

potential

A publication of Kennedy Krieger Institute Fall/Winter 2021

Passionate Collaboration

Jack and His Incredible
Interdisciplinary Team

Kids and COVID-19

New Clinic Helps Kids
With Long COVID-19
Get Their Lives Back

Leaps and Bounds

Joaquin's Amazing Progress
Achieved Through Telehealth

Making a Difference

Kids Help Scientists
Discover New Treatments
by Taking Part in Research



Kennedy Krieger Institute



Greetings From Our President

Dear Friend of Kennedy Krieger,

As we enter the holiday season, I find myself filled with hope and gratitude—hope that we'll continue to see new advances in preventing and treating COVID-19 (and increasing vaccination rates), and gratitude for the incredible effort our employees, faculty members and trainees have made in serving our patients and students.

The development of the COVID-19 vaccines and advances in treatment are examples of the value of research in everyone's lives. In this issue of *Potential*, you'll read on page 11 about research that's happening at Kennedy Krieger Institute's Center for Neurodevelopmental and Imaging Research and how our scientists need children, both those developing typically and those with certain diagnosed disorders, to participate in many of the studies they conduct. Participating in research is a great way for children and teens to take part in scientific discovery and earn some money, too! Learn more at [KennedyKrieger.org/Participate](https://www.kennedykrieger.org/Participate) or use the QR code below.

Also in this issue is a story about our Pediatric Post-COVID-19 Rehabilitation Clinic. Turn to page 12 to read more about the clinic, and to page 6 to read about Hannah, who received care through both the clinic and our Specialized Transition Program, a neurorehabilitation day hospital. Pediatric COVID-19 infection can have lasting, debilitating effects. Our clinic helps kids get their lives and health back.

Lastly, I know you won't want to miss the heartwarming story about Jack, a student at our new Powder Mill Campus school outside of Washington, D.C., who's featured on the cover and on page 8.

I hope you enjoy this issue of *Potential*, and that you have a safe and happy holiday season. Thank you so much, as always, for your steadfast support for our mission and work.

Bradley L. Schlaggar, MD, PhD
President and CEO
Kennedy Krieger Institute



On the cover: Jack is a student at Kennedy Krieger's Powder Mill Campus, and also receives care for SYNGAP1-related intellectual disability at the Institute. Turn to page 8 to read more about Jack.

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Creating Community

After graduating from Kennedy Krieger High School, Emily Rowe and Ryan Ward found their niche in the community—helping others find their niche, too. *By Christianna McCausland*

The transition from high school to young adulthood is not always easy, but for people with cerebral palsy (CP), the move can be uniquely challenging, as Emily Rowe, 22, and Ryan Ward, 21, found out after graduating from Kennedy Krieger High School in 2020 and 2019 respectively.

“It’s tough to jump from Kennedy Krieger High School to the real world,” Ward says. “I would talk to Emily about this frustration—missing school, not being in a day program, trying to figure out my next step. But I was tired of talking about it and wanted to be about it.”

Understanding that they were likely not alone in their feelings, Rowe and Ward established the RELiving with CP Team in June 2020.

A nonprofit organization that brings together teens and young adults with CP to share their experiences and offer supports and resources, RELiving hosts bimonthly roundtable discussions on a wide range of topics. One roundtable hosted a sergeant in the Prince George’s County Police Department, discussing interactions between law enforcement and communities of color and people with disabilities. Others have focused on person-centered planning, and achieving and maintaining good mental health. RELiving launched a podcast this past July, and it hosts social activities as well.

Mentorship is an important aspect of RELiving’s mission of helping young people with CP navigate the transition to adulthood, and Rowe and Ward plan to expand their programming to reach high school students. “We are very interested in partnering with Kennedy Krieger High School to provide mentoring and support to students who have CP,” Rowe says. “Having Kennedy Krieger alums among the RELiving team, we feel, is of benefit to transitioning students.”

Lindsay Turwy, principal of Kennedy Krieger High School, is not surprised that Rowe and Ward have embarked on this task.



“They both were always strong advocates for themselves and their peers,” Turwy says, noting that the school is currently remodeling its store to improve its accessibility after Ward, who participated in the retail industry program, pointed out how difficult it was to access the register when using a wheelchair.

“Our environment at Kennedy Krieger High School is very focused on students and student supports so they can be as successful as possible,” she continues. Rowe, for example, was in the school’s hospitality industry program, which has helped her as a student of food and beverage management at Montgomery College. Still, Turwy acknowledges that leaving the supportive halls of the high school can be hard.

“Our students come from all over the state, so when they are in their local community, it probably is quite isolating,” she says. “To know there is a community of people to connect with and that there are opportunities out there is important.”

“That’s what we’re doing here,” Ward says. “We’re building a sense of community. Once you connect with your peers and get out there a little bit, there’s no stopping you. All you need to do is find your niche, what you’re most passionate about, and run with it.”

Visit relivingwithcpteam.org to learn more about RELiving with CP Team.

“We’re building a sense of community. Once you connect with your peers and get out there a little bit, there’s no stopping you.”

— RYAN WARD



Ryan Ward and Emily Rowe

Leaps & Bounds



In just six months of telehealth physical therapy sessions, Joaquin went from barely standing to running—thanks to the dedicated, collaborative work of his care team and family.

When Joaquin, 4, is excited about something, he jumps up and down, laughing. “If he wants you to get him something out of his reach, he’ll pull at you until you understand what he wants,” his mom, Nancy, says. “When he tries to walk or run, he’ll start to skip and jump at the same time.”

