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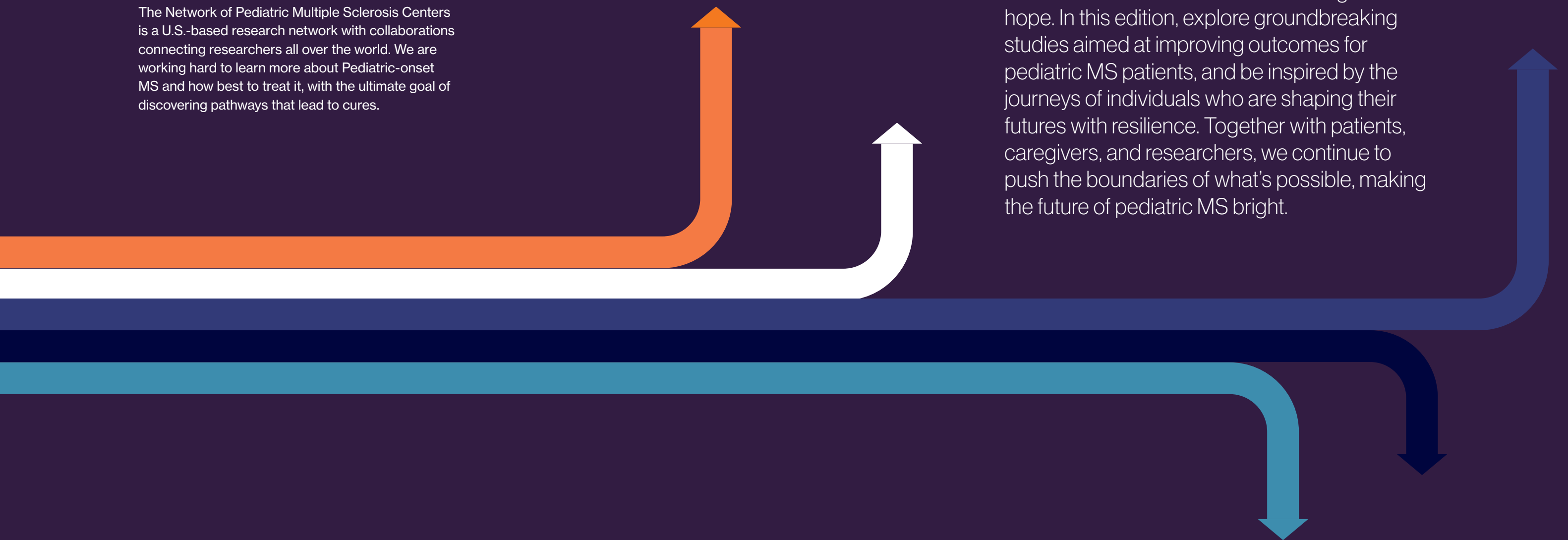
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The Network of Pediatric Multiple Sclerosis Centers is a U.S.-based research network with collaborations connecting researchers all over the world. We are working hard to learn more about Pediatric-onset MS and how best to treat it, with the ultimate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

As we celebrate progress in MS research, we're excited for future discoveries that bring new hope. In this edition, explore groundbreaking studies aimed at improving outcomes for pediatric MS patients, and be inspired by the journeys of individuals who are shaping their futures with resilience. Together with patients, caregivers, and researchers, we continue to push the boundaries of what's possible, making the future of pediatric MS bright.







# Modeling A Hopeful Future.

**Meet Nicole Pedra, a vibrant 36-year-old from the Boston suburbs who's passion for life shines through her love for game nights, dancing, and painting. Despite navigating challenges with MS since childhood, Nicole openly shares her journey to inspire others.**

Diagnosed with Multiple Sclerosis (MS) at the tender age of 10, Nicole's journey has been marked by resilience. The onset of her MS brought with it a series of challenges, including Bell's palsy, transverse paralysis, optic neuritis, and vertigo. Despite the trauma and an initial misdiagnosis (ADEM), Nicole's spirit remained unbroken. Her mother's strength and advocacy played a crucial role in navigating the health-care system, a privilege Nicole acknowledges not everyone has.

