

# NPMSC Newsletter

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

Welcome to the third issue of the NPMSC Newsletter! This year has been unique in so many ways and we're excited to bring you this issue. A lot of research progress has been made in the last year. Inside, we hope you enjoy learning about how children with MS and their families continue to contribute to research efforts in a major way and our latest findings from network research studies.

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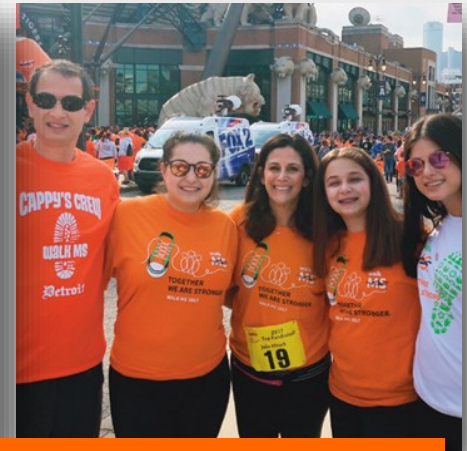
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Peter

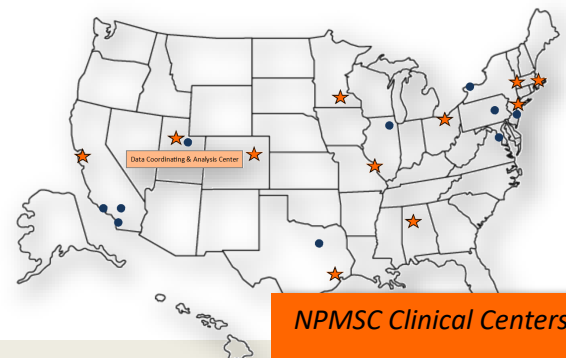


Stacey & her family, MS Walk

**Don't miss the NPMSC spotlight featuring Peter and Stacey (shown above)—page 2**

The NPMSC is a United States based network with international collaborations. We are comprised of adult and child neurologists, scientists and other research professionals whose unifying mission is to discover the causes, investigate determinants of remyelination & neuroprotection, advance therapeutics and improve outcomes of Pediatric MS.

Research is important to discovering the best treatment approaches for kids with MS. As kids develop into adults, there are special windows in development that may hold the keys to understanding how MS starts and how to prevent MS. The NPMSC is supported by the National MS Society.



NPMSC Clinical Centers

**Interested in investing in this great cause?**  
Visit the National MS Society's [website!](#)

# Stacey

Stacey is a freshman at the University of Michigan, where she lives on campus, and has plans of becoming a pediatric neurologist—specializing in MS.

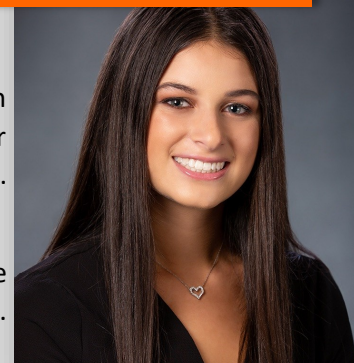
When Stacey was fourteen, she started experiencing numbness in her leg, which soon progressed to the right side of her body and all the way into her arm. Her family, including her father—a family practice doctor—were stumped as to what could be causing her symptoms. So, Stacey did a little research of her own. A month later, she was diagnosed with MS.

Trying to balance high school, along with her new medical issues, wasn't easy. She did more research, which eventually brought her to the MS Society's website. Her mother joined groups. They reached out to friends and others with MS, learning everything they could.

In Stacey's words, her diagnosis has shaped who she is, but it doesn't define her. It's helped her decide on a career path, creating a future she may have not have taken otherwise. She's different now—who she is, what she does, those she chooses to be friends with—it's all changed. COVID has posed some challenges too, altering her perspective on things she can or can't do. She's looking forward to the rest of her college experience—meeting new people and creating new memories. She wants to travel and study abroad, if the opportunity presents. She hopes for the day when groups of kids with MS can meet and easily connect.

Something she wants people with MS to know is that they can live full lives. She's proof. She works out, walks several miles a day and is a straight A student at her university. Keeping her diagnosis from defining her has had a positive impact on her life and she wishes the same for others.

Stacey



# NPMSC Spotlight

## Peter

Born in Harlem, the birthplace of Jazz, 16-year-old Peter is a big fan. He also loves playing basketball and baseball with his friends, especially on long summer afternoons. In his own words, "Ball is life."

When he first learned about his MS diagnosis, he had a lot of questions. He thought maybe he'd injured his head somehow. He's since learned a lot and has made a few changes in his life. Now that he knows what it's called, he can talk to his friends about it. He can explain why they might not understand him at times. They are surprised when they learn that multiple sclerosis sometimes changes how he speaks, walks, and sees. He hopes that by teaching them about it, he can help them understand what it's like.

Peter & his mom



He also makes sure to tell them not to go easy on him, because he certainly doesn't let MS stop him. He says it doesn't make him feel like he's special or anything, he just feels like a normal kid. Some of those normal things include helping his mom around the house by taking out the trash, doing laundry and learning how to bake.

He wants other kids with MS to know that it's not the end of the world. There are treatments that can help. Having a good doctor helps. He loves his own doctor, Lauren Krupp, because "she's very caring" and has made a big impact on his life, helping him work through his diagnosis.

## STUDY UPDATES

### ONGOING: Diet & Relapses in Pediatric MS Study

The purpose of this study is to better understand if diet and metabolism are connected with MS relapses and disease progression in patients with pediatric-onset MS. The National MS Society funds this research study.

Study participants give a one-time blood sample at enrollment and answer questions about food eaten, vitamins taken, and physical activity at three time points (enrollment, 6-months, 12-months) during the study.

