

# Conquering MS with Positivity

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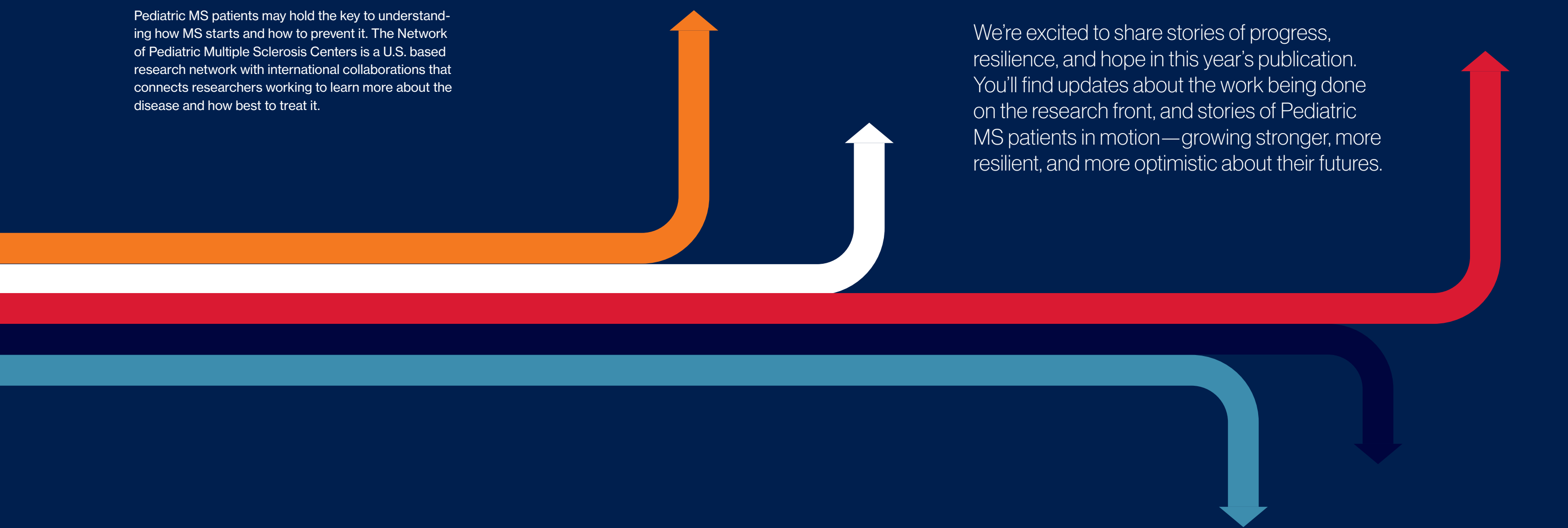
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Pediatric MS patients may hold the key to understanding how MS starts and how to prevent it. The Network of Pediatric Multiple Sclerosis Centers is a U.S. based research network with international collaborations that connects researchers working to learn more about the disease and how best to treat it.

Young people are finding their voices, pursuing their dreams, and leading the way for others. Researchers are gaining new insights about MS and opening new doors to knowledge. Partnerships are bringing patients, care givers, and researchers together to search for solutions. Over the past year, we've continued to see momentum in the fight to conquer pediatric MS.

We're excited to share stories of progress, resilience, and hope in this year's publication. You'll find updates about the work being done on the research front, and stories of Pediatric MS patients in motion—growing stronger, more resilient, and more optimistic about their futures.





# Broadcasting Hope.

**Lyssandra Vera smiles broadly when she talks about her future. Majoring in broadcast journalism and communications studies, her goal is to host a radio show. Based on what she's done so far, she's bound to achieve it.**

"No matter where I go with my career, I want to be a good influence and a role model for those who have MS," she says. As one of the earliest members of MS Youngsters, she's had that opportunity many times. And as the first in the group to go to college, she has also set a wonderful example to follow.

