

potential

A publication of Kennedy Krieger Institute Summer 2020

Awe-Inspiring Determination Ellie's Story of Willpower and Strength

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Staying Connected Through
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Hand-Transplant Surgery

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Project HEAL Helps
Savion Surpass His Goals



Kennedy Krieger Institute



Dear Friend,

Welcome to this special edition of *Potential* magazine.

As we were preparing these stories, COVID-19 changed all of our lives. But the remarkable patients, students, families and staff members highlighted here were not deterred! We're grateful to them for sharing their stories and contributing their personal photographs so we could bring you this edition, which we've produced a bit differently than usual. The stories previewed here are fully told on a special section of Kennedy Krieger Institute's website—visit [KennedyKrieger.org/PS2020](https://www.kennedykrieger.org/PS2020) or use the QR code to read the full stories. I think you'll find, as I did, that these remarkably uplifting stories of perseverance and success are a welcome inspiration during these challenging and troubling times.

I hope you and your loved ones are well. We're so grateful for your continued support.

Warm regards,

Bradley L. Schlaggar, MD, PhD
President and CEO



Use this QR code to access *Potential* stories online.

Awe-Inspiring Determination

Ellie, 15, has a severe form of Marfan syndrome, a connective tissue disorder. She's had more than 20 surgeries, but it wasn't until just a couple of years ago that Ellie followed surgery with inpatient rehabilitation, at Kennedy Krieger Institute. Since then, she's had two more stays at Kennedy Krieger's inpatient rehabilitation hospital, each time increasing her strength and determination to live her life to the fullest. She continues to meet with Heather McLean, her physical therapist at the Institute, every other month, traveling with her parents by car from their home in Virginia to Baltimore, a 16-hour round-trip car ride.

"Strength shows how much you've been through, and survived throughout your life," Ellie says. The surgery that she had right before coming to Kennedy Krieger for the first time was an elective one. It required months of painful rehabilitation, but without it, she wouldn't be able to walk. Ellie was determined to reclaim her independence. "The past matters, but the future matters more," she says.

While Ellie fully understands her medical condition and how it affects her, "she now refuses to let any of it stop her from being a teenager and having dreams," McLean says. "Can't" is a four-letter word no longer in her vocabulary."



Visit [KennedyKrieger.org/EllieVideo](https://www.kennedykrieger.org/EllieVideo) to read more and watch a video about Ellie.

INSPIRING POTENTIAL



Achieving Independence

Zion, 13, can hit a baseball and catch a football—typical stuff for a boy his age, but remarkable milestones for Zion, the first child to undergo bilateral hand-transplant surgery. When Zion was 2, he lost his hands and legs to an infection. He received his new hands when he was 8. Nearly a decade of occupational therapy at the Institute (starting before his surgery) has helped his body adapt and heal, and allowed him to thrive. Since the start of the pandemic, he's been checking in with his occupational therapist, Lindsey Harris, twice a week for telehealth appointments.

"Everybody at Kennedy Krieger is very motivated and helpful," says his mom, Pattie. "Everyone is focused on your child. They're like a family."

Visit [KennedyKrieger.org/Zion](https://www.kennedykrieger.org/Zion) to read more about Zion.

IN MY OWN WORDS

Envisioning Success



When Alyssa Thorn first met Savion, he was struggling—in two years, he'd earned just four high school credits. Savion, 17, has Cogan's syndrome, which can cause progressive vision and hearing loss; he's also been diagnosed with ADHD, anxiety and depression. Thorn, a staff attorney at Project HEAL, a community-based program of the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute, worked closely with Savion and his mom, Dawn, to advocate for a more appropriate school placement that would better serve his needs.

"Working with Alyssa was quite amazing. She knew what was meant for me. I now see myself as actually succeeding."
— Savion

Visit [KennedyKrieger.org/Savion](https://www.kennedykrieger.org/Savion) to read more about Savion.

Serving Our Patients, Students and Families

To help reduce the spread of the new coronavirus, Kennedy Krieger Institute's doctors, nurses, therapists, teachers and other providers have been using digital technology to provide services to patients, students and families remotely. These stories take a closer look at how telehealth and tele-education have benefited the Institute's patients and students during the pandemic, allowing them to continue to grow, heal and learn.

