outcomes when considering treatment changes.

Abrams AW, Waltz M, Casper TC, et al. *Real-World Effectiveness of Switching to Oral or Infusion Versus Injectable Disease-Modifying Therapy in Pediatric Multiple Sclerosis*. *Ann Neurol*. 2025;00:1-15. doi:10.1002/ana.78086.



Krysko KM, Waltz M, Chitnis T, et al. *Study of the Association Between Menarche and Disease Course in Pediatric Multiple Sclerosis*. *Neurology*. 2025;104:e210213. doi:10.1212/WNL.0000000000210213.

Study of the Association Between Menarche and Disease Course in Pediatric MS

Published in *Neurology*, February 2025

We studied 736 girls with MS to see if puberty affects disease activity. Most had their first MS symptoms about 2–3 years after their first period (menarche). Relapse rates were highest around menarche—the year before and after—compared to before puberty. After menarche, relapse risk stayed higher than in the premenarche years. This suggests hormonal changes during puberty may influence MS activity. Our findings highlight that puberty is an important time in the MS journey and help researchers understand how development and disease interact.

Cognitive Function in People With Pediatric MS Over 2 Years

Published in *Neurology*, October 2025

If you have MS, you might wonder: "Will this affect my memory or schoolwork?" A big study followed teens with MS for two years to find out—and here's the good news.

Most teens with MS stayed the same or even improved on thinking tests. Your brain is strong! About 80% were stable or better on one test and over 90% on another. Only about 1 in 5 had some slowing in processing speed, and even then, most skills stayed steady.

Researchers compared teens with MS to healthy teens and adults with MS. The results? Teens with MS performed almost the same as healthy teens and better than adults early in the disease. Both groups had a small dip in verbal learning scores, but this happened in healthy teens too—likely just part of normal brain development.

The study also looked at what might cause changes. Surprisingly, MS-related factors like how long you've had it or your treatment didn't seem to matter.

Instead, social factors played a bigger role. Teens whose parents had less education or who faced fewer resources were more likely to show decline. This means support at home and school really matters.

Things to remember:

- Stick with your treatment plan—it helps keep your brain healthy.
- Speak up if school feels harder. Your care team can connect you with resources.
- Build your support system. Family, teachers, and friends can make a big difference.

O'Neill KA, Charvet L, Waltz M, et al. *Cognitive Function in People With Pediatric Multiple Sclerosis Over 2 Years*. *Neurology*. 2025;105:e214142. doi:10.1212/WNL.0000000000214142. [Published online October 21, 2025].



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