

NEWS & UPDATES FROM THE
**Center for Autism
& Related Disorders**
AT KENNEDY KRIEGER INSTITUTE



Center for Autism and Related Disorders
at Kennedy Krieger Institute
April 2017 • VOL. 10, ISSUE 1

3901 Greenspring Avenue, Baltimore, MD 21211 • CARD.KennedyKrieger.org

Events

April is Autism Awareness Month!

The following events will be happening in celebration of Autism Awareness Month in April. Please take the time to review this list and join us for the activities that are of interest to you.



Sunday, April 2, from 7:30 to 9:30 p.m.: Come out to join in Baltimore's first Light City World Autism Parade in Baltimore's Inner Harbor promenade. We will have a free Tie Dye T-shirt for the first 200 of you who join in the parade. Bring lots of friends so that Maryland can see the importance of embracing individuals with ASD in our communities and homes.



Friday, April 14, 7 p.m.: Take part in the third annual Paint for Autism night in the Bennett Gym at Kennedy Krieger's Greenspring Campus. We'll be fundraising for ROAR for Kids' Center for Autism and Related Disorders (CARD) Dream Team. Last year, attendees created Baltimore-themed autism awareness-inspired artwork. Stay tuned for this year's theme!



Friday, April 21, from 1 to 3 p.m.: Make a splash at a free family swim for children with Autism Spectrum Disorder (ASD) and their families at the Goldfish Swim School, at 11460 Cronridge Drive, in Owings Mills, Maryland. It's a great way for children and their families to spend an afternoon in a 90-degree pool!

For more details about any of these events, please contact Joy Johnson, 443-923-7616, or JohnsonJoy@KennedyKrieger.org.



Monday, April 10, from 11 a.m. to 10 p.m.: Join us for "Eat for Autism" at Tark's Grill and Bar at Greenspring Station in Lutherville, Maryland. The restaurant will donate 20% of the day's receipts (excluding alcoholic beverages) to Kennedy Krieger Institute's CARD. Reservations are highly recommended. Reserve your space at <http://bit.ly/EatforAutism>.



Saturday, April 29, from 8 to 11:30 a.m.: CARD staff members, family members and friends are coming together to form the **CARD Dream Team** for the 12th year in a row, and we need your support!

This year's ROAR for Kids event will be held on Saturday, April 29, at Oregon Ridge Park. Last year, the CARD Dream Team and families of individuals with ASD and their friends turned out in great numbers! This year, we want to have an even bigger turn-out! Our fundraising goal is ambitious because we have great innovations underway that will improve the lives of individuals with ASD and their families. These innovations include social robotics interventions, a new screener for autism, an intervention for infants at risk for ASD, interventions for anxiety in teens with ASD, and much more!

Join the CARD Dream Team or form your own fundraising team for CARD! Be an agent of change for autism!



Please join us as we "roar for kids" and be sure to select the "Center for Autism and Related Disorders" when making your donation or completing your registration so that your donation will support our program. Please contact our team captain at DreamTeam@KennedyKrieger.org to get involved.

Inside this issue

A Word from Our Director	2
Swimming with ASD	3, 4
All About AAC Devices	5

Free Upcoming STAR Trainings

Getting an Autism Spectrum Disorder Diagnosis: Where do I Go From Here?

Monday, April 3, 9:30 a.m. to 11:30 a.m., presented by Cathy G. Groschan, LCSW-C

Toilet Training for Children with Autism: Strategies for Success

Wednesday, April 5, 11:30 a.m. to 12:30 p.m., presented by Elizabeth Stratis, PhD

Deaf Children with Autism Spectrum Disorders

Wednesday, April 12, 11:30 a.m. to 12:30 p.m., presented by Rachael Plotkin, PhD

Special Needs Planning: Caring for All of Your Family Members

Wednesday, April 19, 11:30 a.m. to 12:30 p.m.,

presented by James W. Curran, III, CFP, and Monty Knittle, CFA

Autism, Intellectual and Developmental Disabilities, and Law Enforcement Interactions

Wednesday, April 26, 11:30 a.m. to 12:30 p.m., presented by Officer Laurie Reyes

What is Transition Planning for a Teen with an ASD Diagnosis?

