CARD COMMUNICATOR



Center for Autism & Related Disorders at Kennedy Krieger Institute

CARD Clinic Update

What's New at the Clinic

In the months leading up to summer, the team at Kennedy Krieger Institute's Center for Autism and Related Disorders (CARD) kicked off some new community partnership and engagement activities. During Autism Acceptance Month, we offered a virtual mini-series (see below) that led to some new initiatives and exciting collaboration with our community partners.

One of the initiatives in our clinical program this summer is to enhance our ongoing efforts to improve families' access to care at CARD. For example, through continued, flexible options for in-person, telehealth and hybrid evaluation and treatment services, geographic distance is no longer a barrier to accessing clinical care. Also, we're working diligently to improve access by adjusting and upgrading the intake process. This effort decreases the time families spend filling out paperwork before their appointment yet still enables our team to provide excellent and informed care.



Ericka Wodka, PhD, ABPP-CN Clinical Director, Center for Autism and Related Disorders

Some of our family-focused improvements include:

- Shortened intake forms resulting in fewer pre-scheduling questions for families to answer.
- Removing some screening measures altogether based on data we gathered about their informativeness and family satisfaction.
- Translating more materials to Spanish and adding several bilingual staff and clinicians to support our Spanishspeaking families.

Our recent efforts aim to ensure we have all the information needed to best meet individual needs while reducing the burden on families, with the end goal of increasing access to our services.

July 2022 | Volume 7

CARD Clinic Update

page 1

Director's Corner

• page 2

Summer Fun with OT

• page 3

Introducing our African American Family Advisory Board

• page 4 - 5

ROAR for Kids 2022

page 6

Recapping Autism Acceptance Month Webinar Miniseries

• page 7 - 9

Learn More. Get Involved. Stay Connected.

KennedyKrieger.org/Connect











Director's Corner

A Message From Rebecca Landa, PhD, CCC-SLP

In May, I attended the International Society for Autism Research (INSAR) Meeting in Austin, Texas. It was exciting to work with colleagues and self-advocates from around the world as the CARD team plans for effective global methods for diagnosing autism spectrum disorders (ASD), designing accessible interventions and offering more widespread training for ASD professionals, families, educators and policy makers. It is fulfilling to see how much CARD researchers have influenced and benefitted the work being done in partnership with, and care being offered to, autistic individuals and their families around the world. Some of the topics addressed in our presentations included:

- Improving care and advancing research for mental health disorders and problem behaviors.
- Training teachers to implement effective instructional strategies that improve students' depth and rate of learning.
- Establishing more effective assessment systems.
- Innovating ways to establish global consistency in assessment and care methods and systems.





Left: Dr. Landa (center) with autism experts Dr. Sally Rogers (left) and Dr. Cathy Lord (right). Right: Dr. Landa connecting with former CARD research trainees.

A key message at INSAR was the importance of educating policy makers about autism. The learning and well-being of autistic individuals is possible when assessment and intervention/education methods and systems are well aligned with the evidence base.

The CARD team has been engaged in many exciting endeavors. We have been working with autistic self-advocates more extensively as we expand our neurodiversity affirming work. Each month for the next year, we will hear from autistic self-advocates, family members, and professionals. We will learn about their diverse perspectives on a variety of topics. In addition, our Diversity, Equity and Inclusion (DEI) program has expanded through Simons Foundation funding (see below). Also, visit the <u>research</u> page of our website to learn about research opportunities. We have free research openings for projects focused on early virtual screening for autism, social and communication delays and for free early intervention in the comfort of families' homes.

Wishing you a happy summer,

Rebecca Landa, PhD, CCC-SLP Founder, Executive Director Center for Autism and Related Disorders Vice President, Kennedy Krieger Institute

Save the Date!

