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NPMSC Newsletter

The Network of Pediatric Multiple Sclerosis Centers (NPMSC)

Welcome to the fourth 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.

What's Inside


Julissa

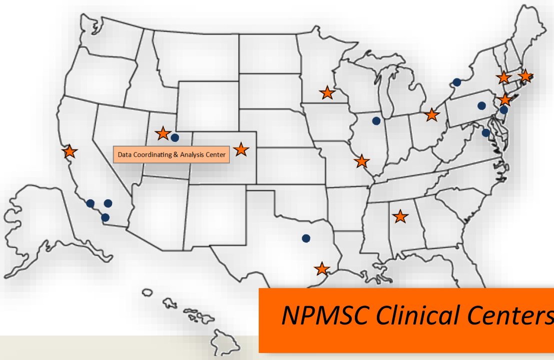

Erick


Jae

Don't miss the NPMSC spotlight featuring Erick and the MS Youngsters—page 2

The NPMSC is a United States based research 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.



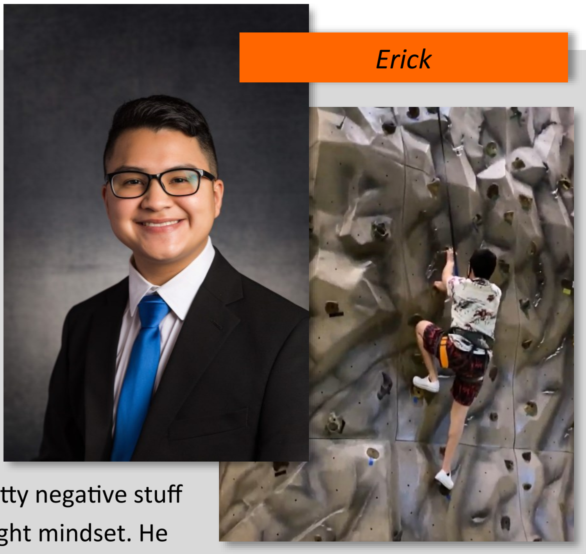
NPMSC Clinical Centers

United States
Network of
PEDIATRIC MULTIPLE SCLEROSIS
Centers

Interested in investing in this great cause?
Visit the National MS Society's website!

NPMSC Spotlights

Erick



Erick

When he was thirteen years old, Erick spent nine days in the hospital for head and neck pain and was diagnosed with multiple sclerosis a month later. He hasn't let it slow him down. In his own words, having MS hasn't stopped him from doing the things he wants to do, but it's put a few limitations on how much he can do. Over the years, he's learned to work around those limitations.

Just last year, Erick graduated from the University of Texas, San Antonio, with a bachelor's degree in cybersecurity. Lately, he's found that his biggest challenge is job hunting during a pandemic, something a lot of us can relate to.

When he was younger, Erick spent some time looking up his diagnosis online. He admits this probably wasn't the best approach because the internet is full of some pretty negative stuff when it comes to MS. For him, finding proper resources was crucial to obtaining the right mindset. He recommends the National MS Society's website as a place for people to connect with the right information.

When asked what he would tell others who are newly diagnosed, he suggests staying in contact with their neurologist and not being afraid to ask for help. Having providers who understand the mindset of a teenager with MS is huge. Finding a support group where he could share his thoughts and feelings was another big stepping stone for Erick along his journey.

Erick plays an active role in the MS community, particularly with the NPMSC. He currently sits on our Scientific Advisory Board, a group of individuals from various backgrounds who assist the network with fulfilling its goals and milestones. He's also a member of our patient-family engagement collaborative that was established as a way for individuals to contribute and share their experiences and opinions on demyelinating disease research.

MS Youngsters

Dawnia | msyoungsters@gmail.com | 424-888-4127
Follow @msyoungsters on Instagram!

MS Youngsters is a support group for young people (sponsored by the National MS Society) and was founded when the group leader, Dawnia (diagnosed at 26), decided it was far past time for such a group to exist. She wanted a place where the younger generations could feel seen and accepted. She's achieved all that and more with this group. They call her their "MS Mama" and she's helped them learn that there's life beyond an MS diagnosis. She moderates their once-a-month online meeting as well as a group chat that remains open between sessions. A couple of the youngsters from the group are spotlighted below.

Jae

Jae is an eleventh grader from London, England. She enjoys cooking and is a big Marvel fan. In her spare time, she enjoys working on her podcast. She hopes she can inspire young people with conditions or those who are going through tough times. She was diagnosed last year, in the height of the COVID pandemic. She remembers her diagnosis being scary, but found that the MS Youngsters gave her a community of people who were going through the same things and it's really helped her. She admits that she can be a little bit shy at first, but has a bubbly personality and loves interacting with others, especially her friends in the support group.

Julissa

Julissa is an ambitious high school senior from California. She just finished her semester finals which included a full course load of AP and Honors classes. She dreams of becoming a criminal justice lawyer and has already set her sights on someday becoming the first female president. Besides taking leadership classes, she is also in a few clubs like the Spanish Honor Society, Make a Wish, Friend in Me, and Swing club. She was diagnosed last May and it took a while for many of her symptoms to set in. When they did, she thought to herself, "Oh, I am different!" She loves the MS Youngsters group and remembers coming home and telling her brother, "I've found my people." While they try, no one can truly understand what she's going through better than those like her. Not everyone struggles the same, but they all get where it comes from. She says having MS has taught her a lot about self-care and prioritizing herself.