Lyssandra was diagnosed with MS when she was 16. A numb right arm on the day after Christmas, followed by a droopy face on New Year's Day, brought her to the hospital where they found a mass on the left side of her brain. They scheduled brain surgery for the following week but first gave her a steroid shot. Immediately upon receiving the injection, sensation returned. Shortly afterward, she was diagnosed with MS.

**“ No matter where I go with my career, I want to be a good influence and a role model for those who have MS.”**

"I was in denial at first. I was feeling fine just a few days ago, and suddenly I have this huge diagnosis," she explains. It took her a while to get used to her new norm with all the medications and doctor visits—and having to constantly explain what MS was. That led her to write a script to help explain it to others, and later to organize a fundraiser and educational campaign during MS Awareness Month. By the time Lyssandra graduated, everyone in her school was familiar with the disease.

For her fundraiser, Lyssandra asked a local boba shop to donate a percentage of sales on certain days to the MS Society and got her high school on board. As secretary of the student body, she was used to handling fundraising and publicity, so she created tickets, got volunteers, and hung posters that advertised the fundraiser and explained

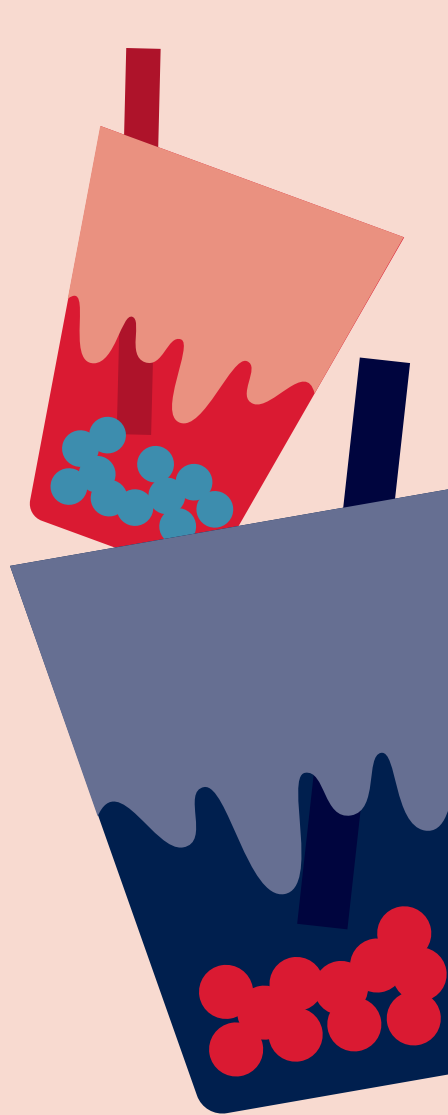
MS. While in the boba shop, she met a woman whose 6-year old niece was just diagnosed with MS. "What I was doing meant so much to her—it was really heart touching."

Lyssandra says she's no longer in denial and encourages anyone with MS to have patience with themselves. "MS came to us," she explains. "People forget that it's out of our control." But there are things you can do, she adds. "Don't let the diagnosis take over. Educate yourself. And advocate for yourself."

It's been four years since her diagnosis, and while she has some brain fog and still suffers from the summer heat which can make her symptoms worse, she's proud of being able to push herself to work and go to college. "To do things healthy people can do," she said, flashing a big smile.



**“Don't let the diagnosis take over. Educate yourself. And advocate for yourself.”**





# Living Life to its Fullest.

**“I feel very optimistic for the future,” exclaims 19-year-old Wesley Choy. “I think we’re going to find a cure for this disease quite soon.”**

Six years ago, however, Wesley was in a very different place. Diagnosed at just 13, he didn’t know what MS was, let alone the MRI machine, which he describes as a terrifying machine that made a lot of noise.

“Getting the diagnosis was scary,” he says, adding that he suffered from depression upon learning the disease would never go away. But with help from a special program at school, a psychiatrist, and a therapist, he’s now more comfortable with his MS. And much more optimistic. “You have to have a positive attitude with MS,” he advises.