On Monday, August 15, 2022, the Center for Autism and Related Disorders (CARD) is hosting its first-ever Charity Golf Tournament, organized by Friends of CARD and held at The Country Club of Maryland in Baltimore. Visit the events@kennedyKrieger.org to learn more.

Summer Fun with OT

There are several occupational therapy (OT) activities for you and your family to enjoy this summer that are fun and may help with fine and gross motor skills.

In Your Backyard:

Scavenger Hunt

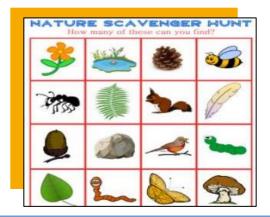
- Make a list of items that can be found in your backyard and have your child see how many they can find.
- Use pictures of the items if that works better for your child's language understanding.

Leaf Rubbing

- o Place a leaf underneath white paper.
- Have your child color with a crayon on top of the leaf until the whole thing appears.

Rock Collecting

- Give your child an empty water bottle with a small mouth.
- Encourage them to fill the bottle with small rocks.



At Home:

• Help in the Garden

 Gardening is a great activity for kids to work on their fine motor skills, upper body strength, and explore their creative side.

Create with Sidewalk Chalk

- For children learning to write or improve their handwriting, varying the surface and tool can be beneficial.
- Using broken pieces of chalk can help to improve grasping patterns.

• Summer-Themed Sensory Bins

- Summer is a fun time to make a themed sensory bin, which allows your child to explore their sensory needs.
- Use dyed dry noodles, rice, or candies as the base of the bin. Add different textures and objects to explore.



At the Park:

• Building Letters with Nature

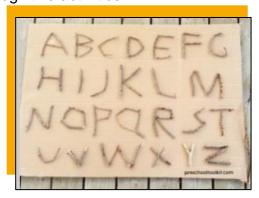
- Help your child to gather a variety of sticks and rocks.
- Use these sticks to build letters, write their name, or create shapes.

• Obstacle Course Races

- Work with your child to design an obstacle course on the playground equipment.
- This task can challenge the mind to remember and sequence, as well as the body's gross and fine motor skills, so get creative!

• Simon Says

 Simon Says is a fun activity to do with your child. This game challenges their command-following abilities as they do a variety of gross motor, fine motor, and cognitive activities.



SPARK for Autism in 2022

Exciting Updates for the SPARK for Autism Research Study

In 2022, SPARK is going further! Supported by the Simons Foundation, SPARK for Autism launched supplemental funding for supporting Diversity, Equity and Inclusion (DEI) efforts to increase the engagement and participation of Black and African American families and individuals in SPARK.

The Center for Autism and Related Disorders (CARD) at Kennedy Krieger Institute has been a SPARK research site since the project's beginning six years ago! We are thrilled to announce that CARD has been awarded supplemental DEI funding, which will help us connect underrepresented communities with resources, information and research opportunities in a more meaningful and inclusive way.

How you can help us Ignite Inclusion:

- Connect with Eva Queen, our DEI Outreach
 Coordinator. Eva is excited to help grow
 CARDS's community partnerships, build
 meaningful relationships with our local
 community, and spread information about why
 it is important that research is inclusive and
 diverse.
- Attend a SPARK Community Outreach event. We will be co-hosting four outreach events with our community partners that include focus groups, health fairs and educational presentations. Stay tuned for more information.
- Visit our <u>Ignite Inclusion website</u> to learn about our new African American Family Advisory Board (AAFAB). The AAFAB includes parent advisors, community leaders and medical professionals. The group serves as a community liaison between the African American community and CARD to increase access to helpful resources, inform our outreach strategies, and discuss obstacles and challenges in research participation.

The AAFAB will assist the SPARK for Autism team at Kennedy Krieger Institute with its efforts to better reach communities of color, who are typically underrepresented in autism spectrum disorder (ASD) research.

Introducing our African American Family Advisory Board Members



Eva Queen, Diversity, Equity, & Inclusion Outreach Coordinator

Eva, who returned to CARD after briefly leaving in 2017, leads the AAFAB.