What’s so extraordinary about Joaquin is that he’s only been walking for about a year. Joaquin has Coffin-Siris syndrome, a genetic condition that often causes developmental delays. He was also born with a cleft palate, which was repaired through surgery, and was tube-fed for much of the first few years of his life.

Joaquin was referred to Kennedy Krieger Institute when he was about a year and a half old. His initial therapy sessions were challenging—Kennedy Krieger was a new setting for him, and he really just wanted to stay in his mom’s lap and arms. After a few months, Nancy and his care team decided to pause his therapies until he was better able to participate.

In April 2020, when Joaquin was almost 3, Nancy reached back out to try again, as he still wasn’t standing or walking independently. This time, because of the COVID-19 pandemic, his therapies were offered via telehealth, meaning that Nancy and Joaquin met with Joaquin’s therapists virtually, on the computer. Nancy wasn’t sure how her son would do with virtual appointments, but to her and Joaquin’s therapists’ surprise, the virtual visits were incredibly successful!

An Opportunity for Success

During the six months that Joaquin worked virtually with physical therapist Tarra Dendinger, “He absolutely thrived with telehealth services,” she says. “He truly made leaps and bounds with his motor development.” He went from not being able to stand without support, to standing independently, to walking a few steps, to jumping and running outside to get to the playground next door. “It isn’t the progress we usually expect within a six-month window. I was amazed, and Mom was ecstatic.”

In fact, Joaquin made so much progress in such a short amount of time that he made breakthroughs every week. “I’d see him for one session, and he’d take one or two wobbly steps on his own, then the next week, he’d be taking 10 steps, and the week after that, he’d be walking down the hallway to look for his sibling,” she says.

Before the pandemic, Dendinger never thought telehealth was something she’d be using regularly with patients, let alone to any great benefit. “But at my first virtual appointment with Joaquin, I saw a different child than I’d seen on-site the year before. He was happy and playful because he was in his house with his family instead of an unfamiliar clinic setting. I knew that with telehealth, we had an opportunity for him to be successful.”

“When he was younger, it was so overwhelming for me that he wasn’t doing the things he was supposed to be doing at that age,” Nancy says. “So when he did start walking, I was just so happy to see him do that.”

A Ham Sandwich

Because Joaquin was born with a cleft palate and was tube-fed for a few years, he needed help from his friends in Kennedy Krieger’s outpatient Pediatric Feeding Disorders Program before he could enjoy a good, hearty meal of solid foods.

Joaquin began working with behavioral therapist Julia Woods and registered dietitian Kathryn Davis in 2019 to help wean him from tube feedings and get him accustomed to chewing and swallowing foods of different textures. Rounding out his feeding team was a speech-language pathologist.

“Kids who have had feeding tubes since birth don’t go through the typical stages of baby food to soft foods to chunky food,” Woods explains. “We would use positive reinforcement to encourage chewing—he’d take a bite, we’d praise him, and he’d play with a toy he likes.” Then, they’d try another bite.

As Joaquin’s tolerance for—and ability to chew—food grew, Davis made recommendations to gradually decrease his tube feedings, in both volume and number. She also made sure he was getting the right amount of calories for a growing toddler.

“How far he came was really exciting,” Davis says. “His success is due so much to his family implementing the recommendations we made.” At one appointment, Joaquin showed up chewing happily away on a ham sandwich—much to Davis’ surprise! He also loves the childhood staple macaroni and cheese, Nancy says.

Something Great

Joaquin still has his feeding tube, but he hasn’t needed it since last spring. Once he’s gone a full year without using the tube, it will be removed.

He’s also worked with occupational therapist Sapna Bansil to help him develop his motor skills and build up his strength. But virtual appointments with Bansil were tough—all he wanted to do was walk! “He didn’t want to do my therapies, because he was just so interested in moving and exploring in a way that he hadn’t been able to do before.” But Bansil still managed to work with him enough that he was able to develop the skills he needed to just be a kid—to play with toys and toss a ball, for example.

After six months of telehealth physical therapy services, Joaquin had made so much progress that he was discharged from the program. “That’s the ultimate goal, for him not to need my services anymore,” Dendinger says.

Nancy used to worry about how Joaquin would do in school, and that he would need a lot of assistance, especially if he wasn’t able to move around independently. “But when he started walking, I was relieved that he would be able to walk by himself at school,” she says. Now in pre-kindergarten, Joaquin is enjoying school, and particularly loves music, dancing and sports. “He loves all types of balls—soccer balls, basketballs—those are some of his favorite things.”

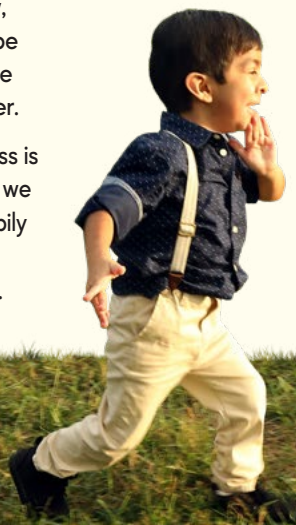
Dendinger attributes Joaquin’s incredible progress, in large part, to Nancy. “During his telehealth visits, she acted as my hands, always giving 100% to our sessions, and she always worked with him on the activities that were part of his home exercise program between appointments,” she says. “Joaquin was always happy to participate because he was in his home environment, and was able to explore and interact with his mother and siblings. He was always smiling and engaged during our visits.”

