

# Children's Specialized Hospital Research Center Newsletter

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### 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/About the Research Center/Join Our Studies 2 Distinguished Lecture Series 2 Getting to Know CSH Video 3 Featured CSH Patient/Family 4 Deeper Dive 4 Recent CSH Publication 5 Featured Researcher 6 Meet the Research Center Team 7 Upcoming Conferences/Grants

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.

## **Distinguished Lecture Series**

Our next speaker, Dr. Laura Simons (Stanford University School of Medicine), will present: "Innovative Approaches for the Treatment of Chronic Pain in Children" on February 29th from 12-1:30pm. The lecture will be held on-site in New Brunswick and on zoom. Free lunch provided! To register to attend, in person or virtually, please click this link.



**Next 2024** speaker:

Be on the lookout for more information about upcoming speakers, and please contact thackett@ childrensspecialized.org with any suggestions for speakers/topics. It is appreciated!

## Getting to Know CSH Video 💖





Getting to Know CSH Research

Recently, Interim Director of Research Claire Marchetta and Research Engagement Coordinator Tomiko Hackett were interviewed by CSH President & CEO Dr. Matt McDonald for his "Getting to Know CSH" video series. They had a great discussion about the work of the Research Center! Please click here to watch the video.

## Featured CSH Patient/Family:

# Meet the Razzano family!



Read why the Razzano family is involved in research:

# Please describe your experience as a research participant at CSH:

Hudson was diagnosed with autism when he was 2 years old in 2015, and this was our first time participating in the research at CSH. We had an amazing experience participating with the CSH research team,



from the first phone call with Amira explaining everything so we completely understood the process, to Uriel who conducted the research with my son. The research team was patient and extremely sweet with Hudson.

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

I decided to get involved with this research because I feel there is so much to be learned about kids with autism and other disorders. The research programs at CSH are in our comfort zone and we have complete trust in the CSH team. This research was for the purpose of studying the way Hudson thinks and understanding the way he processes information when presented with new input.

## Is there anything else you would like to share?

I'd like to recognize all the wonderful teams of doctors and researchers that make such an incredible impact for families like us, and I look forward to being part of more research studies in the future!

# Deeper Dive

Let's take a deeper dive into 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 overreliance on reflexive habits at the expense of flexible goal-directed behavior. Her previous research found 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). 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. Managing the administration of this study will be Amira Herstic, Research Coordinator, and Uriel Richman, Research Assistant. We are excited to see what they find!

This study is actively recruiting! For more information, including study contact information, please <u>click here</u> for the flyer.



## CSH Recent Publications

Dr. Jill Harris, in collaboration with partners at the Boggs Center on Developmental Disabilities as well as other organizations, recently published their article, "Commentary: Determining Economic Factors That Matter to People With Intellectual and Developmental Disabilities and Their Caregivers: A Process Framework" in the journal *Medical Care*.

From the abstract: The 2020–2029 strategic plan for the Patient-Centered Outcomes Research Trust Fund (PCORTF) calls for addressing data infrastructure gaps that are critical for studying issues around intellectual and developmental disabilities (I/DD). Specifically, the plan calls for data collection on economic factors that affect personcentered approaches to health care decision-making. Among people with I/DD and their caregivers, such economic factors may include financial costs of care, decreased opportunities for leisure and recreation, income losses associated with caregiving, and foregone opportunities for skill acquisition or other human capital investments. This commentary supports responsiveness to the PCORTF calls. The framework outlined in this commentary addresses barriers to data collection that hinder measure development in the study of I/DD. This work is significant and timely given the continued movement to integrate and maintain people with I/DD within communities and recent methodological advances for eliciting preferences among people with I/DD.

Read the study <u>here.</u> See the full list of CSH research publications <u>here</u>.

# Featured Researcher: Adrienne Robertiello

# CSH Specialized Health Care Educator & Interim Autism Program Coordinator

Adrienne is certified in Advanced Disability Studies and is an active member of the Disability Equity Collaborative, the nation's leading organization providing evidence-based knowledge and practical solutions and tools to address the complex problems in disability access in healthcare.