Graciella (Chella) Drew, Community Advisor

Chella Drew, MA Ed, is a licensed trainer in restorative practices, and provides training and consulting in multiple urban and suburban school districts throughout the United States.



Erin R. Drew, Community Advisor

Erin R. Drew, MD, is a scientific director for the U.S. Respiratory Division of GlaxoSmithKline (GSK) pharmaceutical company. Prior to joining GSK, Dr. Drew practiced general pediatrics for 10 years in Baltimore.



Abila Tazanu, Community Partner and Parent Advisor

Abila Tazanu, MD, is a pediatrician with over 20 years of health and community service provision. She is a mother of five inspiring adult children, three of whom are on the autism spectrum and have related co-existing emotional concerns.



Alicia Sneed, Parent Advisor

Married to her childhood sweetheart and homeschool mom to three gifts and one angel, Alicia is an-up-and-coming human relations professional, Black maternal health advocate and grassroots community initiatives champion.



Rico Winston, Parent Advisor

Rico is the single parent of an amazing 12-year old, Isra'El, who has an autism spectrum disorder (ASD) diagnosis. Rico is a member of several community advisory boards, including Friends of CARD, the Board of Directors for The Arc Baltimore, and he sits on both the Scientific Advisory Board and Community Advisory Council for SPARK for Autism.



Rodney Toulson, Parent Advisor

Rodney Toulson, JD, is the owner of Restorative Consulting Services and a restorative practices consultant, coach and licensed trainer.



Cierra McFadden, Community Advisor

Cierra is a speech-language pathology graduate student from Baltimore who will graduate with a Neurodiversity Specialization in Autism from Loyola University Maryland.



Randi Smith Delone, Parent Advisor

Randi is a school administrator for Baltimore City Public Schools and owner of Baltimore's We Rock the Spectrum Kid's Gym. She is inspired daily by her husband and their two children, Tyler, a remarkable 24-year-old with autism, and Mimi, an amazing 16-year-old high school sophomore.



Frankie (Henri)
Merrick, Community
Advisor

For the past 31 years, Henri Merrick, MD, has been a pediatrician for neuro-typical and neuro-diverse children in Columbia, Maryland.



Ebony Holliday, Research Advisor

Ebony Holliday, PhD, is a school psychologist and a research scientist at CARD where she focuses on the design, coordination and implementation of various research projects.



Garland Jones, SPARK for Autism Co-Investigator

Garland Jones, PhD, has been employed at CARD for 12 years in assessment and treatment roles, and is currently serving as supervising neuropsychologist at CARD.

An Amazing April!

Fun at ROAR for Kids



Thanks to your support, ROAR for Kids 2022 was a HUGE success! The weather was beautiful, and it was so special to be able to come together for the first time in two years. Many CARD staff showed up to represent the CARD Dream Team and we send a shout-out to our mascot, Roary, who was a fan favorite! The CARD giveaway wagon, which included Roary masks, was very popular among kids and adults. In total we had just under 1,000 participants and raised \$130,653 with more than \$10,000 raised specifically for CARD!



Owen Pike (left) at Roar for Kids 2022 with his new Baltimore Ravens helmet!

Kudos to 12-year-old **Owen Pike** who raised the most money in his age group! Another special shout-out to the team from **Maryvale** and the **Tri-School Team**, **which had students from Roland Park Country School**, **Gilman and Bryn Mawr**. The students led their own fundraising efforts and really raised the energy at the event.

Thank you to everyone who came the event or donated online. We hope to see you again next year!



Some excited members of the Tri-School team after winning their award!

Autism Acceptance Month Webinars

To recognize the significance of Autism Acceptance Month, Kennedy Krieger Institute's Center for Autism and Related Disorders (CARD) hosted the Autism Acceptance Month Miniseries. Experts shared valuable insights during pre-recorded talks that were livestreamed on Thursdays, April 7-28.