Surprisingly, Nicole kept her diagnosis a secret for 20 years, a decision influenced by the stigma and fear of being misunderstood. Today, she is an influential voice in the MS community, using social media to share her journey and connect with others. Her dream for the next



**“ Just because you have this diagnosis doesn't mean that your life needs to be smaller.”**

five years includes delivering a TED Talk, aiming to inspire and educate others about MS, particularly Pediatric-Onset Multiple Sclerosis (POMS), which she has lived with for over two decades.

In her own words, “staying positive is about gratitude and hope.” Despite being told she might be in a wheelchair by 16, Nicole has modeled and even walked a runway. Her story is a testament to the power of hope and perseverance. She emphasizes that MS, though often invisible, should not limit one's dreams and possibilities.

Nicole's support system includes a close-knit group of girlfriends who also have MS. They call themselves the Myelin Mavens, a name that symbolizes their shared journey and mutual understanding. For Nicole, community and open communication are vital, and she encourages others to talk about their experiences and find support.

Nicole's goals are clear: to make a positive impact within the pediatric MS community and inspire children with MS to pursue their dreams. Through her advocacy, Nicole Pedra is not only raising awareness about MS but also shining a light on the possibilities and hope that lie ahead for those living with the disease. Her story is one of courage, creativity, and an unwavering belief in the power of hope.

**“They told me that I would be in a wheelchair at age 16. But now I have modeled. I have walked a runway.”**





# The US Network of Pediatric Multiple Sclerosis Centers (NPMSC)

Past. Present. Future.

The network’s research on pediatric MS and related diseases explores key areas like who is affected, what increases risk, how relapses happen, how treatments are used, and how these conditions impact thinking and daily life. This work highlights the importance of early diagnosis, proactive care, and continued research to better understand and manage pediatric MS and related conditions. The network has secured 16 major grants from federal, foundation, and pharmaceutical sources; established a registry with over 3,000 participants; and identified risk factors like vitamin D deficiency, air pollution, and smoking. With over 67 published manuscripts, participants from 12 network centers, 8 affiliate centers, the network provides critical support and educational resources for individuals with pediatric MS.

“NPMSC continues to make strong contributions across key areas of importance to Pediatric-onset MS and MS in general.”



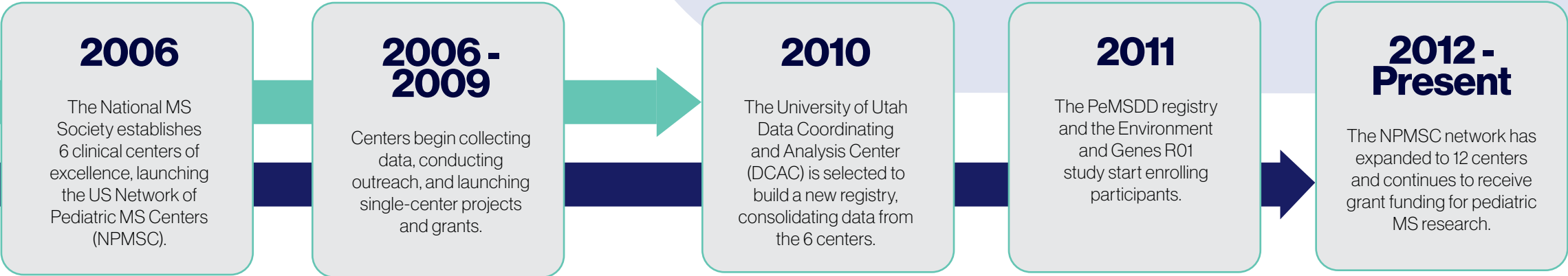
Dr. John Rose, University of Utah



## Looking to the Future

The network is committed to conducting impactful research and aligning future studies to improve outcomes for individuals with MS. Upcoming research areas include:

- Study differences between males and females in pediatric MS
- Identify factors that aid resiliency and recovery after relapses
- Assess long-term safety of new pediatric MS medications
- Develop treatments and vaccines to prevent pediatric MS





# Finding Hope & Purpose.

“ Listen to your body, know your limits, and ask for help when you need it.”