Monday, Sept. 25, 1 to 3 p.m., presented by Cathy G. Groschan, LCSW-C

For more information or to register, visit

KennedyKriegerCARD.eventbrite.com.

A Word from Our Director

Dear Friends of CARD,

Autism Awareness Month is upon us. All of those reading this newsletter have a desire in their hearts to embrace someone with ASD or to lend a hand in some meaningful way to be an agent of change, an agent for good, for those with ASD, whether you personally know someone with ASD or not. Please rally your friends and family, your fellow students, colleagues, and others to join in some of the fun and meaningful events in April to make a difference for people with ASD and their family members.

This month, I was honored to be invited to join the board of Parents Magazine. I accepted the invitation in order to have a broader reach on behalf of individuals with ASD. As you know, there is much public education to be done about ASD. Just yesterday, I was interviewed by a reporter about how a neurotypically developing child benefits from having a friend with ASD. I was flooded with thoughts about the gift of learning to see the world from a different perspective - through the eyes and mind of someone with ASD. The reporter also asked me how parents of neurotypically developing children can be a good role model for their children with regard to embracing the idea of friendship with someone with ASD. I will write an article about this in a future CARD newsletter, but I will share one thought here: Parents can model *non-judgment*. Parents can help their children develop a sincere desire to think of alternate explanations for other children's behavior (whether they have ASD or not). Discussing ways to understand others, rather than presuming something (which has a good chance of being inaccurate anyway), will benefit a child for years to come in many facets of their life.

In other news, we have been collaborating with Baltimore child care centers and with Delaware and Philadelphia preschools to evaluate the effectiveness of a professional development model for Early Achievements. In addition, we are evaluating the effect of teachers' use of Early Achievements instructional strategies on learning in preschoolers with ASD. This is very meaningful work, and has the potential to change how educators think about the design and approach to education for young children with, and at risk for, ASD.

I hope you enjoy the upcoming Autism Awareness events, and I hope to see you at one or more of them!

Warmly,

Rebecca Landa



Dr. Rebecca Landa, PhD, CCC-SLP

Light City Baltimore: Light It Up Blue Autism Parade

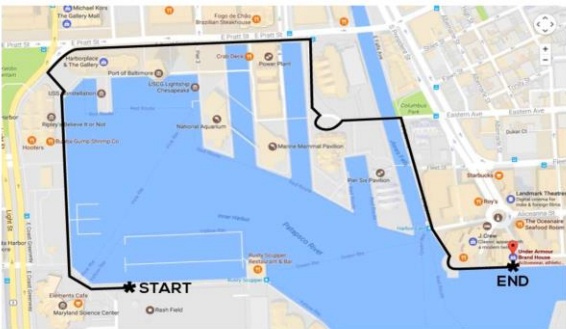
Sunday, April 2, 2017

Join Kennedy Krieger Institute on Sunday evening, April 2nd at the fabulous Light It Up BLUE Parade in recognition of Autism Awareness Month and World Autism Day. Inspiring speakers, including Dr. Ericka Wodka from the Center for Autism and Related Disorders, will kick-off the event from the main stage area on the harbor side of the Maryland Science Center.

The parade will be led by a marching band that includes a member of the autism spectrum community followed by Kennedy Krieger staff, patients, families, friends and community partners. The first 200 people will receive a free tie-dye shirt and a glow stick.

We will meet at Rash Field. The parade will disband at the Under Armour Brand House at 700 S. President Street. Individuals are responsible for parking.