Keep reading to learn more about each of the presentations!

Webinar Miniseries by the **Numbers CARD** hosted four different webinars during April, totaling four hours of content from our experts. The miniseries was viewed more than 680 times by our audience of parents, family members, professionals and community members. People tuned in from 12 different countries, including: United States of America, Brazil, Canada, Ecuador, Greece, India, Ireland, Nigeria, Philippines, Saudi Arabia, South African, and the United Kingdom

Panel 1: Autism: An Evolving Perspective

Summary by Hanna Kent, BA, Research Assistant

To kick off the miniseries, the first webinar highlighted firsthand experiences of living with autism spectrum disorder (ASD). Moderated by CARD's Garland Jones, PhD, the panel included autistic self-advocates Zosia Zaks and Katelyn Szymanski.

Dr. Jones began by asking the panelists what it means to have an autism brain in today's world. Katelyn and Zosia stated their specific strengths as well as some of the challenges they have faced, with Katelyn noting how masking, or hiding certain characteristics in order to be successful in jobs and school, came at a cost to her mental health.

The panel discussed what providers can do to ease different challenges. The panelists highlighted the following points:

- The language used around ASD is extremely important. It is crucial for providers to be more strength focused when discussing supports for autistic individuals.
- Zosia emphasized the importance of destigmatizing challenges and reframing societal expectations.
- Katelyn noted the importance of deemphasizing the need to fit into social expectations, and questioned how society can meet the needs of individuals with autism.

The panel talked about the benefits of moving away from terms like "symptoms", "deficits" and "severity" levels to more layperson's terms, such as "characteristics." Zosia suggested honoring certain terms, like "symptoms", to obtain services but finding ways to create a new language and not fearing terms like "disabled" or "autistic". While much has evolved for individuals with autism, there are still changes that need to occur. As a society, we need to accept a less structured way of doing things and be open to asking questions to keep moving forward.

Panel 2: Briefing on Innovative Autism Research at CARD

Summary by Lauren Duvall, BS, Research Assistant

During the second miniseries presentation, four CARD researchers gave updates on their current studies and future directions of their projects.

- Ericka Wodka, PhD, ABPP-CN, spoke about her work investigating gender disparities related to autism using SPARK data, specifically the differences in symptom presentation in males and females with ASD. Dr. Wodka would like to expand her work to investigate sensory processing differences between males and females on the spectrum.
- Luke Kalb, PhD, discussed his work on mental health crises for individuals with ASD. Currently, Dr. Kalb is working with Roma Vasa, MD, and the CARD social work team to identify individuals with an increased likelihood to experience crisis and offer them a brief crisis navigation intervention service. Dr. Kalb hopes to study the effectiveness of this intervention in a telehealth format in the future.
- Amy Keefer, PhD, MS, spoke about DINOSAUR, her anxiety management intervention for children with ASD aged 4 to 6. In DINOSAUR, children and their parents learn how to identify and manage anxiety. Preliminary results reveal that children and their parents benefit from this training. Dr. Keefer hopes to adapt and share DINOSAUR in other settings, such as in schools.
- Rebecca Landa, PhD, CCC-SLP, gave an overview of findings from a recently completed randomized control trial in public schools across four states. The data show that preschoolers with autism made better social and communication gains if their teacher had been trained to implement certain evidence-based instructional strategies compared to children in classrooms of teachers who didn't receive the training. Dr. Landa and Rachel Reetzke, PhD, CCC-SLP, have launched their First STEPS study in which parents will be coached to use such strategies during daily home activities to boost social and communication development in their toddler with ASD.

Panel 3: Evidence-Based Insights into Medical, Genetic and Psychiatric Conditions and Care in Autism Summary by Jessica Morrel, BA, Research Assistant

The third webinar delivered a thoughtful presentation on how developmental pediatrics, psychiatry, neurology and genetics come together in the assessment, treatment and care of ASD by panelists Deepa Menon, MBBS, Roma Vasa, MD, Christina Morris-Berry, MD, and Alyssa Blesson, genetic counselor.