Today, his MS is in remission, and he feels like he’s living a normal life. He exercises regularly, stays active, and tries to live life to its fullest because he knows that living with MS means he could find himself dealing with huge challenges again.



**“ MS doesn’t change who we are. We’re still the same person, we just need a little extra help sometimes.”**

In the beginning, Wesley was in and out of the hospital and worried that people would judge him—so he tried to hide his diagnosis. But by the time he was in high school, he was very open about it. Finding MS Youngsters gave him another opportunity to talk about his disease—and have a community of other youth who understood what he was going through—because they were too.

Wesley was the very first person to join MS Youngsters, and he now feels like a big brother to newcomers—sharing his story, trying to reassure them it will okay, and helping them understand the different symptoms. “MS is a snowflake disease, which means it’s never the same for two people,” he explains. “I wish more people knew that.”

Describing himself as resilient, Wesley says he won’t let MS stop him. He plans to get his EMT certification and work as a movie star medic—to fulfill his career dream and to live his best life. “MS doesn’t change who we are,” he says. “We’re still the same person, we just need a little extra help sometimes.”

**“I feel very optimistic for the future. I think we’re going to find a cure for this disease quite soon.”**





# Conquering MS with Positivity.

**Madison Capot hadn't even graduated college before landing a job in her major: accounting and business analytics. And she'd already started working there 15-20 hours a week.**

While impressive for any college graduate—it's even more so if you're navigating the challenges of MS at the same time. But those who know Madison don't doubt what she can do. Because as she says, "I love to prove people wrong."

"My famous saying is 'I'll figure it out,'" she explains. And she usually does.

Madison was diagnosed with MS when she was 12. After first experiencing numbness in her hands, she then had extreme weakness in

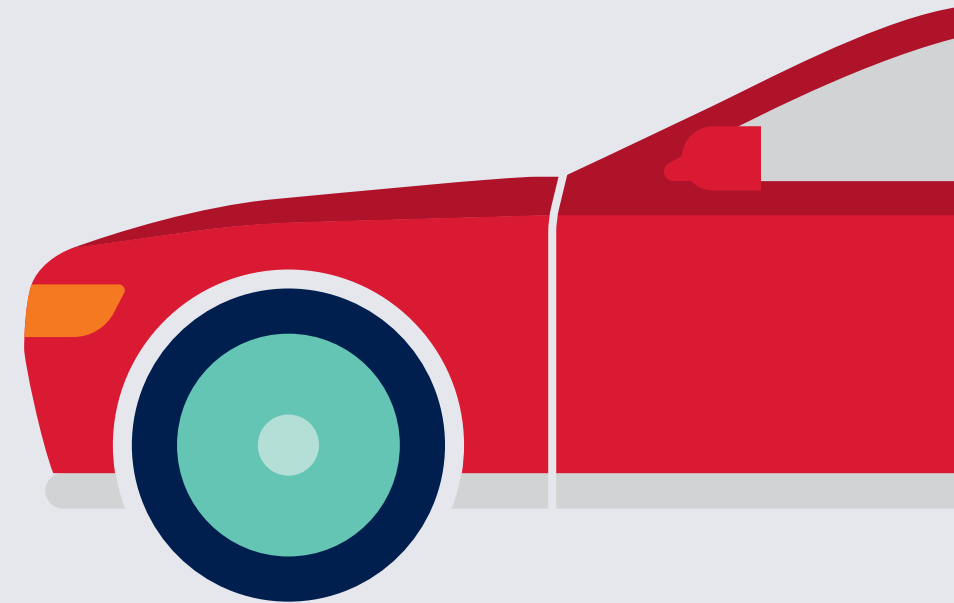
her left leg, which started to drag, buckle, and give out. "At the time, Pediatric MS wasn't on people's radar," she explains, "I went to a ton of different doctors, and no one could figure it out." Finally, a physical therapist did a test on her foot and determined her symptoms were neurological. He sent her to a neurologist who finally diagnosed it.