LIGHT CITY
A FESTIVAL OF LIGHT, MUSIC AND INNOVATION
MARCH 31 - APRIL 9, 2017 - BALTIMORE



Light City Nightly Moments Route
Start: "G" Stage on Maryland Science Center landing
End: Under Armour in Harbor East*
*Some moments may end sooner on parade route

Date: Sunday, April 2, 2017

Time: 7:30 – 9:30 p.m.

**Where: Rash Field, 201 Key Hwy,
Baltimore, MD 21230**

Schedule of Events:

7:30 p.m. – Assemble

8:00 p.m. – Speakers begin

8:15 p.m. – Parade begins

9:30 p.m. – Parade ends



Come for the parade and stay for the lights!
For details about Light City Baltimore and the events, visit LightCity.org.

For more information, visit
KennedyKrieger.org/overview/event/light-it-up-blue-parade



Center for Autism and Related Disorders
at Kennedy Krieger Institute

Center for Autism and Related Disorders at Kennedy Krieger Institute

Eat Out for Autism

*A fundraiser benefiting the
Center for Autism and Related Disorders at
Kennedy Krieger Institute*

*Join us on Monday, April 10th at Tark's Grill between 11:00 a.m. and 10:00 p.m. to
celebrate Autism Awareness Month!*

*When you dine at Tark's, the restaurant will donate 20% of your food bill back to
the Center for Autism and Related Disorders (CARD) at Kennedy Krieger Institute.*

Reservations are highly recommended. To make reservations, please visit tarksgrill.com.

This is a delicious way to impact a child's life!

tark's



Gino Cardinale and Bruce Bodie, new owners of Tark's Grill with business partner's son, Reid.

Date: Monday, April 10, 2017

Time: 11:00 a.m. – 10:00 p.m.

Where: Tark's Grill

Greenspring Station
2360 W. Joppa Road
Lutherville, MD 21093

**The first 500 people who donate \$25 or more
online from April 6-10 will receive a \$10 Tark's
gift card! Visit KennedyKrieger.org/Tarks.**

1 gift card per donor, gift card to be mailed after April 11th

For more information, visit
KennedyKrieger.org/Tarks or tarksgrill.com.



Center for Autism and Related Disorders
at Kennedy Krieger Institute

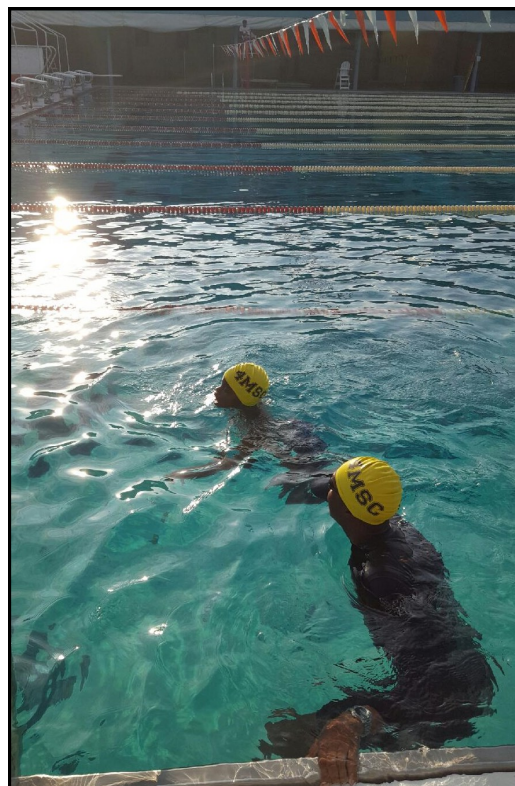
By Avery Rain, Research Assistant

Before 2014, Korey hated baths, and his mother, Mary, would have to wash him standing up. He did not care for the sensory experience of being submerged in water. Korey is nonverbal. He has been a patient of CARD's Dr. Anna Maria Wilms Floet since he was 2 years old.