May Ling Kopecky, 29, from Plymouth, MN, was diagnosed with MS at age 15. Now an artist, advocate, and educator, May Ling uses her experiences to help raise awareness about multiple sclerosis and inspire hope for young people facing similar challenges.

May Ling first experienced symptoms at 13 with an unusual buzzing sensation in her neck and back, called Lhermitte’s sign. By 15, involuntary convulsions led to an MS diagnosis. The journey was isolating at times, especially as few people understood what MS was or believed that someone so young could be affected. “I felt like I was alone,” she recalls. “People would say I ‘looked fine’ or was ‘too young to be sick.’”

While living with MS has brought challenges, May Ling’s story is a reminder that MS doesn’t have to define or limit one’s life. In high school, college, and graduate school, she learned to advocate for herself, listening to her body, learning her limits, and embracing the support of her community. “Finding community has been super helpful!” she says, emphasizing the importance of connecting with others who understand.



Today, May Ling is an accomplished artist with degrees in fine arts, whose work is celebrated nationwide for portraying the realities of living with MS. She has been honored in several exhibitions and publications, and in 2021, she earned second place in the Kennedy Center’s VSA Emerging Young Artist Competition. Through her art, May Ling shares the physical and emotional aspects of living with MS, helping to educate others and offer comfort to those navigating the same path.

Looking to the future, May Ling hopes MS research can lead to treatments that not only manage but cure MS, or even reverse the damage it causes. “You can still live your life,” she encourages others newly diagnosed with MS. Her advice is simple: listen to your body, know your limits, and ask for help when you need it.

Through her art, she’s raising awareness about MS, advocating for accessibility, and helping others with MS feel understood. Her journey reminds us that the future holds promise for those living with MS.



“Finding community has been super helpful!”

# Movement on the Research Front.

At NPMSC, our goal is to uncover causes, advance treatments, and improve outcomes for pediatric MS, and we're excited to share updates on our studies and recent publications.



## The Pediatric MS & Other Demyelinating Diseases Database: A Collective Effort Toward a Brighter Future

The Pediatric MS and Other Demyelinating Diseases Database is making a difference in the lives of young people diagnosed with MS and similar conditions. Created to collect key information about patients with early signs of these diseases, this project helps scientists and doctors understand how MS and other demyelinating diseases affect young people specifically. The database includes details on each patient's age, background, health history, and how they manage their condition. By tracking these factors, researchers can see patterns, learn what affects disease progression, and look for ways to improve treatments.

Over the last decade, more than 3,000 young people from across the country have joined this database. Each story adds valuable insight, helping researchers generate new ideas and design clinical trials that could bring better treatments and, one day, a cure. Thanks to these collective data, the network has already produced many studies, abstracts, and articles for national journals and conferences, making sure that the latest findings reach doctors and scientists everywhere.

The database also supports the National MS Society's Pathways to Cures initiative, focusing on three main goals:

- STOP: Stopping the progression of MS and other demyelinating diseases.
- RESTORE: Developing treatments to restore lost abilities and help young people regain what MS may have taken.
- END: Ending these diseases forever, so future generations don't have to face the challenges of MS.



Each young person who joins the database helps bring us closer to these goals. For those who participate, it's a powerful way to make a difference, both for themselves and for others who share their journey.

By contributing, patients and their families add another chapter to a growing story—a story about resilience, hope, and the shared commitment to finding cures. If you or someone you know might want to take part in this important research, ask your doctor about joining the study. Every experience matters, and together, we're building a future where MS no longer stands in the way of young people's dreams.



Read more about the National MS Society's Pathways to Cures.