The panel gave a deep dive into the complex nature of ASD and how its myriad of medical, psychiatric and genetic features can impact presenting symptomology and timing of evaluation. Dr. Menon noted that individuals may come in for an assessment anywhere between 12 months and 26 years of age and may present with a very wide range of symptoms, including psychiatric symptoms, neurological complaints, gastrointestinal (GI) issues and others. The experts agreed that first and foremost, a treating clinician must tease apart overlapping features of ASD and other psychiatric and medical conditions before they can begin mapping out the best treatment plan.

The panelists agreed that an individualized, multidisciplinary approach to symptom management is crucial. Physicians and genetic counselors often work together to determine whether there are known genetic factors underlying co-occurring medical conditions. This collaboration allows the clinicians to treat cooccurring conditions and tailor behavioral treatments to the specific needs of each patient. Drs. Morris-Berry and Vasa emphasized the importance of minimizing medications to avoid some negative side-effects. The clinicians emphasized the need to work together to treat an individual's core conditions, symptoms and stressors, as well as provide therapies and behavioral interventions.

Panel 4: Autistic Adults and Employment

Summary by Briana Hicks, BS, Research Assistant, and Sarah Winchell, BA, Research Assistant

The final webinar presented a discussion about the experience that adults with autism often have with finding and maintaining employment. Elgiz Sener, PhD, gave an overview of the importance of employment for well-being and the difficulties faced by young adults (YAs) with ASD. Rates of employment are lower in YAs with ASD than among the general population or other disabilities. This discrepancy is more pronounced for racial minorities, youth from low-income households, and those with communication challenges.

Valeria Swartz-Diaz, CCC-SLP, discussed the importance of fostering communication and adaptive skills necessary for employment through ongoing therapeutic interventions such as speech language therapy and occupational therapy.

Stacey Herman, assistant vice president of neurodiversity and community workforce development at Kennedy Krieger Institute, addressed transition services for graduating high school students and YAs with disabilities and emphasized the importance of inclusivity in the workplace and breaking down barriers to employment.

Tyler Shallue, a Kennedy Krieger COVID-19 health screener, described his transition to employment experience with the help of the Institute's Project SEARCH program, a transition to employment program for YAs with disabilities and CORE Foundations adult services. He discussed barriers like transportation, communication and visual impairment and the process of overcoming his barriers to find success in the workplace and a position that suits his needs and strengths.

Maureen van Stone, director of the Maryland Center for Developmental Disabilities and Project HEAL (Health, Education, Advocacy, and Law) at Kennedy Krieger, presented legal aspects of the transition to adulthood and employment for individuals with disabilities. This includes voluntary disclosure of an individual's disability and eligibility for accommodations in post-secondary education and employment settings under the Americans with Disabilities Act (ADA), which differs from entitlement to services in childhood under the Individuals with Disabilities Education Act (IDEA).

Hear from Our Miniseries Viewers!

"What a phenomenal presentation on the deeply complex nature of ASD! Such expertise in this panel. Wonderful way to integrate a multidisciplinary approach to diagnosis and treatment of ASD. Thank you!"

"Great conversation. Thank you for giving the opportunity to allow our fellow autistic peers to lead the conversations."

"Fabulous insights. Thank you so much. As a parent of a young child who has been diagnosed with ASD, this has been invaluable for me."

"WOW! I am so glad that I made the time to listen to all that you had to say. The panel was exceptional in their knowledge, ability and willingness to communicate their experiences. They are spot on with what the families are experiencing and what we need to know."

Watch The Miniseries Now!

Parents, professionals and community members can watch the miniseries for free online at www.KennedyKrieger.org/CARDWebinars