

NPMSC Newsletter

Welcome to the first issue of the Network of Pediatric Multiple Sclerosis Centers e-newsletter!

We're excited to provide a way to keep you connected and informed about the research happening throughout our pediatric focused network. This is the first of planned yearly newsletters. Inside, we hope you enjoy learning about how children with MS and their families are contributing to research efforts in a major way!

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Introduction to the Network

Our mission is to uncover the key mechanisms underlying multiple sclerosis through the study of pediatric-onset demyelinating diseases and to improve the lives of children and families living with these diseases.

Multiple Sclerosis (MS) and other demyelinating diseases of the central nervous system in children have received an increasing level of attention by clinicians and researchers in recent years. Research is key to discovering the best treatment approaches for kids with MS. Since children are just starting out in life, they naturally have a shorter time from environmental exposures to disease onset and their immune systems are also still maturing. These special windows in development may hold the keys to understanding how MS starts and how to stop it in its tracks. Luckily, pediatric onset multiple sclerosis is not that common. Because of its rarity though, many institutions across the country and world need to work together to better understand this disease in children and search for an MS cure.

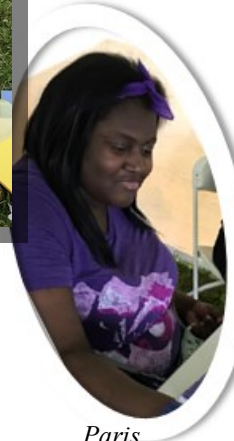


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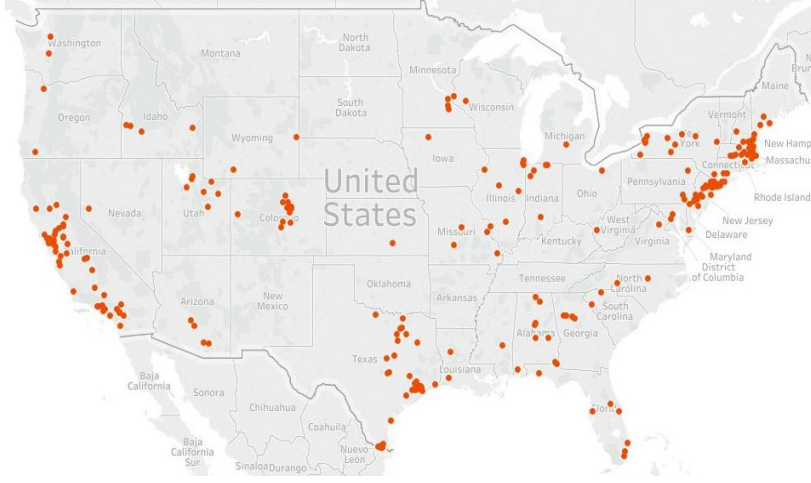
**Patient & Family
Weekend -
Buffalo, New York**



Paris

Medical Heroes

About 2,000 children and adolescents in the United States have participated in our research studies! Insight into why people get MS is limited but, through research, a better understanding of the disease will lead to better care for both children and adults living with MS and may possibly lead to a way to prevent the disease.



United States Pediatric onset MS patients participating in our research studies.



Mara, Age 15 with the Buffalo, NY Research team

The Network thanks and appreciates everyone who gives the gift of clinical research participation. We couldn't do it without you and the support of your family, friends, caregivers and community!

NPMSC

CORE TEAM OF RESEARCHERS

The NPMSC core team of researchers lead the field in pediatric onset demyelinating disease research. They are located in twelve clinical centers throughout the United States and collaborate with other researchers world wide.

Network Core Clinical Centers

- ★ University of Alabama at Birmingham, AL
- ★ University of California, San Francisco, CA
- ★ Loma Linda University, San Bernardino, CA
- ★ The University of Colorado, Aurora, CO
- ★ Boston Children's Hospital, Boston, MA
- ★ Massachusetts General Hospital, Boston, MA
- ★ Mayo Clinic, Rochester, MN
- ★ Washington University, St. Louis, MO
- ★ New York University, NY
- ★ State University of New York at Buffalo, NY
- ★ Cleveland Clinic, Cleveland, OH
- ★ Baylor College of Medicine, Houston, TX



Affiliate Clinical Centers

- Lurie Children's Hospital, Chicago, IL
- Children's Hospital of Philadelphia, PA
- University of Texas Southwestern, Dallas, TX
- Primary Children's Hospital, Salt Lake City, UT
- Children's National Medical Center, Washington DC

Data Coordinating and Analysis Center

- ★University of Utah, Salt Lake City, UT



Introducing the CANDI Study!

Cognition and Neurodevelopmental Influence

This study measures Cognition and Neurodevelopmental Influence (CANDI) in pediatric MS. The goal of our research is to identify any changes in learning and thinking at the earliest point in the disease and to identify those at risk for future decline. This will be the most detailed sample to date leveraging the U.S. Network of Pediatric MS Centers to collect a large, nationally-representative and geographically-diverse sample of children with MS. Study participants will be compared to adults with MS and children without MS.

The main measure of cognitive functioning will be a computer-based assessment called Cogstate that measures cognitive processing speed (the speed with which a person can understand and react to visual information and remember recently seen material). We will also include measures of academic functioning (such as grades, test scores and teacher assessments) to provide a link to the real-world impact on schoolwork. We will repeat all the measurements after two years.