Ongoing: Diet & Relapses in Pediatric MS Study

The Diet and Relapses study began in March 2018 and its purpose is to better understand the role diet and metabolism play in the amount of MS relapses and disease progression.

The study recently completed its third year of enrollment and plans to continue enrollment through September 2022. 197 participants that have been diagnosed with pediatric multiple sclerosis have been enrolled in the study since study start. Of these participants, 107 have completed their follow-up questionnaires. These questionnaires have participants answer questions about food and vitamin intake and physical activity at enrollment, 6-months following enrollment, and 12-months following enrollment.

Enrolled	Completed Follow-up
197	107

Diet & Relapses Study

Ongoing: Patient Family Views on Pediatric Multiple Sclerosis

The Patient Family Views study asks participants and families about their perspectives on pediatric MS research priorities and methods via an electronic survey. The survey was developed by first conducting focus group discussions with research participants and family representatives at three NPMSC centers. Important themes in the focus group discussions were turned into survey questions so that more participants and families can contribute.

Enrollment into the survey portion of the study began in 2018 and since this time we have had 71 adults diagnosed with pediatric-onset MS, 28 teens currently living with pediatric-onset MS, and 26 parents of children who have been diagnosed with pediatric-onset complete the survey. In 2020, we welcomed two more centers to begin enrollment into the study bringing the total number of enrolling centers to 8. 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)

In March of 2019, study participants started returning to the clinic to complete their 24-month follow-up study visit. This study visit was designed to re-evaluate participants using the same measures with which they completed 2 years prior with hopes of giving insight on those living with multiple sclerosis and if/how cognition differs between children with MS and adults with MS and how it differs between children with MS and children without MS.

COVID-19 presented some challenges to both enrolling sites and participants and everyone was forced to innovate but despite the COVID-19 pandemic we are excited to announce that we currently have an 86% follow-up rate. This means that of the 233 participants that were enrolled in the study, 201 have completed their 24-month follow-up testing.

We would like to thank all those that have participated in the CANDI study over the past 4 years and all the participating centers for their hard work. The follow-up period is set to end in March 2022 and we hope to have a few remaining participants complete testing.

Ongoing: Industry-Sponsored Projects

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 achieve different research goals. For one such project, data collected from clinic visits at twelve 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.

Participant & Parent Views of Research

Manuscript Summary
This important evaluation assessed perspectives on Pediatric MS from research participants and their parents. Both participants and parents appreciated the value of research. The participants were pleased to contribute to the knowledge of MS but were more concerned about issues with new medications, while the parents were concerned in regards to routes of medication administration and avoidance of discomfort. Excellent information was obtained that will facilitate the conduct of ongoing and future research in Pediatric MS. Family engagement is an essential component of the research process.

Full Manuscript: Mandel, Leslie A et al. "Family Perspectives on Clinical Research for Pediatric Multiple Sclerosis: Enhancing Equity." *Journal of Patient Experience* vol. 8 23743735211039319. 15 Sep. 2021,

Gut Microbiomes

Manuscript Summary
Our intestines house many individual, families and networks of microbes, collectively designated as the gut microbiome. In these investigations molecular identification of these components of the microbiome revealed prominent microbes and microbial networks (clusters of associated microbes) that are associated with increased disease activity in Pediatric Multiple Sclerosis. Advanced studies of the microbial genes (metagenomics) reveal potential specific biochemical pathways that may play a role in the increased activity of MS in children.

Full Manuscript: Horton, Mary K et al. "Gut microbiome is associated with multiple sclerosis activity in children." Annals of clinical and translational neurology vol. 8,9 (2021): 1867-1883. doi:10.1002/acn3.51441

Vitamin D genes influence MS relapses in children

Manuscript Summary
In this study a vitamin D genetic risk score (vitDGRS) was developed from variations in four genes known to be associated with Vitamin D blood levels. The risk score correlated with lower levels of vitamin D and a higher chance of relapse. The risk score and vitamin D levels will likely prove to be helpful to evaluate and monitor in Pediatric MS Patients to facilitate management of the disease.

Graves, Jennifer S et al. "Vitamin D genes influence MS relapses in children." Multiple sclerosis (Houndmills, Basingstoke, England) vol. 26,8 (2020): 894-901. doi:10.1177/1352458519845842

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Who Are We?

The NPMSC is comprised of ten Clinical Centers and a Data Coordinating and Analysis Center. Various Affiliate Centers participate in individual NPMSC studies and activities and are encouraged to submit research proposals and participate in other ways.

Each clinical center includes a Principal Investigator and a Research Coordinator. Clinical Centers enroll subjects into the Network studies and ensure regulatory compliance, protocol adherence and data quality. Clinical Center Principal Investigators and Co-Investigators are on the Network Steering Committee and are leaders in the field of early onset demyelinating disease.