But today, Korey has no trouble in the tub, where he floats on his back, puts his face in the water, and happily splashes around. Mary credits this to his experience at 4M Swim and Recreation, where Korey, now 9, and his older brother Kevin, 15, take swimming lessons.

4M Swim and Recreation was founded by Marvin Thorpe in 1972 to carry out his passion for teaching water safety. Today, the club is run by Thorpe's son, Marvin A. Thorpe II. All told, father and son have taught more than 20,000 Marylanders how to swim, including a number of children and adults, both verbal and nonverbal, with ASD.

Swimming has been a positive experience for Korey's entire family. It was important for Mary that Korey learn how to swim because she was unsure if he would be careful around water or realize how dangerous it can be. Now that she knows he's comfortable in water, she can worry less. Korey loves the physicality of swimming, and enjoys working every part of his body and getting in some great exercise. He has a history of wandering off, but can experience some freedom in the pool. Kevin, who has struggled with low self-esteem and other difficulties, takes pride in knowing how to swim.



Korey and Marvin participating in the Swim Across America Cancer swim in 2016



Kevin and Mary with a light-up sign that Mary made

“A lot of people in the African-American community do not know how to swim,” and having this skill has improved Kevin's sense of self-worth, Mary says. In 2015, inspired by her sons, Mary learned how to swim! Now, they go to the pool together. “Regardless of what your physical or mental abilities are, swimming is an activity that everybody can do,” she said.

Getting Korey involved in swimming has led to his participation in an abundance of other activities. Mary used to refer to herself as “Cinderella” and Korey as “Cinderfella,” due to the amount of time they spent at home. But recently, a fellow swim team parent remarked to Mary that Korey has a better social life than she does!

By swimming and participating in other excursions with Korey, Mary has gradually become more comfortable with having him out in the world. His behavior has gotten better, and she feels more confident going places with him. And, as Marvin Thorpe II adds, other kids benefit from spending time with Korey because being around a child who is different from them helps them grow empathy and open-mindedness, Marvin says. Also, swimming levels the playing field of communication between children. Korey doesn't need to talk to have fun with other kids in the pool. He and his peers splash and play like they've been friends for years, without needing to talk.

Mary got Kevin a shirt with a picture on it of a person wearing flippers. It says, “Not all athletes wear tennis shoes.” Recently, Kevin looked at it and said, “That's right, Mom, I'm an athlete!” As for Korey, Mary hopes that he'll one day swim in the Special Olympics.

For more information on swimming for children with ASD, see page 4.

Swimming with Children with ASD

By Anna Maria Wilms Floet, MD, FAAP

Swimming and aquatic therapy are wonderful activities for children with ASD. Teaching children with autism to swim offers opportunities for physical fitness and fun. Water safety is extremely important for children with ASD. Some children with ASD may be drawn to water, but may not understand the dangers of water. Children with ASD are at higher risk for the development of seizures. This makes it extremely important to have a child with ASD be supervised in the water at all times.

Research conducted by the National Autism Association (NAA) has revealed that accidental drowning accounts for the majority of fatal accidents for children with ASD. Children with ASD are at high risk for wandering which places the child at risk for drowning accidents to occur. To address this concern, the NAA has published a document called the “Big Red Safety Box,” which can be downloaded on the internet at no cost and offers specific tips regarding swim lessons for children with ASD and water safety tips for families.

Water safety is not only important in the context of the swimming pool, but also needs to be considered in the home. Supervision during bath time activities and checking the home for drowning hazards (toilets, buckets, home swimming pools) keeps children out of harms way.

Teaching a child with ASD to swim is NOT a substitute for swim safety. Be sure to discuss water safety with your doctor, in particular if your child with ASD has a history of seizures. Also, make sure that the swim instructor that teaches your child is aware of your child’s medical history in addition to your child’s previous experiences and responses to water, understands your child’s communication abilities and has training in working with children with special needs. All this will help the instructor to design a safe and fun experience for your child.