“Working with Kennedy Krieger was a really good experience for us,” Nancy says, “because while it was a lot of work, and it took time, in the end, something great came out of it.” – *LT*



“Working with Kennedy Krieger was a really good experience for us.”

– *NANCY, JOAQUIN'S MOM*



Visit KennedyKrieger.org/PhysicalTherapy and KennedyKrieger.org/Feeding to learn more about Kennedy Krieger’s outpatient physical therapy and feeding programs, and visit KennedyKrieger.org/Joaquin to watch a video about Joaquin.

DETERMINATION AND RESILIENCE

After experiencing debilitating long COVID-19 symptoms for months, Hannah found hope at the Institute's Specialized Transition Program, a neurorehabilitation day hospital.

Hannah, 20, is a nursing student and collegiate soccer player. She's smart, athletic, outgoing and always ready to help a friend or teammate. And until last year, she always enjoyed good health.

Last fall, Hannah and her parents and brother all came down with COVID-19. While her parents and brother recovered fully, Hannah developed long COVID-19.

"I couldn't do much," Hannah says. "I couldn't go to school. I couldn't go out and socialize with friends. My parents had to take care of me."

Long COVID-19 occasionally develops in people who have had COVID-19, and healthcare professionals are still learning about the condition. Its symptoms, which can linger for months, vary from person to person and include fatigue, dizziness, headaches and brain fog—all of which Hannah experienced. She also began having epileptic seizures.

"I felt like I was a zombie walking around," she says.

"I was there physically, but nothing was going on inside. Everything was dull, and I couldn't really function. It was very debilitating."

"Watching your child go through this isn't easy," says Alyssa, Hannah's mother.

"I can't imagine waking up every day and not feeling well for as long as Hannah did," adds Brian, her father. Alyssa and Brian researched rehabilitation programs that might help their daughter.

Someone mentioned Kennedy Krieger Institute, about an hour from their home in Pennsylvania.

Alyssa gave the Institute a call.

THE RIGHT TRACK

By the time Hannah had her first appointment with the Institute's Pediatric Post-COVID-19 Rehabilitation Clinic, she'd already worked for several months with physical and occupational therapists near where she lives, but she wasn't improving. She didn't have her old self back—not even close.

But at that first appointment, which lasted around five hours, Hannah and her parents began to feel just a little bit hopeful. A full complement of clinicians—including a pediatric rehabilitation doctor, a pediatric neurologist, a behavioral psychologist, a nurse and a social worker—met with Hannah and her parents to learn as much as they could about Hannah and her illness. "I felt relief that we now had a whole team of doctors looking at her holistically," Alyssa says. "I felt like we were finally going down the right track."

When they suggested that Hannah might benefit from Kennedy Krieger's Specialized Transition Program (STP), a neurorehabilitation day hospital,

"They were all working together and collaborating. I liked it from the first day."

— HANNAH

"I thought that was just what I needed," Hannah says.

Hannah spent four weeks at the STP this past summer, doing intensive physical and occupational therapies for several hours a day, five days a week, and receiving several sessions of psychological services each week. Hannah appreciated her care team's interdisciplinary approach. "They were all working together and collaborating," she says. "I liked it from the first day."

Within a week, Hannah was starting to notice changes in herself—in her rallying energy levels and ability to think more clearly. Her parents noticed, too. "She told us she felt like she was getting her old self back again," Alyssa says.

Hannah was one of the STP's first patients with long COVID-19. The STP offers neurorehabilitation in a day hospital setting for pediatric patients with a variety of conditions, from traumatic brain injury to chronic pain. Developing a protocol to treat patients with long COVID-19 was not much different from developing a protocol for any other patient—the diagnosis was new, but the symptoms were all ones the program had treated before.



“Patients with long COVID-19 tend to have milder symptoms in all areas, but because they have symptoms in so many areas, they tend to be more anxious than other patients,” says Dr. Joan Carney, assistant vice president of clinical programs and the STP’s director. “They’re not as coordinated as they used to be, and they’re tired in school and can’t think clearly, and that tends to make them a little more depressed. We help them sort out the ‘Why me?’ and equip them with strategies to help them cope and feel better.”

INTERDISCIPLINARY CARE

On Hannah’s first day at the STP, a vestibular screening revealed she was experiencing visual impairment and intolerance to movement. Physical therapist Dr. Katlyn Billups led Hannah through a vestibular training program: While keeping her eyes fixed on a single object, Hannah would slowly move her head back and forth. Once she could do that for 10 seconds, she increased the time—until she could keep it up for a whole minute. By then, she was feeling much less dizzy and nauseous.

Hannah also spent a lot of time on the treadmill—first walking, then running, then running while turning her head from side to side, to simulate running down a soccer field during a game. “She was really motivated to get better, and so receptive to everything,” Dr. Billups says. “She didn’t get discouraged, and really pushed hard to get better.”

Twice a week, Hannah met with psychologist Dr. Effie Mougianis, who helped her mentally process what she was experiencing. “Before the pandemic, she was a very healthy, very talented student-athlete—that was her identity,” Dr. Mougianis says. “COVID-19 stripped her of that—at least temporarily—leaving uncertainty in its place. I gave Hannah a space to sort through all the things she was dealing with. And she accepted the invitation, talking with me about what she’d learned about her diagnosis and symptoms, which is all part of navigating a complex medical condition.”