These measurements will help us understand if and how cognitive processing speed and other areas change over two years in pediatric MS. Identifying changes in cognitive processing speed is critical to our current understanding of how to approach the treatment of pediatric MS. Please contact Ashley Clayton (Ashley.clayton@nyumc.org) if you or someone you know is interested in participating in this study.



Ashley Clayton,
Study Coordinator



Dr. Leigh Charvet,
Co-Investigator



Dr. Lauren Krupp,
Principal Investigator

Environment and Genes Study Update

Environmental and Genetic Risk Factors of Pediatric Multiple Sclerosis Study



*Lead site study team at The University of
California San Francisco.*

Enrollment is continuing in the “Environmental and genetic risk factors for pediatric MS” study. This research aims to determine environmental and genetic risk factors that make children and adolescents susceptible to developing MS. Funded by the National Institutes of Health (NIH), this study has enrolled 507 children with MS or clinically isolated syndrome (CIS) and 731 children without MS or CIS participating at 17 US pediatric MS centers.

From this study, we have found that diet may alter the risk of relapses of pediatric MS. We hope to study more in depth the role of diet in pediatric MS in the future. If you are interested in participating in this research study (or if your friends are interested in participating as a non-MS control), please contact Janace Hart (janace.hart@ucsf.edu) for more information. Together, we will overcome this disease!

Network studies are made possible through research support from The National Multiple Sclerosis Society, The National Institutes of Health and The Guthy Jackson Charitable Foundation. If you or someone you know is interested in donating to the efforts of the network, please do so through the National MS Society www.nationalmssociety.org/donate

Obesity and Puberty

This study looked at what effects obesity and puberty have on the risk and age of MS onset. 254 children with MS were compared to 420 children without MS. Body Mass Index (BMI, a calculation using height and weight) was used to estimate body fat. A higher BMI is a measure of higher body fat. We only looked at BMI in children that were not experiencing movement limitations that could temporarily decrease activity and increase weight. We found that children with MS had a higher BMI than children without MS. We also found that MS children with a high BMI had first symptoms at an earlier age. This doesn't mean that if a child is overweight, they'll have MS but it means that they may experience puberty earlier and puberty appears to be a turning point for the onset of MS in those at risk. Further studies in this area will look into biological processes and puberty hormones that appear to play a key role in the early stages of MS.

What's Known on This Subject: Onset of pediatric multiple sclerosis is most common around the age of puberty. Obesity is thought to be linked to (but not the only cause of) earlier puberty in girls.

What This Study Adds: An earlier age at sexual maturity contributes to earlier age at MS onset, especially if BMI is high.

Questions & Answers from this study

Q: Do children with MS have a higher or lower BMI compared to children without MS?

A: Higher BMI was seen in children with MS.

Q: Do children with MS reach puberty sooner than children without MS?

A: Girls with MS reached puberty at about the same age as girls without MS. This study couldn't address this question in boys very well because puberty in boys cannot be tied to a specific point in time like in girls and would need to be studied differently.

Q: Does BMI have an effect on time to first MS symptoms?

A: Higher BMI was associated with experiencing first MS symptoms at a younger age.

Full Manuscript: *Distinct effects of obesity and puberty on risk and age at onset of pediatric MS*, Ann ClinTransl Neurol. 2016 Dec;3(12):897-907.



Keep active - higher BMI was associated with experiencing first MS symptoms at an earlier age in this study.

Allergies and Asthma

MS and allergies are both considered to be related to immune responses. We wanted to know whether allergies are more or less common in children with MS. We also wanted to know whether someone with both allergies and MS has more or fewer relapses. To study this, we looked at 271 children with MS compared to 418 children without MS and their parent-reported allergies in the first five years of life. We also looked at relapse rate in the children with MS. We did not find a difference in the prevalence of allergies between MS and non-MS, but results did suggest that children with MS and food allergies had fewer relapses than those without food allergies. Future studies would be specifically designed to collect more details about the type of allergies and reactions to better understand what we found.



What's Known on This Subject: MS and allergies are related to immune responses.

What This Study Adds: Children with MS have about the same occurrence of allergies and asthma as children without MS. Pediatric MS patients who also had food allergies in the first five years of life had fewer MS relapses than those without food allergies.

Questions & Answers from this study

Q: Are allergies more common in children with or children without MS?

A: There was no difference in allergies between children with and children without MS.

Q: Does having allergies early in life cause earlier MS onset?

A: No difference in age at MS onset was seen in MS children with or without allergies

Q: Does having allergies early in life affect relapse rate in children with MS?

A: Children with MS that reported food allergies had lower relapse rates compared to those without food allergies. All other allergies did not show a difference.

Q: Does the allergic trigger (food, pollen, etc.) or allergic response (rash, stomach upset, etc.) make a difference in relapse rate?

A: Based on the findings with food allergies, it appears that the type of trigger and immune response may make a difference. Future studies could be designed to study this more closely.

Full Manuscript: *Evaluating the association of allergies with multiple sclerosis susceptibility risk and disease activity in a pediatric population*, J Neurol Sci. 2017 Apr 15;375:371-375.