

Children's Specialized Hospital Research Center Newsletter

October 2025 | Volume 5 Issue 3

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.

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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:ASD-ADHD Study

Cognitive Correlates of Action-Control in Children with Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder

The focus of this issue's Deeper Dive section is on the research of Dr. Joman Y. Natsheh, Research Lead of the Developmental and Behavioral Pediatrics section at CSH. To understand some behavioral patterns in children with Autism Spectrum Disorder (ASD) and Attention-Deficit Hyperactivity Disorder (ADHD), Dr. Natsheh launched a study entitled "Cognitive Correlates of Action-Control in children with Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder." Children with ASD show patterns of restricted or repetitive behavior, which can be difficult to change, even in situations where such behaviors could lead to negative consequences. In this study, Dr. Natsheh is investigating whether these restricted interests are due to an over-reliance on reflexive habits at the expense of flexible goal-directed behavior. Preliminary findings from previous research suggest a deficit in behavioral flexibility in children with ADHD, therefore, it is expected that a dual diagnosis of ASD and ADHD will result in a further bias toward habitual control.

The study involves a computer-based cognitive task as well as a battery of neuropsychological assessments. A total of 50 children will be enrolled in the study (25 children with ASD and 25 children with ASD and ADHD). We have currently enrolled 37 participants in the study, so we are only looking for 13 more (6 children with ASD and 7 children with ASD and ADHD)!

Characterizing the role that habits play in ASD and ADHD behavioral manifestations will advance our understanding of the cognitive profile of these disorders, and will inform the development of behavioral interventions that can improve the quality of life of children with ASD and ADHD. This study is actively recruiting, for more information see the flyer on page 6.

Featured Researcher: Dr. Noemi Spinazzi

Special Needs Primary Care Physician and Director, Down Syndrome Center of Excellence

Noemi Alice Spinazzi is a primary care physician in the CSH special needs primary care office in Hamilton, NJ. She is also the director of CSH's new Down Syndrome Center of Excellence. She studied biology and psychology at Boston University and received her medical degree at the University of Pennsylvania School of Medicine. She then moved to Oakland, CA to complete her residency at UCSF Benioff Children's Hospital Oakland, where she served an additional year as the Chief Resident. After graduating, Dr. Spinazzi founded a Down syndrome program at UCSF (Charlie's Clinic) and became an active member of the international professional organization, Down Syndrome Medical Interest Group (DSMIG). She developed a special interest in children with a dual diagnosis of autism and Down syndrome (DS+ASD), and was elected to lead the DS+ASD workgroup for DSMIG. In this role, she became passionate about research as a tool to understand how to best support her patients and to give families hope.



After conducting some exploratory survey-based studies querying caregivers of DS+ASD about their journey from initial concerns to diagnosis, Dr. Spinazzi began collaborating closely with Down syndrome leaders from institutions around the country to better understand which medical conditions co-occur more frequently in children with DS+ASD compared with those with Down syndrome alone. Three years ago, Dr. Spinazzi and collaborators at UCSF, Colorado State University, the Sie Center and Crnic Institute at the University of Colorado, and Boston Children's Hospital were awarded an R01 grant from the NIH to run the first longitudinal study of development in children with Down syndrome. The study, CAPEabilities, sets out to describe development in children with Down syndrome beginning at age 18 months, and to learn how medical co-occurrences may influence development. Additionally, the study sets out to identify early predictors of autism in young children with DS. The multi-site team now collaborates on a second study, the Birthday study, to correlate developmental information with immunophenotyping data in young children with Down syndrome. In addition to her work on DS+ASD, Dr. Spinazzi has collaborated with colleagues on diverse topics including health equity for patients with Down syndrome, Down Syndrome Regression Disorder and assessing self-management skills in caregivers of children with medical and/or developmental complexity.

In her "spare" time, Dr. Spinazzi hangs out with her two young daughters, her husband, and her pets. She loves to cook (Italian food, of course) and go on walks.

Selected publications:

- Spinazzi, N.A., Velasco, A.B., Wodecki, D.J. and Patel, L., 2023. Autism Spectrum Disorder in Down Syndrome: Experiences from Caregivers. Journal of Autism and Developmental Disorders, pp.1-10.
- Spinazzi, N.A., Santoro, J.D., Pawlowski, K. et al. Co-occurring conditions in children with Down syndrome and autism: a retrospective study. J Neurodevelop Disord 15, 9 (2023). https://doi.org/10.1186/s11689-023-09478-w
- Santoro, J., Spinazzi, N., Filipink, R., Rezvan, P., Kammeyer, R., Patel, L. Rafii, M. et al. 2023. Immunotherapy Responsiveness and Risk of Relapse in Down Syndrome Regression Disorder. Neurology, 100 (17 Supplement 2). https://doi.org/10.1212/WNL.000000000202313
- Olsen, D, Patel, L, Spinazzi, NA, Nyp, S. 2023. Access to Care Limitations: When Distance and Lack of Evidence Meet. Journal of Developmental and Behavioral Pediatrics. 44(8), e1-3 DOI: 10.1097/DBP.000000000001213
- Spinazzi, N. (2025). Instruction for Use: Developmental Milestones in Down Syndrome. Pediatrics, e2024069954C.