Because she’d recently been diagnosed with epilepsy, Hannah also met with neuropsychologist Dr. Danielle Ploetz. “I couldn’t say for certain if her epilepsy was related to COVID-19, but I could say what difficulties she was having because of it,” says Dr. Ploetz, whose assessments helped the rest of Hannah’s care team better understand Hannah’s ability to focus and concentrate, both of which improved greatly while she was at the STP.

Hannah also developed postural orthostatic tachycardia syndrome (POTS) after getting COVID-19. POTS sometimes develops in patients recovering from a viral infection, including COVID-19, explains Dr. Christina Kokorelis, director of Kennedy Krieger’s POTS clinic. Hannah’s POTS

symptoms included lightheadedness and headaches. Dr. Kokorelis prescribed new medication for Hannah as well as hydration and physical activity—which, of course, Hannah was already doing at the STP. “With the new medication and other interventions, Hannah’s symptoms improved, and she was able to get the most out of STP,” Dr. Kokorelis says.

To help Hannah return to college, Alecsandra Adler, the STP’s educational specialist, coached her in working with her university’s disability office to request any accommodations—such as extra time on exams or listening to digital books—she might need. Adler offered to advocate on Hannah’s behalf, and remains available to help Hannah at any time, “but she politely declined,” Adler says. Hannah was ready to take charge of her life again.

‘EVENTUALLY, THINGS WILL GET BETTER’

Shortly after Hannah returned to college this past August, she relapsed, passing out and having a seizure. After recovering consciousness, she called Dr. Billups and Dr. Mougianis. “They walked me through ways to manage the relapse,” including doing about an hour of physical therapy exercises a day.

Hannah isn’t back to taking a full load of classes, but she’s working up to it. And she’s back on the soccer team—not yet playing in games, but practicing with the team. She loves being at school again, surrounded by her teammates, who keep an eye out for her in case her symptoms flare up again.

“Hannah’s always smiling,” Dr. Mougianis says. “She has a great sense of humor, and I think her laughter and smiling are the things that have allowed her to be as resilient as she has been in this challenging time.”

Hannah’s advice to others with long COVID-19 is to stay positive and not give up. “It’s hard at first to see the big picture and the other side of things, but just keep pushing on, and you’ll make it to the other side,” she says. “Eventually, things will get better.” – *LT*



Occupational therapist
Mallorie Brown
and Hannah

Turn to page 12, use the QR code or visit KennedyKrieger.org/PostCOVID to read more about the Institute’s Pediatric Post-COVID-19 Rehabilitation Clinic.



Passionate Collaboration and Care

JACK, A STUDENT AND PATIENT AT KENNEDY KRIEGER WITH A RARE INTELLECTUAL DISABILITY, LOVES WORKING WITH HIS TEACHERS, THERAPISTS AND DOCTORS, WHOSE CLOSE COLLABORATION GIVES JACK'S PARENTS HOPE FOR HIS FUTURE.



*Dr. Liz Wohlberg,
Jack, Lizzie Orr
and Jessica Berry*

Jack, 12, loves toys and puzzles, music and dancing, and swimming in the ocean. He loves car rides, being read to, and playing games on his iPad. And he absolutely loves school.

“He’s so happy when he comes off the bus at the end of the day,” says his mom, Julie. That’s how she knows he’s had a great day at school.

Jack attends Kennedy Krieger Institute’s Powder Mill Campus school in Prince George’s County,

Maryland, which serves students with intellectual disabilities in grade two through age 21. This past August, the school moved into a new building. “When I toured the new school, I cried—it’s outfitted with everything the kids need,” Julie says. “It was so nice to walk around a beautiful building and see all these wonderful rooms for the kids.”

Transitions are tough for Jack, but Jack’s teacher, principal and therapists soon reported that Jack was loving the new space, clapping his hands and smiling under his face mask. “I can see the twinkle in Jack’s eyes and the excited expression on his face when he’s walking down the hallways,” Principal Julie Kim says. “He really enjoys being here.”

“He’s just so happy to come to school every day,” adds Jessica Berry, his teacher. “Sometimes, we even have to remind him to calm down and take some deep breaths, because he’s laughing so much.”

A Complex Diagnosis

Jack was diagnosed with autism spectrum disorder (ASD) when he was 3, but it wasn’t until he was 9 that he was also diagnosed with SYNGAP1-related intellectual disability. SYNGAP1 is a gene that makes a protein (SynGAP) that is important for proper brain function, explains neurologist Dr. Constance Smith-Hicks, director of Kennedy Krieger’s SYNGAP1 Center of Excellence and medical director of Kennedy Krieger’s Center for Autism and Related Disorders.

“Some variants in the SYNGAP1 gene can disrupt protein function,” she explains. “When this happens, individuals may have disruptive behaviors, sleep problems, epilepsy and impairment in cognitive function.” ASD is also common among people with SYNGAP1-related intellectual disability. Only about 600 people in the world have been diagnosed with the disorder.

Jack and his family live in Montgomery County, Maryland, and his parents worked hard to find just the right school for him. “We were overjoyed when we got a spot at Kennedy Krieger” in January 2020, Julie recalls. “It was like winning the special needs lottery.” At the end of Jack’s first day, his teachers “focused on the positive, which was really heartwarming,” Julie says. “They told me all that he’d accomplished that day. I just had a really good feeling about the placement.”

“They genuinely care about Jack.”