The Data Coordinating and Analysis Center (DCAC) is based at the University of Utah. The DCAC provides expertise in study design and central repositories for data from each of the Network studies. The DCAC also works with each of the Clinical Centers to implement Network wide standards for data collection and analysis in order to ensure uniformity and quality of the data and monitor the safety and timely progress of the research studies.

PICTURED ABOVE

NPMSC Steering Committee Principal Investigators (Top Two Rows): Jayne Ness (ALAB), Yolanda Wheeler (ALAB), Mark Gorman (BOST), Leslie Benson (BOST), Mary Rensel (CLEV), Gary Hsich (CLEV), Aaron Abrams (CLEV), Teri Schreiner (DECH), Moses Rodriguez (MAYO), Jan-Mendelt Tillema (MAYO), Tanuja Chitnis (MGHB), Lauren Krupp (NYUM), Leigh Charvet (NYUM), Tim Lotze (TCBC), Nikita Shukla (TCBC), Emmanuelle Waubant (UCSF), Soe Mar (WASH), Manu Goyal (WASH), Charlie Casper (DCAC), John Rose (DCAC)

DCAC Team (Bottom Row): Brad Barney, Melissa Bolton, Brittany Brown, Liz Rodriguez, Michael Waltz, Rachel Codden, Skyler Peterson, Regan Jackson, Thomas May, Shelly Roalstad

PEDIATRIC ECHO PROGRAM

The International Pediatric ECHO MS program is a new and exciting program offered by the National MS Society in collaboration with the International Pediatric MS Study Group. This ECHO MS program will increase core content knowledge of the diagnosis and treatment of pediatric MS and related demyelinating diseases. Doctors from 20 countries will come together three times in 2022 for continuing medical education utilizing the Project ECHO® guided-practice model for reducing healthcare disparities and improving patient outcomes. A panel of global experts will share best practices and evidence-based solutions for diagnostic and treatment dilemmas. Participants will discuss case studies and ultimately children and teens around the world will benefit from this innovative physician education activity.

RECENT PUBLICATIONS

1. Mandel LA, O'Donnell E, Canenguez K, et al. Family Perspectives on Clinical Research for Pediatric Multiple Sclerosis: Enhancing Equity. J Patient Exp. 2021 Sep 15;8:23743735211039319. doi: 10.1177/23743735211039319. PMID: 34541304; PMCID: PMC8447100

2. Santoro JD, Kerr LM, Codden R, Casper et al. Increased Prevalence of Familial Autoimmune Disease in Children with Opsoclonus-Myoclonus Syndrome. Neurol Neuroimmunol Neuroinflamm Nov 2021, 8 (6) e1079; first published Sep 2021, 2 DOI: 10.1212/NXI.0000000000001079,

3. Greenberg BM, Casper TC, Mar SS, et al. Familial History of Autoimmune Disorders Among Patients With Pediatric Multiple Sclerosis. Neurol Neuroimmunol Neuroinflamm Sep 2021, 8 (5) e1049; DOI: 10.1212/NXI.0000000000001049

4. Gaudioso C, Oo S, Mar S, et al. PedsQL Multiple Sclerosis Module Domain and Item Development: Qualitative Methods. J Child Neurol. 2021 May 28:8830738211015016. doi: 10.1177/08830738211015016. Epub ahead of print. PMID: 34048290.

5. Horton, M.K., McCauley, K., Fadrosh, D., et al. Gut microbiome is associated with multiple sclerosis activity in children. Ann Clin Transl Neurol. https://doi.org/10.1002/acn3.51441

6. Wallach AI, Waltz M, Casper TC, et al. Cognitive processing speed in pediatric-onset multiple sclerosis: Baseline characteristics of impairment and prediction of decline. Multiple Sclerosis Journal. 2020;26(14):1938-47

7. 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

8. Santoro JD, Waltz M, Aaen G, et al. Pediatric Multiple Sclerosis Severity score in a Lare U.S. Cohort [published online ahead of print, 2020 Jul 20]. Neurology. 2020;10.1212/WNL.0000000000010414. doi:10.1212/WNL.0000000000010414

9. Chitnis T, Aaen G, Belman A. et al, Improved relapse recovery in pediatric compared to adult multiple sclerosis, Brain, Volume 143, Issue 9, September 2020, Pages 2733–2741, https://doi.org/10.1093/brain/awaa199

10. Graves J, Barcellos B, Krupp L, et al. Vitamin D genes influence MS relapses in children. Multiple Sclerosis. 2019 May 13.

11. Rhead B, Shao X, Graves JS, et al. miRNA contributions to pediatric-onset multiple sclerosis inferred from GWAS. Ann Clin Transl Neurol. 2019 May 15;6(6):1053-1061.

12. Chi C, Shao X, Rhead B, et al. Admixture mapping reveals evidence of differential multiple sclerosis risk by genetic ancestry. PLoS Genet 15(1):1007808.

13. Aaen G, Waltz M, Vargas W, et al. Acquisition of Early Developmental Milestones and Need for Special Education Services in Pediatric Multiple Sclerosis. J Child Neurol. DOI: 10.1177/0883073818815041 Epub 2018 Dec 17