





Children's Specialized Hospital Research Center Newsletter

March 2025 | Volume 5 Issue 1

Welcome!

The Children's Specialized Hospital (CSH) Research Center Newsletter provides an overview of research conducted at CSH. We regularly share information about CSH studies, lectures, and resources. Each issue also features CSH research news and upcoming events and activities. Please reach out with any suggestions or questions.

About the Research Center at CSH

The Research Center at Children's Specialized Hospital strives to advance pediatric rehabilitation by initiating and supporting evidence-based studies that explore innovative interventions, technologies and approaches to specialized care for children and adolescents.

In This Issue:

- 1 Welcome
- 2 Deeper Dive
- 3 Featured Family
- 4 Physiatry Update
- 5 Neurodevelopmental Update
- 6 Featured Study (Recruiting Now!)
- 7 Internship Update
- 7 Recent Publication
- 8 Meet the Research Center Team

~}~}~}~}~}~}

- 9 Upcoming Conferences
- 9 Contact Us

JOIN OUR STUDIES

Several research studies are actively recruiting participants. To see which studies you may be eligible to join, and to learn more about how to participate, see our autism, brain injury, chronic health conditions, cognition, and mobility studies.

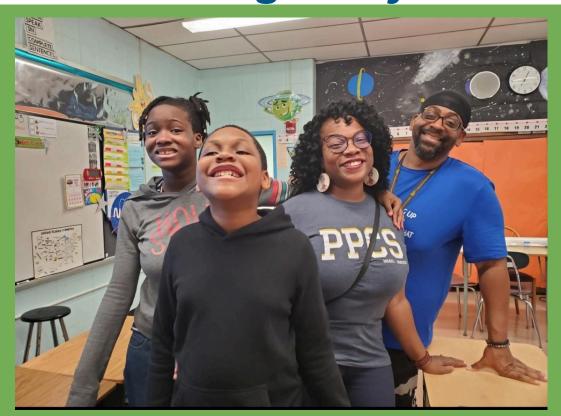


Deeper Dive: SOMNOLENT Study

In collaboration with colleagues at Kessler Foundation, CSH is involved in a research study funded by the NJ Commission on Brain Injury Research, Sleepwake Objective MeasuremeNt Of adoLEscents Navigating TBI (SOMNOLENT study). Traumatic brain injury (TBI) often results in disruption of brain processes involved in the regulation of the sleep-wake cycle. In the inpatient rehabilitation (IR) setting after TBI, sleep aids are frequently prescribed, but there is less reliance on objective measures of the sleep-wake cycle to guide treatment. As the gold standard in sleep assessment, polysomnography (PSG), involving application of electrodes to scalp, face, chest, and legs, is costly and invasive and not feasible for routine use in the IR setting. Actigraphy, on the other hand, using a wrist-worn device, captures rest-activity cycles in a less expensive and less invasive manner. It records information that is analyzed by computer software and shown to differentiate sleep vs. wake with over 90% accuracy compared with the gold standard of PSG. Because it can be worn continuously over many days and nights, it is useful in the study of circadian rhythms that drive sleep-wake regulation. Two actigraphy indices show great promise for assessing sleep quality and sleep cycle regulation: the sleep fragmentation index (SFI) and rest-activity ratio (RAR). However, there is a scarcity of studies examining these indices in children, and research regarding how they relate to adolescents with TBI in the IR setting is almost nonexistent. The proposed study aims to examine these sleep-wake indices to gain a better understanding of their relevance among adolescents with TBI at a point in recovery where quality sleep is crucial both for neural repair and promoting greater efficiency during the day where patients are expected to work hard to achieve treatment goals. This study will set the groundwork for future studies examining their utility as a routine part of clinical care to identify adolescents in need of more extensive evaluation using PSG, as well as studies examining the effectiveness of treatments for post-TBI insomnia so that patients can make the most of their time in IR and improve long term outcomes.

Featured CSH Patient/Family: Meet the Dowling family

Read why the Dowling family is involved in research:



Please describe your experience as a research participant at CSH.

The experience was an awesome one! It was in a calming atmosphere. Our guide made us feel very assured about the process. Even when it came down to answering the QandA as the parent- he made it so that I found it easy to answer the questions. I felt needed to answer these questions and be a part of something much bigger.

Why did you decide to get involved in research at CSH?

At the beginning of this journey (circa 2011: when our daughter was first diagnosed with ASD) I knew then that we had to be diligent in getting any and everything we can to enrich her life. Research at CSH as a part of that enrichment journey. My husband and I are very proactive in getting what we believe will benefit not only are 2 beautiful nuerodivergents, but other parents and caregivers as well!

Is there anything else you would like to share about your experience as a research participant?

The Research Assistant was very good at letting us know thoroughly what participants should know. He made both my daughter and I very comfortable and self-assured. He made such an impact on my daughter too- she spoke about what she had to do as her part, and said the Research Assistant was 'the COOLEST guy, mom!' She talked about it for a week after. We were happy.

