CARD COMMUNICATOR



Center for Autism & Related Disorders at Kennedy Krieger Institute

Director's Corner

A Message From Rebecca Landa, PhD, CCC-SLP

What really makes a difference in the life of a child with autism spectrum disorder (ASD)? And how does that change across childhood and into adulthood? These questions are central to the work of the clinicians, researchers and staff members of the Center for Autism and Related Disorders (CARD). We seek insights from autistic self-advocates and their family, attend training sessions by self-advocates, and read the literature to answer these questions. We use the resulting information and knowledge to ensure neurodiversity-affirming practices, to focus on relevant research questions, and to support a worldwide culture of inclusivity and respect.

Our commitment to racial and ethnic diversity is also strong. There is no universal approach to care that meets the preferences and cultural norms of all people. Thus, we invest in recruiting ethnically and racially diverse staff members, provide care in English and Spanish, engage in active listening to ensure that patients and families are heard, and seek to understand our patients' and their families' insights and cultural norms.

In addition to our commitment to the care of local families, we are committed to supporting teachers, families, clinicians and researchers around the globe so that access to state-of-the-science care is possible for children and youth everywhere. This is accomplished via groundbreaking research and through training professionals who go on to different parts of the United States and beyond.

In closing, I invite you to consider supporting the high-impact work being done at Kennedy Krieger Institute's CARD in your year-end giving plans. Thank you for all your support, financial and otherwise, now and in the future.

Best regards for a holiday and new year filled with good health and peace.

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

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CARD Clinic Update

What's New at the Clinic

As we bring 2021 to a close, we celebrate our continued provision of excellent clinical care to our CARD families despite continued challenges related to the pandemic. While we made decisive changes to our clinical models in the spring of 2020, this year, we began to adapt to a "new normal," in which we increased our on-site services while continuing to provide telehealth and hybrid (a mix of telehealth and on-site appointments) models of care.

We prioritize meeting the preferences of autistic individuals and their families we serve while ensuring that our clinical care is aligned with best practices in the field. With flexibility and determination, our staff will continue to be a source of stability in a time of uncertainty. We have exciting plans for 2022, and I look forward to sharing them with you in the new year.

We wish you a safe and peaceful holiday season.

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



CARD for Non-English Speakers

Getting Care in Your Language

At CARD, our patient population is diverse, and every family we see is unique. Should you or a member of your family have limited proficiency in English, we can make sure a certified medical interpreter is present at your next appointment—just let us know.

Did you know that CARD offers documents in Spanish and has Spanish-speaking staff members? Here's how Spanish-speaking families can receive care at CARD:



INTAKE STAFF

SPEAKING WITH SOMEONE ON THE PHONE

When you call to ask about getting care at CARD, you speak directly with our Intake team. You can ask for an Intake staff member who speaks Spanish.



CLINICAL TEAM

RECIEVING CARE

Some clinicians at CARD are certified in Spanish, including one Developmental Pediatrician, one Clinical Psychologist, and two Speech-Language Pathologists.



APPOINTMENT

Ask about which patient forms may be available in Spanish.



THE CARE CENTER

SCHEDULING YOUR APPOINTMENT

The Scheduling Coordinators in the Care Center help schedule your appointments. Ask about speaking with Care Coordinator who speaks Spanish.



CARD Continues to Grow

Meet our New Staff Members

When CARD was founded more than 25 years ago, the center had just three employees. In 2021, CARD welcomed many new employees across its different locations and specialties, bringing our total to almost 250 staff members. We are delighted to see how much CARD has grown in the last year alone.

Some of our new employees are delivering services primarily via telemedicine, while others primarily provide services on-site at our Ashland, Greenspring and Odenton locations. We have added social workers, clinical psychologists, administrative services coordinators, occupational therapists and more!

In some especially exciting news, Eva Queen joined CARD as the equity, diversity and inclusion (EDI) outreach coordinator for our SPARK research team. In this role, Eva serves as a liaison to traditionally underrepresented communities and establishes partnerships with community organizations. We are excited to have Eva on the SPARK team!

Zozia Zaks, MEd, CRC, is also working closely with our staff in an important advisory role. Zosia is a self-advocate and the manager of programs and education at Towson University's Hussman Center for Adults with Autism. He will consult with CARD on key issues related to clinical care and research initiatives, particularly regarding neurodiversity.

To learn more about the entire CARD team, visit our website.

A New Look for Friends of CARD

Meet the Executive Committee

Friends of CARD is a volunteer group with an important mission: building and strengthening CARD's connection with the community, to advance family supports, research innovations and knowledge dissemination.

Early in 2021, Friends of CARD established an executive committee consisting of individuals from the CARD community and beyond. The group meets twice a month to organize and execute friend-raising, fundraising and parent support events. Meet the Friends of CARD Executive Committee below:

Events & Awareness Task Force

Beth Ann Torr
Dave Williams
Rico Winston
Michelle Zarren (founding member)

Relationship-Building Task Force Shannon Carmen (founding member)

Angela Chambers
Julie Waldron

The committee has had a busy year, with regular meetings and event-planning. In November, the group organized a Dine Out for Autism event at all eight of Liberatore's restaurant locations. The event was a huge success and fun for all who enjoyed a dine-in or dine-out night with friends and family!



A Dine Out for Autism poster at the Liberatore's Restaurant in Eldersburg.