As a specialized health care educator, Adrienne focuses on developing and providing education and outreach statewide and nationally in areas of disability inclusion, acceptance, accessibility, services, and safety. In January 2021, CSH received an Inclusive Healthy Communities grant (Living Safely with Disabilities and Special Health Needs) from the New Jersey Department of Human Services, Division of Disability Services.

Limited research indicates a higher rate of unintentional injury-reported hospitalizations for individuals with disabilities compared with those without disabilities. Despite having a greater need for injury prevention and safety efforts, existing resources and education primarily focus on the general public, often lacking accessibility in terms of design, content, literacy, and dissemination. At the onset of the Living Safely initiative, the grant team partnered with disability advocates and community organizations to gather baseline data focused on safety-related education and experiences. Survey questions focused on safety knowledge, how and where safety education was received, and interactions between emergency responders and people with disabilities. This survey provided the initial step in advocating for content and methods of delivery for safety education and emergency responder training, directly informed by lived experiences of the disabled population. The culmination of this initiative was the delivery of the <a href="CSH Living Safely Online Center for Safety">CSH Living Safely Online Center for Safety</a>, inclusive of tools, resources, and guidance documents focused on these needs.

Currently, Adrienne serves as the grant lead for another CSH IHC grant, Learn to Live Safely with Disabilities and Special Health Needs. This initiative embeds inclusive and accessible education and practices within New Jersey academic and municipal systems with a focus on under-resourced communities. Learn to Live Safely continues the hospital's ongoing collaboration with Rutgers University by partnering with their graduate interprofessional programs to develop a model educational curriculum based on the inclusive and accessible tenets of Living Safely.

The dearth of research on the impact of safety on people with disabilities creates a substantial gap in health disparities literature. Recently, Adrienne led CSH's advocacy among national leaders to establish people with disabilities as a population with health disparities within the National Institutes of Health. Further, as unintentional injuries among individuals with disabilities represent a pressing public health issue, Adrienne provided public comment to the Office of Disease Prevention and Health Promotion to advocate for comprehensive research to explore potential correlations and causative factors between disability characteristics and various injury types. With this data, safety education programs can be developed to more inclusively implement and measure injury prevention strategies for those with physical, sensory, and intellectual and developmental disabilities.

## **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 outdoor recreation in all forms – especially hiking, camping, skiing and running.



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 playing with her baby.

#### 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.

Tomiko Hackett, MPH
Research Engagement Coordinator

Research Focus: Mental health/ substance use disorders as well as other chronic illnesses



Tomiko enjoys traveling, being in nature, reading, and spending time with friends.



## **Upcoming Events/Conferences/Grants**

- American Physical Therapy Association Combined Sections Meeting February 15-17, 2024. Boston, MA
- <u>APA-Rehabilitation Psychology Mid-Year Conference</u>
   February 22-25, 2024. Austin, TX
- <u>Children's Hospital Association Transforming Quality Conference</u> March 11-13, 2024. Chicago, IL
- National Association of Pediatric Nurse Practitioners Conference March 13-16, 2024. Denver, CO
- <u>Association for Behavior Analysis International Annual Autism Conference</u> March 18-20, 2024. Las Vegas, NV
- American Academy of Ambulatory Care Nursing Annual Conference April 2-6, 2024. 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 Marchetta, MPH Interim Director of Research cmarchetta@childrens-specialized.org, 732-258-7288
- Joman Y. Natsheh, MD, PhD Research Lead, Developmental and Behavioral Pediatrics <a href="mailto:jnatsheh@childrens-specialized.org">jnatsheh@childrens-specialized.org</a>, 908-588-9608
- Mayank Seth, PhD Research Lead, Physiatry mseth@childrens-specialized.org
- **Tomiko Hackett, MPH** Research Engagement Coordinator thackett@childrens-specialized.org, 732-258-7296