# Research In Progress.

## Effects of Avonex/Plegridy

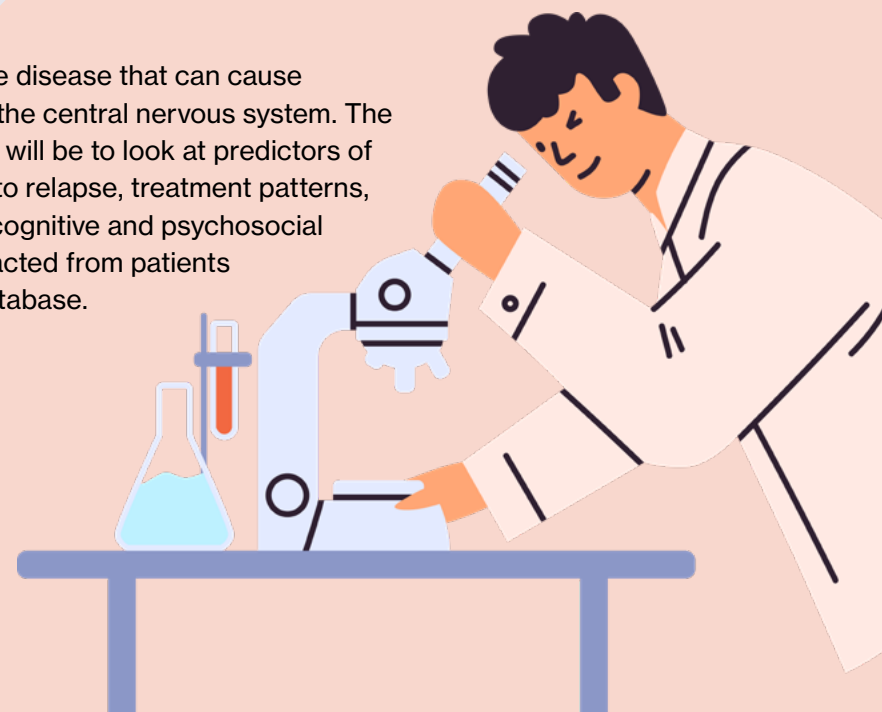
IM interferon beta 1-a (Avonex®) and peginterferon beta-1a (Plegridy®) have shown to be effective as disease-modifying therapies (DMTs) for adults with relapsing forms of MS, however, very few studies of DMT's impact on pediatric MS patients have been completed. The purpose of this study was to look at the time between treatments and relapse for patients who used Avonex or Plegridy prior to age 18 as a DMT. A retrospective analysis of registry data was conducted from patients who were enrolled into the Pediatric MS and Demyelinating Diseases (PeMSDD) Database. It was concluded that estimates of patients relapse-free were almost 70% for both Avonex and Plegridy DMTs for the first year. This is consistent with previously reported clinical outcomes used in adult populations. A manuscript utilizing this study and its findings is in the process of publication.

## Biological Age in the Pediatric MS Population

By using pediatric participant's samples and data, we were able to look at biological age to study whether or not MS pathology may relate to premature aging. For this study we will be using multiple biomarkers in a large cohort of pediatric-onset multiple sclerosis participants and age-similar healthy controls. The final analysis and manuscript publication for this study are still ongoing.

## MOGAD

MOGAD is a rare autoimmune disease that can cause inflammation and damage to the central nervous system. The main objectives for this study will be to look at predictors of pediatric MOGAD in relation to relapse, treatment patterns, and the short and long term cognitive and psychosocial outcomes. Data will be abstracted from patients enrolled into the PeMSDD database.



## When Pediatric Patients Become Adults

Dr. Aaron Abrams from Cleveland Clinic leads a Transitions Working Group to improve the transition of patients from pediatric- to adult-focused care. So far, we have found that transition practices vary widely, such as the age when patients are typically transitioned, and the timing and ways families are prepared for the transition process. Currently, we are exploring whether patients are at greater risk of experiencing lapses in care once they turn 18, so we can then identify risk factors to help prevent this from happening. The ultimate goal will be to establish best practice guidelines providers everywhere can use to improve the care of their patients.



## Diet & Relapses

**“Our study highlights that a healthy diet may also help prevent relapses in patients with MS.”**

Dr. Emmanuelle Waubant

Patients and families are often curious to hear about dietary recommendations when they are diagnosed with MS because they worry specific foods may make their disease worse. The truth is that few studies have addressed this question, especially in children with the disease. It is also a very challenging question to address. Our network has led a large study of diet in pediatric MS to understand if there was any relationship between diet and the risk of relapse or new MRI scars. This work was supported by a grant from the National MS Society.