"It was the scariest thing ever," she recalls. Not knowing much about the disease except that her uncle had it, she was afraid she'd be bound

**"I'm not afraid to ask for help. I've learned that over the years, and I'm still trying to do it more. But I do as much as I can on my own."**

to a wheelchair. "I had no hope," she says about those early days when the medicine wasn't working and her disease progressed.

Madison eventually started a new drug that stopped the progression of the disease. But COVID made it difficult to continue physical therapy, and that impacted her mobility and her endurance. She still has spasticity in her legs, which she describes as walking on stilts, and currently has to use a walker.



Despite these challenges, she's proud of her positive attitude, being able to drive, and to live on her own. "I'm not afraid to ask for help. I've learned that over the years, and I'm still trying to do it more. But I do as much as I can on my own."

Madison has the same positive attitude about her future. Her absolute dream would be "to do something for MS 24/7." Oh, and move to a warmer climate. "Chicago isn't easy with a walker."




**“ My famous saying is ‘I’ll figure it out.’”**



# Seeing the Upside.

Ruby will never forget a particular first period during her sophomore year. After struggling with her vision over the weekend, it got worse during class, to the point where she lost all peripheral vision in her left eye—then couldn't see anymore. Little did she know that day was the beginning of her journey with MS.

Unlike some patients, her diagnosis came quickly. But it was soon followed by numbness in her legs—again coming on at school. “At first I thought it was the end of the world because I didn't know what MS was,” she recalls. But she had a huge support system of friends and family, and a wonderful nurse she felt was an angel—aptly named Angela—to help her through. “When you get diagnosed, you'll get tired of everyone saying you'll be okay. But you actually will be,” she says.



**“ I've grown comfortable with my diagnosis. It's now a part of me and it doesn't mess with me anymore.”**

Ruby has grown comfortable with her diagnosis, declaring, “It's now a part of me and it doesn't mess with me anymore.” Her medicine is working, she's happy with how her body is doing, and she avoids inflammatory foods to keep it that way. She says she feels “back to normal,” using air quotes because she says there really isn't a normal with MS.

Although Ruby describes herself as unique, she's been able to do things most teenagers do—including having a great sweet sixteen party. Just a few days before her party she had a relapse and was hospitalized. But she was determined to still have it and made the doctors promise she'd be out of the hospital in time. And she was. “It was the best day ever. I was living my life.”

MS Youngsters has played a huge role in Ruby's journey with MS. She joined the group when they only had five members and watched it grow to more than 20 youth. “I met so many amazing, strong people,” she wrote in an Instagram post, adding that MS Youngsters gave her the courage to tell the world about her diagnosis.

Now that she's in college, Ruby isn't as involved with MS Youngsters, but when someone needs something, everyone's right there for support. “We all rewind, slow down and help them. We all have each other's back.” Then she held up a MS Youngsters shirt with eight words chosen to describe the members of the group: Strength. Love. Resilience. Invincible. Care. Hope. Awareness. Warrior.

Ruby feels strong and powerful these days. She's in college at Los Angeles Harbor College and wants to be a nurse. She encourages others with MS to make sure they have a support system. “Find your group,” she advised. Then added, “Join MS Youngsters!”



**“When you get diagnosed, you'll get tired of everyone saying you'll be okay. But you actually will be.”**

# Movement on the Research Front.

Our goal at NPMSC is to connect adult and child neurologists and other research professionals whose mission is to discover the causes, investigate determinants of remyelination and neuroprotection, advance therapeutics, and improve outcomes for those with Pediatric MS. We're pleased to share updates on our current studies and our latest manuscript publications.

## Diet and Relapses in Pediatric MS – Ongoing Study



Families often ask if there are specific diets that trigger the onset of Pediatric MS or later relapses. So this study began in 2018 to better

understand the role that diet and metabolism play in the amount of MS relapses and disease progression. Participants complete a questionnaire about their food and vitamin intake as well as their physical activity three times during the study: at enrollment, six months later, and 12 months after enrollment.

There are currently 215 participants, and of those, 193 have completed their enrollment questionnaire, 131 have completed their six-month follow-up questionnaire, and 120 have completed their twelve-month follow-up questionnaire. The ideal number is 500 participants, so if you're interested in being part of it, ask your physician about the possibility of enrolling.