– Julie, Jack’s mom

It wasn’t their first experience with the Institute. After Jack’s SYNGAP1 diagnosis, they learned that one of the country’s few designated SYNGAP1 Centers of Excellence was just up the road in Baltimore, at Kennedy Krieger.

“We thought, ‘What luck! It’s practically in our backyard!’” They immediately got in touch with Dr. Smith-Hicks, who now evaluates Jack each year and oversees his SYNGAP1 care.

Recently, Jack started seeing Dr. Jay Salpekar, director of the Institute’s Neuropsychiatry in Epilepsy Program. “Sometimes, Jack’s tolerance of stressors and flexibility for adjusting to new circumstances are low,” Julie explains. “Medication can help with his attention and behavior, but he’s very sensitive to medications and their side effects,” so Dr. Salpekar tweaks Jack’s medications as needed.



Jack and his occupational therapist, Lizzie Orr

Working with Jack’s entire care and education team, “I collect as much data as possible about Jack, and tailor a treatment plan that targets all of Jack’s challenges at any given time,” he explains.

Last year, Dr. Marian Galan-Torres, supervising psychologist for the Institute’s Pediatric Developmental Disabilities Clinic, began working with Jack’s family to develop behavioral strategies for helping Jack master self-care routines and behavior management.

“We put a treatment plan of behavioral strategies in place that are effective, but which require significant parent support and commitment,” Dr. Galan-Torres says. “Jack’s parents were so on board with everything I recommended and worked so hard with these strategies that within a month, we started seeing so much improvement in Jack.”

“He’s just so happy to come to school every day.”

– Jessica Berry, Jack’s teacher



Jack and his teacher, Jessica Berry

An Incredible Interdisciplinary Team

A couple of months after Jack started school at Kennedy Krieger, the school switched from in-person to virtual learning due to the COVID-19 pandemic. Julie wasn't sure if Jack would be able to learn from home, but ultimately found herself extremely impressed at how far he was able to come during that time. "When we were virtual, we were in extremely close contact with his team at school. I was floored by their energy and dedication to all of their students."

Initially, Jack didn't understand why he had to attend school from home, in front of a computer. But within a few months, "He would hear his teacher's voice on the computer and come running over to respond to her," Julie says. The following spring, Jack was in school for part of each week, on a hybrid schedule, and by the summer, he was back to in-person learning every day.

Dr. Liz Wohlberg, Jack's physical therapist, works with Jack twice a week, helping him with coordination, balance and core strength. "Working with Jack really challenged me to think outside of the box," she says. "From his intake with us, I knew Jack would not respond as well to traditional therapy, but I wasn't sure what would work for him. I began to research SYNGAP1 so I could understand what areas of his brain were affected and how."

Using that research, Dr. Wohlberg prepared a virtual presentation on Jack and SYNGAP1-related intellectual disability and provided it to his entire education and care team at school. "SYNGAP1 affects every function of the brain," she explains. "With some brain disorders, the part of the brain that is affected is known, and we can treat the impairment based on that knowledge. With SYNGAP1, all the areas of the brain are affected, but we don't necessarily know how. So we have to stimulate all areas of Jack's brain to make progress."

"Jack's team at school does such a great job in breaking down instruction in a way that makes sense to Jack, so he can remain engaged and motivated to participate," Julie says. "They're always willing to adjust their plans to accommodate his unique learning needs. They genuinely care about Jack."

Jack has worked closely with speech-language pathologist and assistive technology specialist Kara Miller for speech therapy and to learn how to use a special iPad app to communicate. "His hands and fingers learn how to 'say' a word through pushing certain buttons in the same order, and he gets better through practice," Miller explains. "He likes using buttons with both pictures and words on them to make requests, greet others and respond to questions, and often types for fun."

Twice a week, Jack sees occupational therapist Lizzie Orr, who's been helping Jack develop the fine motor strength and coordination skills needed to navigate his iPad and other classroom materials with increased independence. "Jack is incredibly smart and shows great motivation to participate in the activities we do together to target his fine motor needs.

*Physical therapist
Dr. Liz Wohlberg and Jack*

His favorite activities include puzzles, marbles and pop tubes, and matching letter stickers. He brings positive energy into our sessions, and it's been such a pleasure working with Jack, his team and his family."

Berry, Kim, Orr, Miller and Dr. Wohlberg collaborate closely to ensure that all of Jack's needs are being met throughout the school day. There are only five other kids in Jack's classroom, which allows for plenty of individualized instruction. And in one corner of the classroom, Berry has created a special leisure area for her students, with books, toys and a rug to sit on. "He loves spending time there," she says.

Looking Ahead

In addition to being a student and patient at Kennedy Krieger, Jack also participates in research studies designed to learn more about SYNGAP1-related intellectual disability. "We are interested in understanding how the genetic variations affect individuals, with the goal of informing care and guiding treatment strategies," says Dr. Smith-Hicks, who directs SYNGAP1 research at the Institute. "We're studying some of the common challenges seen with SYNGAP1—sleep, learning difficulties and behavior—and we're very excited about what we're finding."

Jack's twin brother, Aidan, who does not have SYNGAP1, has also participated in research, as part of a neurotypical "control" group. "By participating in research studies, you're helping the greater community in getting closer to treatments that may impact not only a small patient population, but also potentially a much wider group of people with related disorders," Julie says. "Participating in a study may seem like one more thing to do in your day, but the only way we can improve quality of life for all is if we all participate in research."