References: NationalAutismAssociation.org
Awaare.org
Epilepsy.com

Research

SPARK Update

By Bonnie Van Metre, MEd,
BCBA



CARD continues to be one of 21 select sites participating in the SPARK National Research Study. SPARK’s mission is to facilitate research that accelerates our understanding of the causes of autism and how autism impacts all those affected. To date, close to 1,700 individuals affiliated with CARD are registered in the study. SPARK participants have access to resources such as webinars and notable current research findings. Additionally, participants have opportunities to participate in other research across the country. Nationally, there are more than 10,000 individuals with ASD registered in the SPARK study, and the numbers continue to grow.

For more information, please visit SPARKforAutism.org/KKI or contact Bonnie Van Metre at 443-923-7598.



CARD Staff enjoyed a creative and productive retreat in January.



'But I Want Him to Talk!' Augmentative Communication and Its Impact on Speech Development and Overall Communication

By Fatima Salem, MS, CCC-SLP, and Melissa Subock, MS, CCC-SLP

With technology moving at such a rapid pace, we have seen dramatic advances that have changed the way we live our day-to-day lives. These advances have also changed the resources and tools we have at our disposal to deliver intervention to individuals with ASD.

Alternative and augmentative communication (AAC) is any form of communication used to augment traditional verbal speech. This can include a range of options, including signs and gestures, pictures and paper systems (e.g., the Picture Exchange Communication System [PECS] and communication books), and more complex voice output devices (e.g., Go Talk, TouchChat and LAMP).

For years, AAC interventions have consistently been used to support the communication of individuals with speech and language impairments. However, over the past five years, treatment of minimally verbal individuals has been revolutionized by the invention of tablets and numerous communication applications. In recent years, a wider variety of AAC options has become readily accessible to more and more individuals. But, with these technological advances come questions—and some hesitations—that we address in this article.

Some of the most common questions about AAC from caregivers and professionals include: What does use of AAC mean for the overall communication of the users? And, does this impact or replace the development of verbal speech in these individuals?

If AAC has been recommended for your child, and you have these questions, you are not alone. These questions have been asked in the research community for years. Fortunately, answers have emerged from numerous scientific studies. Here are some important facts and statistics related to AAC and speech and language development that you should know:

The most important fact that has been proven, time and time again, is that **AAC does NOT hinder speech development.**

When first introduced to the idea of AAC, many parents fear that this alternative may take away from their child's motivation to speak. However, this is simply not supported in the literature. In fact, the opposite has been proven true.

Two studies conducted in 2006¹ and 2008² provided information about the relation between a child's use of AAC and the child's speech production:

89% of children showed an increase in speech production during and after AAC intervention

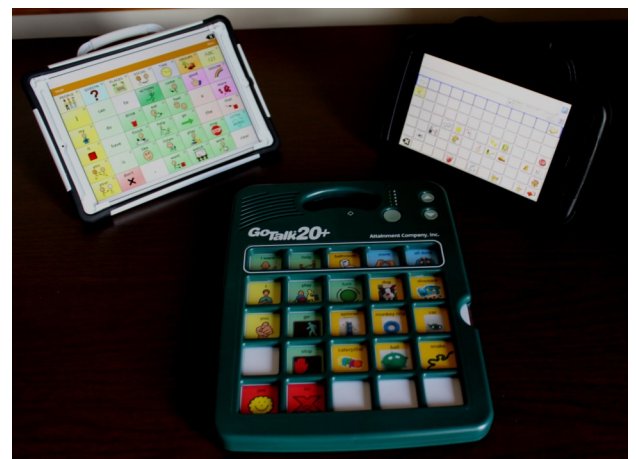
11% of children showed no change in speech production during and after AAC intervention

0% of children showed a decrease in speech production during and after AAC intervention

The most striking fact is that AAC has never had a negative effect on speech production. Although progress made is variable from child to child, we know that AAC will **not** hinder an individual's speech production. (*Continued on Page 6*)