If you would like to learn more about volunteering with Friends of CARD, email FoC@KennedyKrieger.org

Research Discoveries

Sharing Knowledge Around the Country and Around the World

The faculty and research staff at CARD had an extremely productive 2021. While international and domestic travels were limited due to the COVID-19 pandemic, CARD's experts still delivered meaningful training sessions, presentations and seminars to local, national and global audiences. CARD researchers also had more than 50 peer-reviewed manuscripts published in leading medical journals. Here are some of the presentations and publications from CARD experts in 2021:

A Global Reach

CARD's founder and executive director, Rebecca Landa, PhD, CCC-SLP, is a global leader in ASD early detection and intervention. In June, she presented virtually to an audience throughout Europe about developmental pathways, from infancy to middle childhood, in children with ASD. Such information is important for determining how interventions are designed. In November, she delivered a virtual keynote address on the implementation of developmental science-informed early intervention to research and clinical professionals in Turkey. In total, CARD's experts presented virtually to audiences in 37 states and 24 countries across six continents.

Sex Differences in ASD

Sex Differences in Autism: Examining Intrinsic and Extrinsic Factors in Children and Adolescents Enrolled in a National ASD Cohort.

Ericka Wodka, PhD, led a team of national collaborators investigating characteristics that influence age of diagnosis and symptom presentation in individuals with ASD. Using data from the SPARK national ASD cohort, the research highlights how certain markers for ASD, including language and motor difficulties, can impact diagnoses differently in males and females.

COVID-19 Pandemic and Children with Disabilities

Supporting COVID-19 School Safety for Children with Disabilities and Medical Comorbidities.

Luke Kalb, PhD, and a group of researchers from around the country conducted a study that examined the positivity rate of COVID-19 school transmission in children with intellectual and developmental disabilities (IDD). The study findings highlight facilitators and barriers to COVID-19 testing, and the authors discuss how schools can support families of students with IDD who may be reluctant to return to in-person learning. Dr. Kalb and Maureen Van Stone, Esq., MS, presented the findings from this research study at the Association of University Centers on Disabilities Virtual 2021 Conference in November.

Motor Activity and ASD

<u>Patterns of Objectively Measured Motor Activity</u> <u>among Infants Developing ASD and Concerns for</u> ADHD.

Rachel Reetzke, PhD, and her colleagues examined patterns of measured motor activity during early development for children at high and low risk for ASD or ADHD. The researchers used continuous motion-based activity recordings to track motor activity. The findings suggest that overactivity may be a precursor of atypical development in infants and toddlers developing ASD and concerns for ADHD.

Assessing Pragmatic Communication Skills at School-Age

<u>Psychometrics of the Pragmatic Rating Scale for School-Age Children With a Range of Linguistic and Social Communication Skills.</u>

Rebecca Landa, PhD, and colleagues examined whether the Pragmatic Rating Scale-School Age (PRS-SA) was effective in identifying social communication characteristics during a semi-structured conversation sample across five diagnostic groups. Results showed that the PRS-SA is a reliable and valid measure of pragmatic communication skills for verbally fluent children with a range of social and language abilities.

Connecting to the Community

Bringing CARD to You in 2021 and Beyond

The power of connection is as meaningful now as it has ever been. At CARD, our goal is to connect patients and their caregivers, students, and research participants with state-of-the science innovations, world-class care, and high-impact informational trainings. While 2021 was a challenging year for connecting in-person, CARD staff still made meaningful connections both near and far. Here are some highlights of the connections we've made this year:

- Rebecca Landa, PhD and Ebony Holliday, PhD launched the Infant Public Health Initiative (IPHI), a research project with the long-term goal of developing interventions to address disparities in language development in children living in under-resourced communities. The IPHI has established partnerships with six Baltimore City organizations to promote community engagement and ensure that stakeholders' perspectives shape the work being done. Dr. Holliday also joined the Baltimore City Early Childhood Advisory Council (ECAC), which works to ensure all young children in Baltimore City are healthy, thriving, and ready for school.
- A total of 320 professionals, parents and caregivers attended at least one of CARD's Virtual Fall Training Series webinars. To learn about the CARD Training Series webinars, which are available for free to parents and caregivers, click here.
- CARD's experts partnered with Delaware government leaders and advocacy/service providing agencies to help inform leaders' next steps toward establishment of state-wide services to improve life and wellbeing for kids and adults with ASD, and help them find care.

• CARD is proud to partner with SPARK for Autism, the largest study of autism ever. SPARK celebrated its 5th anniversary in 2021! In the five years since SPARK launched, over 250,000 participants have joined, over 50 scientific papers that use SPARK data or SPARK Research Match data have been published, and over 50,000 participants' DNA have been sequenced for genes associated with autism. To read SPARK's research publications, visit the <u>publication page of the</u> <u>SPARK website</u>. To learn more about how you can participate in SPARK, <u>click here.</u>





Season of Giving

During this season of giving, we would be honored if you would consider making a contribution to CARD. Gifts of all sizes are appreciated – **you** can make a difference!

Anytime of the year is the right time of year to purchase a toy from <u>CARD'S Amazon wish</u>
<u>list!</u> These toys will be replacing some of our "well-loved" toys in our waiting rooms and will help patients with their developmental skills while waiting for their appointment.