Enrollment began in March 2018 and the study is still actively enrolling. 168 patients that have been diagnosed with pediatric-onset MS have been enrolled in the study to date. We have also seen the completion of 84 follow-up questionnaires from those that were enrolled 1 year prior.

Enrolled	Completed Follow-up
168	84



*Diet & Relapses Study*

### ONGOING: Patient Family Views on Pediatric Multiple Sclerosis

This study consists of a survey asking patients and families about their perspectives on pediatric MS research priorities and methods. The survey was developed by first conducting focus group discussions with patient and family representatives at three NPMSC centers. Important themes in the focus group discussions were turned into survey questions so that more patients and families can contribute.

We currently have 70 adults diagnosed with pediatric-onset MS, 27 teens currently living with pediatric-onset MS, and 28 parents of children who have been diagnosed with pediatric-onset MS enrolled in the survey. Enrollment is set to end in March 2021. We believe that people living with the disease will provide unique insight into what research is important to them and what barriers exist for them to participate in research. This knowledge will be used to better guide research priorities and design.

### WRAPPING-UP: Cognition and Neurodevelopmental Influence (CANDI)

We would like to thank everyone who has participated in the Cognition and Neurodevelopmental Influence (CANDI) study so far! This includes children living with MS, adults living with MS, and children without MS. We have reached exciting milestones in the study. In March of 2019, study participants started returning to clinic for their 24-month follow up study visit. During this follow-up visit, participants are re-evaluated using the same measures with which they were tested two years prior. The findings from this trial will provide a significant look into cognition of those living with multiple sclerosis over time, and if/how cognition differs between children with MS and adults with MS and also how it differs between children with MS and children without MS.

COVID-19 slowed down the follow-up process slightly but we have seen an increase in those returning to complete their testing in the last month. To date, we currently have 101 participants out of 166 that have completed their follow-up testing. With the follow-up period set to end in early 2021 we hope to have the remaining participants complete their testing soon.

Enrolled	Completed Follow-up
166	101



*COVID-19 Virus*

### COVID-19

The network recognizes the great impact that COVID-19 has had on children with MS and their families. We are currently collecting information about children with MS who have contracted COVID-19 in order to better understand possible risk factors and the best course of action for children that contract COVID-19. A COVID-19 working group has been established with a number of pediatric MS experts and scientific investigations are currently underway. The National MS Society's website is a great resource of [COVID-19 information for people living with MS](#).



## Pediatric Multiple Sclerosis Severity Score

### Manuscript Summary

Because there are many differences between adults and children with MS, investigating the disease in children can be challenging. The ability to detect more subtle changes would allow doctors to know earlier if a new therapy is working or if a change in treatment is indicated. In this study the goal was to develop a sensitive clinical scale for continuous disability assessment specifically for pediatric-onset MS (POMS). The study analyzed the records of 873 people across twelve centers, and compared the findings to data that had been previously published about MS in children and adults. In pediatric-onset MS (POMS), children have increased numbers of relapses when compared to adults. Children are also harder to test because it takes them a long time to reach checkpoints, such as those that show an impaired gait or the need for an assistive device. This study measured the way the subjects moved and thought, and created an optimized disease and disability modeling scale for the unique population of children with MS. The innovative clinical scale that was developed is entitled the Pediatric Multiple Sclerosis Severity Score (Ped-MSSS) and is a more sensitive method of evaluating disease severity in patients with POMS. In the future, use of this scale made specifically for POMS will make it easier to monitor disease activity and identify the children who would likely benefit from a change in treatment. [Full Manuscript: Santoro JD, Waltz M, Aaen G, et al. Pediatric Multiple Sclerosis Severity Score in a large US cohort. \*Neurology\*. 2020;](#)



## Effectiveness of Disease-Modifying Therapies

### Manuscript Summary

The goal of the study was to compare newer disease-modifying therapies (DMTs) to injectable therapies in pediatric patients with MS and clinically isolated syndrome (CIS). The study followed 741 children with MS/CIS across twelve clinics in the US, each of which either received the newer or the injectable therapies as part of their standard care. The study found that those on the newer DMTs had lower relapse rates than those on injectables. Additionally, those on the newer DMTs had fewer new lesions and slower growing lesions than those on injectables. Initial treatment of pediatric MS/CIS with newer DMTs led to better disease activity control when compared to injectable therapies. However, longer term safety monitoring of the newer DMTs in POMS will be required and is the focus of ongoing research. [Full Manuscript: Krysko KM, Graves JS, Rensel M, et al. Real-World Effectiveness of Initial Disease-Modifying Therapies in Pediatric Multiple Sclerosis. \*Ann Neurol\*. 2020;88\(1\):42-55. doi:10.1002/ana.25737](#)

## Improved Relapse Recovery

### Manuscript Summary

The incomplete recovery from relapses can lead to worsening of disabilities and also the progression of MS. The goal of this study was to investigate how age plays a role in relapse recovery after a relapse. The study looked at patient data from two long-term studies that had already concluded. Recovery from relapse was evaluated in 132 children with MS and 632 adult patients with MS. In this study, the research team compared disease severity at the time of a relapse to the disease severity after recovery. The accumulation of new disabilities was significantly lower in children compared to adults. Importantly, this improved recovery was found even though children have more frequent relapses than adults. The finding that younger age is associated with improved recovery from relapses, suggests that understanding the age-related mechanisms could lead to new discoveries and improved therapies. [Full Manuscript: Chitnis T, Aaen G, Belman A, et al. Improved relapse recovery in paediatric compared to adult multiple sclerosis. \*Brain\*. 2020](#)

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