**“I believe studying this in children will be more effective than similar studies in adults who've had MS for a long time. That's because children are younger and closer to disease onset.”**

**Emmanuelle Waubant, MD, PhD, Professor of Neurology, UC San Francisco**

## Patient Family Views on Pediatric MS – Ongoing Study



This study is designed to understand what research is important to those living with the disease, and what barriers keep them

from participating in clinical research and clinical trials. It began with a series of focus groups in three areas of the country. Taking what we learned from the groups, we then launched a study in eight centers across the U.S., with questionnaires for three different groups: Teens with MS, their parents, and young adults with MS. We will use the insights gained to better guide future research priorities and design.

This study has been going for two and a half years. Due to COVID delays, it currently has 32 teens, 36 parents, and 82 young adults enrolled. The study will run through the summer, and investigators hope to get 250 participants. Your opinion is important, so if you want to share your thoughts, ask your physician about enrolling.

**“What we learn will inform new research, including for therapies and clinical trials. Patients and families are more likely to participate in clinical trials in the future if the research is important to them.”**

**Tanuja Chitnis, MD, Professor of Neurology at Harvard Medical School, Director of Pediatric MS Center at Massachusetts General Hospital**

## Cognition and Neurodevelopmental Influence (CANDI) – Wrapping Up



This 4-year study examined if and how cognition differs between pediatric MS patients and adult MS patients, as well as between children with

MS and those without it. The average age of youth participants at enrollment was 15, and most had MS for five years or less.

Participants have completed all assessments, data has been collected, and initial data analysis has begun. Researchers have presented baseline findings in some abstracts and the manuscript is under review. What they're seeing is very encouraging: Proportionately speaking, most children with

MS did quite well and, as a group, those with pediatric MS had fewer cognitive problems than what they see with adults who have MS. Further, the kids with MS were remarkably similar to the kids who had neither MS nor any other significant medical diagnosis. The next question they want to answer is, "What happens over time?"

**"The overall conclusion of what we see so far is very optimistic. It's very challenging, for sure, to have an autoimmune disorder during adolescence. Fortunately, most of the time thinking is not severely affected."**

**Lauren B. Krupp, MD, Director, Multiple Sclerosis Division, Professor of Neurology and Pediatrics at NYU Grossman School of Medicine**

## Industry-Sponsored Projects – Ongoing

As one of the only pediatric multiple sclerosis registries in the world, and certainly the largest, our network sometimes teams up with industry sponsors to do a deeper dive into the data we're collecting to achieve different research goals. For one such project, data collected from clinic visits at 12 centers

are being analyzed to compare things like age, relapse rates, and the different treatments used. We are also in protocol development for a new study that will take a closer look at registry data to determine safety and effectiveness of certain MS treatments.

# Published Research Manuscripts

## [Association Between Time Spent Outdoors and Risk of Multiple Sclerosis.](#)

Sebastian P, et al. US Network of Pediatric Multiple Sclerosis Centers, Neurology. 2022 Jan 18;98(3):e267-e278. doi: 10.1212/WNL.0000000000013045. Epub 2021 Dec 8. PMID: 34880094

This study found that spending more time in the sun during summer may be strongly protective against developing pediatric MS. Daily outdoor activity lasting from 30-60 minutes was significantly beneficial, and longer than one hour even more beneficial. It is likely that living and exercising outdoors in sunny locations may reduce the risk of developing MS.

## [Gene-environment interactions increase the risk of pediatric-onset multiple sclerosis associated with ozone pollution.](#)

Ziaei A, et al. Mult Scler. 2022 Jan 8;13524585211069926. doi: 10.1177/13524585211069926. Online ahead of print. PMID: 35000467

This study evaluated the interactions between ozone pollution and HLS-DRB1\*15, the strongest genetic variant associated with Pediatric MS, as well as CD86, an immune pathway gene. The findings support the belief that ozone levels plus additive effects from the genes are associated with the risk of developing the disease.