Ensuring Continuous, Patient-Centered Care Through Telehealth



At the start of the COVID-19 pandemic, Kennedy Krieger Institute moved quickly to transition thousands of patients from in-person to telehealth appointments. "Within days, we had completely transformed our service delivery model," says

Dr. Jennifer Crockett, director of the Institute's Behavioral Health Program for Military Families. The week of March 1, Kennedy Krieger offered more than 5,000 in-person appointments and eight telehealth appointments. By mid-April, the numbers had flipped.

"We coalesced around it in just a couple of weeks," explains Dr. Deepa Menon, assistant medical director for the Institute's Center for Autism and Related Disorders. What makes it work, she says, is that "we keep patients and families in the center of all we do."

Visit [KennedyKrieger.org/TelehealthModel](https://www.kennedykrieger.org/TelehealthModel) to read more about telehealth at Kennedy Krieger.

Occupational Therapy at Home

To get ready for Journey's occupational therapy appointment, her parents, Ahsha and James, set up a laptop and yoga mat in Journey's room. They click on the secure Zoom meeting link they've received specifically for the appointment, and voila! They're connected in real time—via video conferencing—with their daughter's occupational therapist.



Journey, 7, is one of the many thousands of patients currently receiving healthcare services from Kennedy Krieger Institute through telehealth. "I'm so proud of our department for quickly coming up with a way to continue to provide services in such a hands-on profession," says Kristin Stubbs, the Institute's director of occupational therapy.

Visit [KennedyKrieger.org/Journey](https://www.kennedykrieger.org/Journey) to read more about Journey.

Developing Innovative Approaches to Education and School-Based Services

Stay-at-home orders presented a particular challenge to Kennedy Krieger School Programs: How would teachers, assistant teachers, therapists, behavioral psychologists and other school-based service providers continue to serve students while school buildings remained closed? With each of Kennedy Krieger's approximately 500 students having their own individualized education program, there was no easy—let alone established—solution.

But in just two weeks, school staff members developed a continuity of learning plan for each student, working closely with each student's parents or guardians and local school system to be sure that students' learning, therapeutic, behavioral and other needs would be met. It was no small feat, with staff members designing innovative solutions to ensure the very best for their students.

Visit [KennedyKrieger.org/Tele-Education](https://www.kennedykrieger.org/Tele-Education) to read more about tele-education at Kennedy Krieger.

Learning and Striving in Virtual School

Noah, 11, has autism spectrum disorder. Before he began attending school at Kennedy Krieger Institute's Montgomery County Campus last year, he often felt angry. But within a few months of switching schools, he'd made a dramatic change for the better. As his behavior improved, he began to truly shine in his schoolwork.

Noah continues to make strides during the pandemic.

He is loving his virtual classes with his teacher, Alyse Marselle. When they were virtually reunited, he was so happy that he kissed the iPad he was using. "He loves seeing his teachers on Zoom," says his mom, Tracy. "It's really important for him to know they're still there for him."



Visit [KennedyKrieger.org/Noah](https://www.kennedykrieger.org/Noah) to read more about Noah.



Kennedy Krieger Institute

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Your support helps amazing patients like Ellie.

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

Visit KennedyKrieger.org/PS20 to make your donation today!

Ellie works with Kennedy Krieger physical therapist Heather McLean.

Events Supporting Kennedy Krieger Institute

Due to the COVID-19 pandemic, many of our events have been postponed, or will be held virtually (i.e., online) or as hybrid events, with some in-person and some virtual elements. Our signature events **Festival of Trees** and **Hats & Horses Benefiting Kennedy Krieger Institute** are still happening this year, and will be held in ways that will be both safe and fun.



Hosted by the Women's Initiative Network for Kennedy Krieger Institute, **Hats & Horses** will take place on September 25 at 7 p.m., and will be held virtually. Join us from the comfort of your home for powerful storytelling and compelling moments of hope, as well as some friendly competition. Wear your Derby best, and help us raise funds for the Institute's International Center for Spinal Cord Injury! Visit KennedyKrieger.org/Derby for more information.



Festival of Trees will take place November 27–29, and will be mostly virtual. We're preparing many exciting activities, including online viewing and purchasing of hundreds of one-of-a-kind, designer-decorated trees; an online auction; photos with Santa; and much more! Visit FestivalOfTrees.KennedyKrieger.org for more information.



Visit KennedyKrieger.org/Events for the latest information on our events, all of which benefit the patients, students and families of Kennedy Krieger.