Exciting Updates from the Physiatry Research Team at Children's Specialized Hospital:

Read more about two recently published articles from our Chronic Pain Management Program (CPMP) team!

CSH co-authors Mayank Seth, PhD, Kate Vieni, PT, DPT, TPS, Kate Hottinger, PhD, and Kate Bentley, MD, recently published a paper titled, "Physical function and perceived pain following inpatient intensive interdisciplinary pain treatment for children and adolescents" in PM&R Journal, the official scientific journal of the American Academy of Physical Medicine and Rehabilitation (AAPM&R). It focuses on research and studies related to the field of Physical Medicine and Rehabilitation (or physiatry). Read the paper here.

CSH co-authors Mayank Seth, PhD, Kate Bentley, MD, Kate Hottinger, PhD, and Kate Vieni, PT, DPT, TPS, in collaboration with partners at the CSH Pain Program at Rady Children's Hospital in San Diego, recently published a paper titled, "Physical function estimates change in pain following IIPT among children with chronic pain" in PAIN Practice Journal, an international peer-reviewed medical journal that focuses on research and clinical advancements in pain medicine. It is the official journal of the World Institute of Pain (WIP) and publishes a wide range of articles related to the assessment, diagnosis, and treatment of pain.

Read the paper here.

CONGRATULATIONS

Developmental and Behavioral Pediatrics Research Team Update: New Team Members!

Shannon Desbiens

Developmental and Behavioral Pediatric Research Intern

Shannon is a post-baccalaureate researcher who joined the team in September 2024. Shannon plans to pursue her Ph.D. in clinical psychology and wants to study how health behaviors can impact psychopathology in youth populations. Shannon has extensive experience in working with youth populations as a Registered Behavioral Technician and Cognitive Development Researcher. Shannon also enjoyed her time as a researcher at Rutgers University and at Montclair State University. Shannon believes that her accumulation of experiences allows her to address each domain from a well-rounded perspective and has also assisted her in finding her niche in the field of psychology. Overall, Shannon enjoys helping others improve their quality of life through scientific findings and direct therapy.



Eman Al-Jayeh, M.S., CCC-SLP

Speech Therapy Consultant for the Echolalia Study & Assistant Research Coordinator



Eman is a licensed Speech-Language Pathologist with extensive experience across diverse clinical settings, specializing in dysphagia management. She is passionate about interdisciplinary care, patient advocacy, mentoring future clinicians, and advancing evidence-based practices. Eman has contributed to research on bilingualism and executive function, presenting her work at national conferences and collaborating on multidisciplinary projects. She is excited to join Children's Specialized Hospital as a Volunteer Assistant Research Coordinator, where she looks forward to leveraging her clinical and research experience to advance pediatric care and impactful research initiatives.



RECRUITING NOW FEATURED STUDY



Children's Specialized Hospital



Children's Specialized Hospital

Seeks participants to study IRB Approved at the

Protocol Level Oct 31, 2024

20242025

Validating an Assessment Tool for Echolalia in Autism Spectrum Disorder

This research study aims to understand repetitive speech in children diagnosed with autism spectrum disorder. It involves completing online assessments by the parent/guardian.

Who's eligible?

Children Diagnosed with Autism Spectrum Disorder

Participants Requirements:

- √ The child should have a diagnosis of autism spectrum disorder.
- √ Age between 2 and 21 years old
- √ Participant should be verbal or have some productive language.
- √ Parent/guardian should be fluent in English.

Participation in this study will be via email communication. It includes two sessions that will be scheduled 3 months apart. Each session will last for approximately 45 minutes to 1 hour. Children who complete the study will receive a completion certificate.

For more information, please contact:

- √ Dr. Joman Y. Natsheh, Principal Investigator, at 973-391-7858.
 - Email: jnatsheh@childrens-specialized.org
- Amira Herstic, Research Coordinator, at 908-705-1764.
 - Email: aherstic@childrens-specialized.org

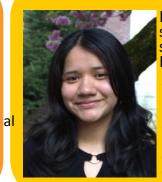
Meet our current Research Center interns!



Sarah Elmer

Sarah is a junior at Rutgers-New Brunswick and is majoring in Psychology.

She is working with the Neurodevelopmental research team. Her other research interests include psychotherapy and program evaluation. In her free time, she enjoys reading and working on craft projects.



Lisbet Garcia-Ortiz

Lisbet is a Master of Public Health student at TCNJ and is specializing in Epidemiology and Health Analytics.

She is working with the Brain Injury research team. Her other research interests include chronic illnesses, environmental health, and neurodevelopmental conditions. In her free time, she enjoys hiking, reading, and spending time with family.



Shalini is a recent graduate from Rutgers-New Brunswick and majored in Cell Biology & Neuroscience.

She is working with the Chronic Illness Management Program research team. Her other research interests include pediatric oncology and scientific communication. In her free time, Shalini enjoys baking, biking, and yoga.