## [Familial History of Autoimmune Disorders Among Pediatric Multiple Sclerosis Patients.](#)

Greenberg BM, et al. Neurol Neuroimmunol Neuroinflamm. 2021 Aug 5;8(5):e1049. doi: 10.1212/NXI.0000000000001049. Print 2021 Sep. PMID: 34353894

This study sought to determine if family members of patients with Pediatric MS are more likely to have autoimmune conditions. It used the NPMSC database of patient and their relatives, and compared their data to a control group of families without the disease. The findings show a substantial risk for autoimmunity in first and second-degree relatives, such as Autoimmune Thyroid diseases, Rheumatoid Arthritis, MS, Diabetes, and Inflammatory Bowel Disease—including Chron's disease. Future studies may uncover critical shared mechanisms that stimulate these diseases, which could lead to improved therapies and disease prevention.



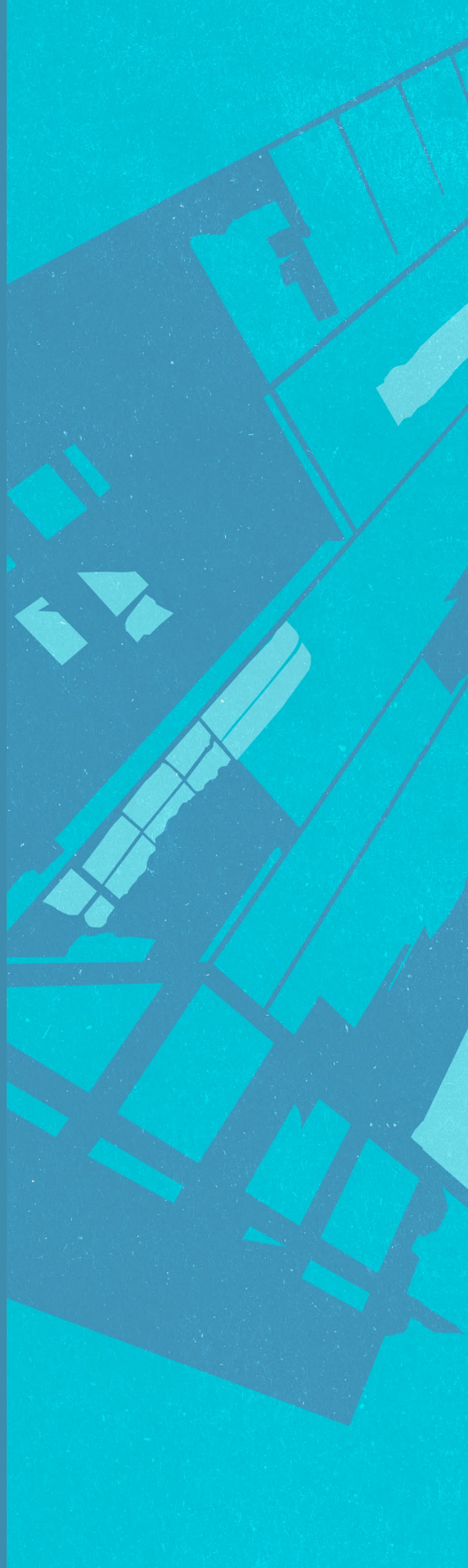
**Scan here to see all published research manuscripts**

## iConquerMS: Let's change the future together

NPMSC collaborates with iConquerMS, which brings together people with MS, their care partners, researchers, and others to better understand the disease and search for solutions. It's an opportunity for those living with the disease to help shape the future of MS. What questions do you have about MS? What do you wish was

better understood? Are you interested in being part of a research study? Your questions and thoughts are valuable. Whether you have MS, care for someone who has it, or want to support MS research, iConquerMS would love your input. You can learn more at [iConquerMS.org](https://iConquerMS.org).





The Network for Pediatric Multiple Sclerosis Centers is sponsored by the National MS Society.

[www.usnpmsc.org](http://www.usnpmsc.org)