Julie's current goals for Jack are that he's happy and as independent as possible. Looking ahead, "I want Jack to be able to have meaningful employment and leisure activities that keep him happy and healthy. Thanks to Kennedy Krieger, I'm hopeful he'll achieve that." – *LT*

Visit [KennedyKrieger.org/Foundation](https://www.kennedykrieger.org/foundation) to support our programs that help kids like Jack.



STUDY PARTICIPANTS OPEN DOORS FOR Therapeutic Possibilities

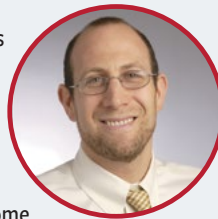


Researchers at the Institute's Center for Neurodevelopmental and Imaging Research are uncovering new information about **AUTISM, ADHD and TOURETTE SYNDROME.**

While some of the children and teens visiting Kennedy Krieger Institute's Center for Neurodevelopmental and Imaging Research (CNIR) may be too young to realize it, they're helping researchers learn more about neurodevelopmental disorders—and develop new treatments, too. These children and teens are participating in critical research studies at the CNIR, which is dedicated to better understanding the behaviors and brain circuits involved in neurodevelopmental disorders such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and Tourette syndrome. The CNIR recruits youth who are neurotypical and youth with neurodevelopmental disorders for the studies—meaning that all young people have the opportunity to make a difference.

CHILDREN WITH ASD SHOW DIFFERENCES IN IMITATION

In one study, researchers are investigating differences in imitation ability between children with and without ASD. Imitation is something that neurotypical children generally do very easily, and it's part of how children learn a wide range of skills—from motor (holding a pencil) to social (interacting with others). But for children with ASD, imitation doesn't always come naturally, explains Dr. Stewart Mostofsky, the CNIR's director.



Using cutting-edge video technology developed in collaboration with colleagues at The Johns Hopkins University, researchers study children's ability to imitate fun dance movements. The technology reveals prominent differences in the ways children with and without ASD imitate the dance moves. Children with ASD show more difficulty with imitation, and that difficulty predicts both ASD diagnosis and clinical severity. "Using a one-minute video, we can determine, with 90%-plus accuracy, whether a child has autism, based on how well they imitate," Dr. Mostofsky says. The goals of the study are to improve ASD diagnosis and develop new interventions to help children with ASD improve their social skills.

CLEAR PATTERNS OF MOTOR DIFFERENCES REVEALED IN CHILDREN WITH ADHD

In another study, the team is focusing on motor function in children with ADHD, who can have difficulties controlling their actions. The CNIR team uses safe brain imaging and brain stimulation to measure how the motor cortex—the brain area that controls movement—might be different in children with and without ADHD.

"We've identified clear motor patterns distinguishing children with ADHD from their neurotypical peers," Dr. Mostofsky explains. "We're determining whether these measures are consistent and whether they predict particular behavior profiles for children with ADHD. This could help us identify specific subtypes of ADHD and therefore help improve how we target treatments—both medication and behavioral."

MINDFUL MOVEMENT PRACTICE HELPS CHILDREN WITH ADHD

In this long-running study, the CNIR team has discovered that mindful movement instruction such as tai chi can help children with ADHD. "Specifically, we found that with just eight weeks of tai chi practice, children show profound improvements in their attention, as well as reduced impulsivity, hyperactivity and oppositional behavior," Dr. Mostofsky says. "We are now looking at whether these improvements can be sustained and whether mindful movement practice that is part of a Baltimore City public in-school curriculum can help a wide range of children improve their ability to regulate their attention, behavior and emotional responses."

DIFFERENT TRAJECTORIES IN GIRLS AND BOYS WITH ADHD

For this longitudinal study, researchers are looking at differences in brain development between girls and boys, ages 8 through 17, with and without ADHD. "Boys and girls can have very different ADHD trajectories, and we're determining factors—brain-behavioral measures in childhood that predict outcomes later in adolescence—to better guide intervention strategies," Dr. Mostofsky says.

"We're gathering information about behavior, cognitive functioning, and brain structure and functioning, and looking at whether ADHD symptoms improve and whether other mental health issues emerge as children age into adolescence," he adds. "Crucially, we are also trying to identify patterns that might predict important life outcomes, such as school and job performance, socialization, and mental health. One of the things we've already discovered is that during adolescence, girls diagnosed with ADHD in childhood seem to be having more difficulties than boys with ADHD. We're now working on understanding why this is true, and on identifying specific patterns that contribute to poorer outcomes in girls with ADHD."

These are just a few of the CNIR's ongoing studies, all of which are in need of participants. Most studies require just a few visits to Kennedy Krieger and involve playing fun games or doing simple tasks under observation—an easy way to make an important contribution to science. "The goal of our work is to improve how we care for, and intervene to help, children facing neurodevelopmental challenges," Dr. Mostofsky says. "Without our study participants, we would not be able to gather the information we need to make progress in our research." – LT

Visit [KennedyKrieger.org/CNIRStudy](https://www.kennedykrieger.org/CNIRStudy) to learn more about participating in a research study with the CNIR, and visit [KennedyKrieger.org/Participate](https://www.kennedykrieger.org/Participate) or use the QR code to learn about research studies at the Institute that are currently recruiting participants.



Next, team members gather to discuss their observations and compile a set of recommendations. Any patients experiencing brain fog or difficulties with attention or concentration—more than half of the clinic’s patients—are referred for neuropsychological assessment.