Ameya Patel

Ameya is a sophomore at Rutgers-New Brunswick and is majoring in Cell Biology & Neuroscience.

He is working with the Physiatry research team. His other research interests include neurodegenerative diseases and neurodevelopmental disorders. In his free time, he enjoys playing cricket, basketball, and watching movies.



Recent Publication

CSH colleagues, including Claire M. Marchetta, Dr. Mayank Seth, Dr. Joman Y. Natsheh, Dr. Anna Malia Beckwith and Dr. Matthew B. McDonald III recently published "Caregiver and self perception of quality of life in children with autism spectrum disorder and co-occurring attentiondeficit/hyperactivity disorder" in *International Journal of Developmental Disabilities*.

About the study: Emotional and social impairments associated with autism spectrum disorder (ASD) negatively impact children's quality of life (QoL). A co-occurring diagnosis of attention deficit/hyperactivity disorder (ADHD) may worsen perceptions of QoL. This study assessed QoL in children with ASD and ASD/ADHD using self-reports and caregiver proxy-reports. Children and caregivers were invited to complete the Pediatric Quality of Life Inventory (PedsQL) survey during outpatient therapy between 1/1/2015 and 12/31/2016. 1094 surveys were included in the analysis. Self-reports represented 18.2% of sample (n = 92 ASD, n = 107 ASD/ADHD) while proxy-reports made up the majority (81.8%) (n = 687 ASD, n = 208 ASD/ADHD). Children with ASD and combined ASD/ADHD reported similar QoL scores, 64.4 vs. 62.8. Caregiver proxy-reported scores were significantly lower by diagnosis, 60.3 in ASD vs. 55.3 in ASD/ADHD. This study highlights the influence of combined ASD and ADHD on child and caregiver perceived QoL, emphasizing the importance of considering both perspectives.

Read the full article <u>here</u>. See all CSH publications <u>here</u>.

Meet the CSH Research Center Team

Michael Dribbon, Ph.D.



Vice President of Business
Development and Chief
Innovation & Research
Officer

Research Focus: Intervention outcomes, Social Determinants of Health

Michael likes music, travel, and time with family.

Claire Marchetta, MPH

Interim Director of Research

Research Focus: Epidemiological factors for developmental disabilities and birth defects

Claire enjoys travel, outdoor recreation, and spending time with family and friends.



Joman Y. Natsheh, M.D., Ph.D.

Research Lead, Developmental and Behavioral Pediatrics



Research Focus:
Neural and behavioral
correlates of action-control
in children with neurodevelopmental disorders

Joman enjoys reading, especially Arabic literature. She loves to travel and explore, and she can spend hours immersed in graphic design.

Mayank Seth, Ph.D. Research Lead, Physiatry

Research focus:
identification of factors
underlying poor clinical
outcomes, with an eye
towards developing more
efficacious rehab
interventions

Mayank enjoys spending time with family & friends, reading, and listening to music. He also enjoys going on hikes and biking.



Amira Herstic, MS

Research Coordinator, Developmental and Behavioral Pediatrics



Research Focus:
Neuroscience of language
and motor development in
children with ASD and ADHD

Amira enjoys reading, crocheting, traveling, and spending time with family.

Savannah Dziepak, MPH Research Coordinator, Physiatry

Research Focus: Improving population health outcomes for chronic illnesses, pediatric chronic pain

Savannah enjoys spending time in nature, exercising, photography, listening to audiobooks and playing video games on PC.



Uriel Richman, MA

Research Assistant, Developmental and Behavioral Pediatrics



Research Focus: Cognition and child development

Uriel enjoys hiking, camping, visual arts and playing tabletop games.

lan Origenes, MPH Research Assistant, Physiatry

Research Focus: Improving clinical and chronic health outcomes in pediatric populations

lan enjoys playing piano, coaching and playing soccer, longboarding, and reading comics and manga.





Upcoming Events/Conferences/Grants

- American Occupational Therapy Association (AOTA)
 April 3-5, 2025. Philadelphia, PA
- NJ Association for Behavior Analysis Annual Conference April 24-25, 2025. Somerset, NJ
- Society of Pediatric Nurses Annual Conference April 30-May 2, 2025. Anaheim, CA
- Association of Child Life Professionals May 22-25, 2025. Los Angeles, CA
- American Diabetes Association Scientific Sessions June 20-23, 2025. Chicago, IL





To learn more about our research, if you are interested in discussing potential collaborations, or if you have questions or comments, please contact us:

- Claire M. Marchetta, MPH Interim Director of Research cmarchetta@childrens-specialized.org, 732-258-7288
- Joman Y. Natsheh, MD, PhD Research Lead, Developmental and Behavioral Pediatrics jnatsheh@childrens-specialized.org, 908-588-9608
- Mayank Seth, PhD Research Lead, Physiatry mseth@childrens-specialized.org, 908-588-9609