We collected information on diet using a standardized food questionnaire from 353 children with MS enrolled shortly after disease onset. These patients were followed at our clinics for 4 years on average. We found that those eating 50% more dairy than recommended and those with higher intake of saturated fats had a higher risk of relapse and/or new scar on MRI. On the contrary, those eating more fruit and vegetables than recommended, and those eating more

fibers had a decreased risk of relapse. We also used a global dietary index called the Healthy Eating Index that captures food items weighted according to whether they are thought to be healthy or not. We found that children who had a higher Healthy Eating Index score had a much lower chance of relapse.

In summary, this work supports the possible influence of diet on the risk of relapse, but does not establish a causal relationship between various foods and MS course. However, the foods that we found to be associated with the risk of relapse in our study are foods that the American College of Pediatrics recommends to limit to optimize health in general.



# Recent NPMSC Publications and Abstracts.

## Promising Results for Young People with MS on Newer Treatments

*Demographic Features and Clinical Course of Patients with Pediatric-Onset Multiple Sclerosis on Newer Disease Modifying Treatments*

We are excited to share the results of a recent study published in *Pediatric Neurology* examining the impact of newer Disease Modifying Treatments (DMTs) for pediatric-onset multiple sclerosis (POMS). Conducted through the U.S. Network of Pediatric MS Centers (NPMSC), our study followed nearly 500 young people who started treatment with medications like dimethyl fumarate, fingolimod, natalizumab, rituximab, and ocrelizumab before the age of 18. While these medications are often used in adults with MS, there have been limited data on how effective they are in younger patients – until now.

Our findings show highly encouraging early results. Within the first year of treatment, these newer DMTs dramatically reduced both relapse rates and the number of new active spots seen on brain MRIs. Many patients achieved “NEDA,” or No Evidence of Disease Activity, during their treatment, meaning they experienced no new symptoms and had no new

signs of disease activity on MRIs for months. Specifically, we observed that between 66% and 84% of patients showed no disease activity after one year.

Although our study covered only a short treatment period, these early improvements suggest that these newer DMTs may play an important role in helping young people with MS experience fewer relapses and manage their disease more effectively. We hope these results serve as a valuable guide for future research, ultimately leading to better long-term outcomes for young people with MS and their families.

- Shukla, N.M., et al. (2023). Demographic Features and Clinical Course of Patients With Pediatric-Onset Multiple Sclerosis on Newer Disease-Modifying Treatments. *Pediatric Neurology*, 145, 125-131. <https://doi.org/10.1016/j.pediatrneurol.2023.04.020>

## New Insights on Fingolimod and Ocrelizumab for Pediatric-Onset MS

*Clinical and Magnetic Resonance Imaging Outcomes in Pediatric-onset MS Patients on Fingolimod and Ocrelizumab*

Our team at the U.S. Network of Pediatric MS Centers recently investigated how the medications fingolimod and ocrelizumab affect young people with pediatric-onset multiple sclerosis (POMS). We included nearly 140 patients from 12 centers who started these treatments before turning 18. Our aim was to evaluate these treatments’ impact on relapses and brain changes seen in MRI scans, which are crucial indicators of MS progression.

Before starting treatment, patients with POMS showed frequent relapses and new lesions in the brain, a sign of ongoing disease activity. After beginning fingolimod or ocrelizumab, however, there was a notable decrease in both relapses and new lesion formation. For patients on fingolimod, the annualized relapse rate dropped from 0.43 to 0.12. Those on ocrelizumab saw an even more dramatic reduction,

from 0.64 to 0.09, with almost all new lesion activity disappearing entirely.

These results show the potential of fingolimod and ocrelizumab to reduce relapses and limit new brain damage in pediatric MS. This knowledge is invaluable as it guides ongoing clinical trials and shapes future treatment strategies, ultimately aiming to improve outcomes for young people with MS and give their families hope for a better-managed condition.

- Nasr, Z., Casper, T.C., Waltz, M., et al. (2024). Clinical and magnetic resonance imaging outcomes in pediatric-onset MS patients on fingolimod and ocrelizumab. *Multiple Sclerosis and Related Disorders*, 87, 105647. <https://doi.org/10.1016/j.msard.2024.105647>



See all published NPMSC research manuscripts





# The US Network of Pediatric Multiple Sclerosis Centers

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The US Network of Pediatric Multiple Sclerosis Centers (NPMSC) is  
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