Featured CSH Patient/Family

Meet the Holmes family!

And learn why the Holmes family is involved in research:



Please describe your experience as a research participant at CSH.

The process was very easy and straight forward. I received a series of questions that were easy to answer. It did not require much and did not take up too much of my time. I am open to participating in future research studies. Especially if it will help another family.

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

This was a wonderful opportunity to provide insight on echolalia. I understand how hard it is as a parent of a child with autism. Every little bit of information shared by a parent living through the experience helps.

I see echolalia as a superpower, a steep learning curve. Because of it, my son retains so much information which he is now able to process and apply. In my opinion, some of my son's brilliance is attributed to echolalia.

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

I encourage all families to get involved. Your input can change the lives of others. More research is needed to help improve the services provided to our children with disabilities.



Recent Publication



In collaboration with investigators at Thomas Jefferson University, Joanne Hunt, OT Clinical Lead at CSH, contributed to a study and recently published article "A Comparative Trial of Occupational Therapy Using Ayres Sensory Integration and Applied Behavior Analysis Interventions for Autistic Children" in *Autism Research*.

About the study: Many autistic children demonstrate sensory integration differences that impact their participation in daily living activities and tasks. Occupational Therapy using Ayres Sensory Integration (OT-ASI) is an evidence-based intervention for autistic children that addresses the sensory integrative factors impacting daily living skills and participation in a variety of tasks and activities. Applied Behavior Analysis (ABA) is the recommended evidence-based practice for autism to improve a range of developmental domains. This study compared Occupational Therapy using Ayres Sensory Integration, Applied Behavior Analysis, and no treatment on daily living skills and individualized goals for autistic children who also show sensory differences. A parallel arm comparative effectiveness trial design with participants randomized equally to OT-ASI, ABA, or no treatment. Intervention consisted of 30 one-hour sessions. Significant gains in individualized goals, measured by Goal Attainment Scaling, were found in both treatment arms over the no treatment group. Both the OT-ASI and the ABA groups improved in daily living skills measured on the Pediatric Evaluation of Disabilities Inventory; although the improvements over the no treatment group were not significant. Both OT-ASI and ABA improved individualized goals and daily living skills at comparable levels. These findings are discussed in light of their implications for intervention. Trial Registration: <a href="https://doi.org/10.1001/nn.nd/

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

Distinguished Lecture Series

Join us on October 14 for
"Understanding the
Experiences of Autistic Girls
and Women: Implications for
Clinical Care and Research"
presented by Dr. Alison Ratto
(Children's National
Hospital). To register to
attend in person or virtually,
please click this link.



FEATURED STUDY

#34793091.1

IRB Approved at the
Study Level
Mar 15, 2023

Children's Specialized Hospital seeks participants to study

Cognitive Correlates of Action-Control in Children with Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder

This research study aims to understand how children diagnosed with autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) control their behavior and choose their actions. It involves completing paper-and-pencil measures and computer-based games.

Who's eligible?

Children's

Specialized Hospital

Children diagnosed with ASD OR Children diagnosed with ASD and ADHD

All participants should be:

- √ Between the ages of 6 and 16
- √ Able speak English well
- √ Able to play a computer-based game

Participation in this study will last for 2-2.5 hours. Visits will primarily take place at the following Children's Specialized Hospital location:

√ 2840 Morris Ave, Union, NJ 07083

Parents can request other Children's Specialized Hospital locations.

Participants will be compensated for their time and 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!



SAANVI NARAVA

Saanvi is a senior at Rutgers-New Brunswick and is majoring in Biological Sciences.

She is working on projects related to research engagement and working with the Physiatry team. Her other research interests include binge eating and neuropathic pain. In her free time, she enjoys hiking, spending time with family and friends and baking.



JULIA TRAVIS

Julia is a senior at Rutgers-New Brunswick and is majoring in Psychology.

She is working with the Autism/Behavioral research team. Her other research interests include neurodevelopmental disorders and their clinical treatments. In her free time, she enjoys thrifting and watching psychological thriller movies.



AMEYA PATEL

Ameya is a senior 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.

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 Academy for Cerebral Palsy and Developmental Medicine (AACPDM)
 October 15-18, 2025. New Orleans, LA
- <u>Autism New Jersey Annual Conference</u>
 October 16-17, 2025. Atlantic City, NJ
- American Academy of Child and Adolescent Psychiatry (AACAP)
 October 20-25, 2025. Chicago, IL
- Academy of Pediatric Physical Therapy (APTA)
 October 31-November 2, 2025. Colorado Springs, CO
- American Public Health Association (APHA)
 November 2-5, 2025. Washington, D.C.
- American Speech and Hearing Association (ASHA)
 November 20-22, 2025. Washington, D.C.





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