“Recommendations and follow-up are very individualized,” Dr. Malone says. “Occasionally we’ll recommend medication, but we focus on lifestyle modifications, exercise and physical therapy, and when needed, seeing mental health providers. But we also complete diagnostic work-ups to rule out other conditions that might be mimicking some of the symptoms of long COVID-19.”

For patients visiting Kennedy Krieger from far away, “We’ll provide as much guidance as possible for finding the right people to partner with locally,” she adds. Baltimore-area patients often receive care through the Institute’s outpatient clinics or Specialized Transition Program, a neurorehabilitation day hospital, to receive weekly-to-daily physical, occupational, speech and behavioral health therapies.

Families usually return for a follow-up appointment three to six months later. “And they’re always welcome to reach out to us in the meantime with any questions or concerns,” Clark says.

‘We’re Here to Help’

Long COVID-19 often impacts patients’ mental health, and children and teens are no exception. Clinic psychologist Dr. Ellen Henning screens patients for anxiety and depression, which can be impacted by the disease, and connects them with resources and interventions—such as cognitive behavioral therapy—that can help.

“Some of our patients are high-achieving students who can’t remember complex math equations anymore, and no longer feel confident in themselves,” Fulford says. “We’ve seen a lot of kids with severe anxiety and depression because they’re not able to have a regular school day or see friends. It’s impacted their whole life—and their whole family. I look at all the stressors and barriers they’re facing, and provide recommendations—as well as comfort and validation.”

“The fatigue the kids are experiencing is really difficult for outsiders to understand,” and many patients’ parents have long COVID-19, too, Clark says.

“Some patients and families say this is the first time anyone has believed their symptoms,” Fulford adds, “and the first time they’ve been able to get help.”

The clinic is working with Kennedy Krieger’s Specialized Health Needs Interagency Collaboration (SHNIC), directed by Dr. Joan Carney, assistant vice president of clinical programs. Funded by the Maryland State Department of Education, SHNIC is staffed by nurse educators and education specialists who work with schools across Maryland—free of charge—to help facilitate the inclusion of students with special health needs, including those with long COVID-19, in the classroom. SHNIC nurse educators



Clinic team members meet to discuss their recommendations for each patient at the end of each clinic session.

conduct training sessions for school health supervisors and student services directors as well as home and hospital educators, and offer case-by-case consultations to support student success in the classroom.

The clinic is part of national and international research studies to learn more about the effects of long COVID-19 on children. “We’re hoping to better define the symptoms, and better understand the course of the illness and what treatments are best,” Dr. Morrow explains.

In the meantime, the clinic’s patient list is growing. “We are dedicated to making sure families are heard, and that we can give them next steps to promote comfort and functioning,” Dr. Henning says. “Feedback is often, ‘Wow, this is really helpful.’”

“The greatest thing I’ve learned while working in this clinic is that validation goes a long way, especially for families who’ve been told that these symptoms aren’t real,” Fulford says. “But these symptoms are absolutely real. We’re here to help, and we won’t dismiss what you’re saying.” – LT

Visit [KennedyKrieger.org/PostCOVID](https://www.kennedykrieger.org/PostCOVID) and [KennedyKrieger.org/SHNIC](https://www.kennedykrieger.org/SHNIC) to read more about the Institute’s Pediatric Post-COVID-19 Rehabilitation Clinic and Specialized Health Needs Interagency Collaboration, and turn to page 6 to read about Hannah, a patient of the clinic.

“Validation goes a long way, especially for families who’ve been told that these symptoms aren’t real.”

– Bridget Fulford, social worker

During his internship with Project SEARCH, John Good developed two podcast series, including “Life with Disabilities,” and learned valuable skills for living independently.

By John Good



'Stay Focused AND Be Kind'

I graduated from Kennedy Krieger High School in 2018, and from Project SEARCH at Kennedy Krieger Institute in 2021. Project SEARCH taught me how to focus on myself and learn independent skills. My Project SEARCH internship was with Kennedy Krieger's Marketing and Communications Department.

During my internship, I developed two podcast series, “The Good Intern Show” and the “Life with Disabilities” show. I learned about interviewing people, making storyboards, typing scripts, and editing and finalizing the episodes. I interviewed several people, including Dr. Bradley Schlaggar, Kennedy Krieger's president and CEO, and Maureen van Stone, director of the Maryland Center for Developmental Disabilities at Kennedy Krieger. I also interviewed my friend Tyler, and we talked about life with autism. “The Good Intern Show” was the longest project I've ever created.

When I was younger, I was afraid of loud noises. For a long time, I wore headphones or ear plugs all the time. It's gotten better over the years, but it's something many people with autism go through.

At Kennedy Krieger High School, I attended the information technology class, and I learned about typing. I also did some volunteering, including at Ronald McDonald House Charities Maryland, in Baltimore near Kennedy Krieger, where I sanitized guest rooms and toys. Some of Kennedy Krieger's patients and their families stay at the Ronald McDonald House while receiving medical care in Baltimore.

I've been very interested in game shows since I was a kid. I am looking forward to one day living independently with my brother and working on game shows. Maybe one day, I could have a brand-new TV channel called “Game Show Masterpiece” that is dedicated to classic game shows, such as “Who Wants to Be a Millionaire,” which is one of the best classic game shows. Or maybe I could host “It's Academic,” a local, long-running quiz game show featuring high school contestants.

I live with my family, and I like cooking. I cook spaghetti and chicken, and I bake cookies and pizza. My advice to other young people my age is to stay focused and be kind.