Some of CARD's expert AAC team, including the authors of this article!
From left: Sharon Conty, Melissa Subock, Fatima Salem, Zaneta Liu, and Julie Feuerstein



AAC options used by patients of CARD
Clockwise from top left: TouchChatHD-AAC app for iPad,
Accent 800, and Go Talk 20+

"But I Want Him To Talk!" (Continued from Page 5)

With such a dramatic improvement in speech production resulting from AAC intervention, one must ask, "Why does this happen?" And, "What is it about AAC intervention that positively impacts speech production? Here are some reasons that have been presented in the research:

The use of AAC reduces the motor, cognitive and attention demands needed to communicate: When communicating, one needs to think about the construct of language (vocabulary, grammar, etc.) as well as the motor movements needed to produce speech sounds. This can be a lot to think about, especially for an individual with speech and language impairments. AAC helps to reduce these pressures and turn individuals into competent communicators. Once individuals become more automatic with language use via AAC, more cognitive and attention resources can be allocated to the actual motor production of speech sounds.

AAC devices provide immediate and consistent speech models. We know that all individuals learn language and learn to produce speech sounds by hearing words and sounds spoken in their environment. The more models for language and speech that a child is exposed to, the better. AAC does just that. As a child selects icons on an AAC device, the child immediately hears the word he or she intended to produce. These models are heard in a way that is controlled by the child. We also know that children with ASD are strong visual learners. So, the ability to hear immediate acoustic feedback coupled with the visual system helps to promote an internal knowledge and familiarity with speech sounds and production.

Individuals will inevitably choose the easier, more efficient way in which to communicate. If a child has the ability to produce sounds, this is a more efficient way to communicate a message. Even if it is a word approximation, a child will often use speech rather than an AAC system to communicate a word if he or she is able to do so. As more and more speech sounds are developed, it often takes priority over the AAC system, with the AAC system acting as more of a back-up system.

Years of research tells us that AAC does not impede speech production and can dramatically increase a child's communicative competence. It is easy for us, as professionals, to read the research and make a decision about a recommendation for our patients. But we know that making the decision for one's own children takes more than that. Often, hearing about experiences from other parents can help us feel more confident in the recommendations made by professionals.

Stay tuned! In our next edition, we will hear from CARD parents about the progress of their children at our center.

¹Millar, D., Light, J., & Schlosser, R. (2006). The impact of augmentative and alternative communication intervention on the speech production of individuals with developmental disabilities: A research review. *Journal of Speech, Language and Hearing Research, 49*(2), 48-264.

²Schlosser, R. & Wendt, O. (2008). Effects of augmentative and alternative communication intervention on speech production in children with autism: A systematic review. *American Journal of Speech-Language Pathology 17*, 212-230.

Expansion at Odenton

By *Melanie Pinkett-Davis, LCSW-C, and Joy Johnson*

CARD's Odenton campus has been serving patients and their families since November 2015. It serves as a comprehensive multidisciplinary outpatient clinic uniquely designed to support children ages 2 to 12 who live in the Odenton area and who have social communication difficulties and autism spectrum disorders.

This satellite location provides a multitude of outpatient treatment services, including group speech therapy using Kennedy Krieger's Achievements Therapeutic Day Program model. Its talented clinicians include speech-language pathologists, occupational therapists, clinical psychologists, a licensed marriage and family therapist and a clinical social worker. Recently, the location began offering STAR trainings.

The facility is currently being expanded to include five Achievements classrooms, two occupational therapy gyms and four treatment rooms. Each classroom and treatment room includes attached observation rooms, three of which are able to serve as small conference rooms. There's also a large conference room, three private offices, three shared office spaces, a large waiting and play room, and a family café with vending options.

For additional information about services at this location, please contact Maraya Bitner at Bitner@KennedyKrieger.org.



Odenton's Occupational Therapy Gym

Questions or Comments? Please email:
CARDnewsletter@KennedyKrieger.org