John Good is a graduate of Kennedy Krieger High School and Project SEARCH at Kennedy Krieger Institute, and a former intern of Kennedy Krieger's Marketing and Communications Department. Currently, he receives career support services from the Institute's CORE Foundations program. Visit [KennedyKrieger.org/JohnGood](https://www.kennedykrieger.org/JohnGood) for links on YouTube to “The Good Intern Show” and “Life with Disabilities” podcasts.

Project SEARCH at Kennedy Krieger Institute is a 10-month transition program for individuals 18 through 24 years old that provides hands-on job training through integrated worksite rotations, career exploration, innovative adaptations and mentoring from experienced staff members at Kennedy Krieger. Visit [KennedyKrieger.org/ProjectSEARCH](https://www.kennedykrieger.org/ProjectSEARCH) to learn more.

CORE Foundations at Kennedy Krieger Institute is a community-based program and certified and licensed DDA adult provider for the state of Maryland that supports individuals with disabilities in obtaining and maintaining meaningful employment and community engagement for lifelong success. Visit [KennedyKrieger.org/COREFoundations](https://www.kennedykrieger.org/COREFoundations) to learn more.

*“Maybe one day, I could have a brand-new TV channel called ‘Game Show Masterpiece’ that is dedicated to classic game shows.”
- John Good*

NEWS & EVENTS

23,820 Acts of Kindness

Earlier this fall, Baltimore credit union SECU selected Kennedy Krieger Institute as a charity partner for its “Kindness Connects” campaign, a special initiative to celebrate SECU’s 70th anniversary. An ardent community partner and loyal supporter of Kennedy Krieger, SECU committed to completing 70,000 acts of kindness during the month of October, and challenged the Kennedy Krieger community to complete 10,000 acts of kindness during the month—all to brighten people’s lives during these difficult times.

“We’re proud to announce that Kennedy Krieger’s patients and students, and their families, as well as employees, donors and friends, reported 23,820 acts of kindness throughout the month,” says Linda Schaefer Cameron, the Institute’s vice president of philanthropy. “It’s an incredible testament to the Kennedy Krieger community’s passion for helping others.”

Having met and surpassed its goal, Kennedy Krieger will receive a \$25,000 donation from SECU—an act of kindness that will allow the Institute to continue providing the best care and education possible to its patients and students.

Visit KennedyKrieger.org/TeamSECU to learn more about SECU’s work with Kennedy Krieger.



Hats & Horses Raises Nearly \$130,000 for Kennedy Krieger Clinical Trial

In August 2021, the Women’s Initiative Network (WIN) for Kennedy Krieger Institute made the difficult decision to postpone its in-person Hats & Horses event until May 5, 2022, due to the pandemic.

But the funds to be raised during the event were urgently needed to support the Institute’s clinical trial of PediaCORE, an innovative movement training system designed to help young children with movement disorders. So on September 30, WIN launched a weeklong online campaign to raise the funds right then and there, rather than waiting until the spring. To encourage donations, the Baltimore-based Charles T. Bauer Charitable Foundation offered a matching gift challenge: The foundation would match all donations, dollar for dollar, if the campaign raised at least \$50,000.



Over the course of one week, supporters donated \$79,505! With the match, WIN and Kennedy Krieger realized a total of \$129,505 to support the immediate needs of the PediaCORE clinical trial.

Thanks to our generous donors, our sixth annual Hats & Horses event will be even more of a celebration! **We hope you can join us on May 5 at The Winslow in downtown Baltimore.**

Visit KennedyKrieger.org/Derby for more information, and visit KennedyKrieger.org/BauerDonorWall for an online commemoration of the campaign’s generous supporters.

Join us on social media! Visit: KennedyKrieger.org/Connect



Patients and Students at Kennedy Krieger Need Your Help!

Do you want to make a difference for children and families? Help our patients and students by becoming a monthly donor. Visit KennedyKrieger.org/Monthly to learn more and sign up.

Another way to make a lasting impact is to include Kennedy Krieger in your estate and charitable gift plans. Leave a legacy to reflect the values you want to express and pass down to future generations. Visit KennedyKrieger.org/PlannedGiving to learn more.

One of the easiest ways to help Kennedy Krieger is to give through a donor-advised fund. Donate the amount you want, when you want to give it, in a way that is tax-advantageous to you. Visit KennedyKrieger.org/DonorAdvised to learn more.



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When you give to Kennedy Krieger Institute, you're helping us see beyond limits for children like Jack. Your gift supports groundbreaking education, research and care that bring hope and transform lives. Thank you so much!

Make your donation today using the return envelope in this issue, or go online—use the QR code or visit: KennedyKrieger.org/PW21



Giving to Kennedy Krieger

WHY I GIVE

“When I give to Kennedy Krieger, I feel an overwhelming sense of ‘good.’ I often talk about my experiences volunteering at the Institute with my sons and husband, and that has opened up discussions in my family regarding giving back and helping others. My boys have seen how giving back has positively influenced my life, and I hope that they will always find time in their lives to give.”

– Shari Tompkins, Women’s Initiative Network (WIN) for Kennedy Krieger Institute member and co-chair of WIN’s 2021 and 2022 Hats & Horses Benefiting Kennedy Krieger

Visit KennedyKrieger.org/WIN for more information about WIN, and visit KennedyKrieger.org/WINShari to learn more about Shari’s volunteer work with Kennedy Krieger.



Shari Tompkins