Dear Colleague,

For over 75 years, Kennedy Krieger Institute has been a national leader in providing patient care for children and young adults with disorders and injuries of the brain, spinal cord, and musculoskeletal system. Our medical staff of more than 200 physicians, representing more than 50 specialties, and a staff of more than 2,400 dedicated employees provide your patients unique access to the latest in research and treatment models in the areas of neurorehabilitation, behavioral disorders, and other developmental disorders.

To ensure that your patients receive the best care possible, we take an interdisciplinary team approach that starts with you, the referring physician. Our staff works closely with you and your patients and families to develop comprehensive and individualized treatment plans. Depending on their needs, we can offer your patients care in a variety of settings, including a 70-bed inpatient unit, outpatient programs that see more than 20,000 patients each year, day treatment services, and home- and community-based programs.

In addition to the news, updates, and inspiring stories you’ll find inside Potential magazine, we’ve provided an overview of the Institute’s programs and services, as well as clinical and research updates. If you have any questions or would like to learn more about any of our patient care programs, please call our Physician Referral Line at 443-923-9403 or email us at findspecialist@kennedykrieger.org.

Sincerely,
Gary W. Goldstein, MD

PROGRAM NEWS & UPDATES:

• New Moser Center for Leukodystrophies Launched
• Management of Orthopedic Conditions in Children and Young Adults
• Research Briefs: Muscular Dystrophy and Concussion
• Upcoming Events: Educational Events Geared Toward Healthcare Professionals

INSIDE POTENTIAL MAGAZINE:

• One in a Billion: rare genetic disorders
• Recognizing and treating catatonia in autism
• Rehabilitation after a brain tumor

Visit potentialmag.kennedykrieger.org to access articles and search publication archives.

To support the needs of physicians and healthcare professionals, our care management team is available to provide information on appropriate clinical programs, handle referrals, obtain consultations with Institute specialists, and schedule appointments for patients and families.

Call 443-923-9403 to reach our Physician Referral Line or visit referrals.kennedykrieger.org for information and resources for physicians and healthcare professionals.

For general information, call 1-888-554-2080 or visit kennedykrieger.org.

OUR CULTURE OF CARE
Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Care is provided in a manner that preserves cultural, psychosocial, spiritual and personal values, beliefs, and preferences. We encourage patients and families to become active partners in their care by asking questions, requesting resources, and advocating for the services and support they need.
NEW PROGRAM: MOSER CENTER FOR LEUKODYSTROPHIES OFFERS COMPREHENSIVE CARE, RESEARCH, AND SUPPORT FOR PATIENTS WITH DEBILITATING NEUROLOGICAL DISORDERS

The Moser Center for Leukodystrophies at Kennedy Krieger Institute consists of an interdisciplinary team of neurologists, rehabilitation and physical medicine specialists, urologists, endocrinologists, physical therapists, occupational therapists, genetic counselors, and social workers. These specialists offer comprehensive diagnostic evaluations, counseling for individuals and families, and treatment of leukodystrophies and related white matter diseases in children and young adults. For patients with unknown leukodystrophies, the center also offers an individualized medicine approach using advanced genomic techniques, in addition to the standard tests and MRIs.

Drawing on the broad range of services offered at Kennedy Krieger Institute, treatment encompasses management of muscle tone and pain (including Botox), incontinence, seizures, adrenal dysfunction, and osteoporosis; evaluation for gait and balance problems; and family carrier counseling and gene testing.

In addition to ensuring comprehensive treatment, the center is actively researching new therapies and drugs aimed at preventing and treating leukodystrophies.

To learn more about the Moser Center, see the article inside the spring 2014 issue of Potential magazine or visit potentialmag.kennedykrieger.org. To make a referral, please call our Physician Referral Line at 443-923-9403 or visit referrals.kennedykrieger.org.

EVENTS, RESOURCES, AND TOOLS FOR HEALTHCARE PROFESSIONALS:

Save the Date: Upcoming Professional Development Events at Kennedy Krieger Institute

Progress in Practice: Activity-Based Restorative Therapy (ABRT)
Dates: September 19 – 20, 2014
Location: Kennedy Krieger Institute’s Broadway Campus
For more information or to register, visit ABRTtraining.kennedykrieger.org.

The Assisting Hand Assessment, a new perspective on evaluating hand function in children with unilateral impairments (coming to Baltimore for the first time)
Dates: September 22 – 24, 2014
Location: Kennedy Krieger Institute’s Fairmount Campus
Space is limited. For more information, contact Teressa Reidy at reidy@kennedykrieger.org.

14th Annual Autism Conference – Autism: Transforming the Future
Dates: October 16 – 17, 2014
Location: North Baltimore Plaza Hotel
Timonium, MD 21093

For more information about session topics, keynote speakers, and other conference details, visit autismconference.kennedykrieger.org.

Convenient New Ways to Make Rehabilitation Referrals

The Rehabilitation Department at Kennedy Krieger is now offering the convenience of an online referral form for patients with a range of physical medicine and rehabilitation needs. A referral pad is also available for physicians who prefer to complete a hard copy of the form to give to patients and families by calling our Physician Referral Line at 443-923-9403.
To access the online referral form, visit kennedykrieger.org/RehabReferral.

Neurorehabilitation Research, Treatment, and Trends Newsletter

In each issue of Kennedy Krieger’s Neurorehabilitation Updates newsletter, we feature one of the Institute’s neurorehabilitation programs and share how our innovative therapies, equipment, and technologies are enhancing patient outcomes. We also include updates on clinical research and notes about staff and programs. Past topics have included rehabilitation after a brain tumor, disorders of consciousness, and innovative rehabilitation technology. To receive your copy of Neurorehabilitation Updates, visit kennedykrieger.org/patient-care/health-care-professionals.
potential

A publication of Kennedy Krieger Institute

OPERATION SAVE MEGAN
A MILITARY FAMILY’S QUEST FOR THEIR DAUGHTER’S CARE

Neurorehabilitation:
Life After a Brain Tumor

Born to Run, Despite Autism & Catatonia

Research: A Biomarker for Concussion?
Every day, we strive to improve the lives of children and their families through pioneering research, world-class patient care, special education, and community initiatives. And we are committed to spreading our knowledge to help children around the world through professional training. Unless you have experienced it firsthand, you may not realize the critical need the Institute fills for children with special healthcare needs. For many families, Kennedy Krieger provides the answers they have long been searching for.

As Megan Miceli’s family knows, Kennedy Krieger is home to doctors with the expertise to care for even the most rare and complex conditions. Only a handful of others with Megan’s genetic disorder have been reported in the world. When the Micelis moved hundreds of miles away, doctors didn’t know how to care for her, and Megan’s health declined. Fortunately, her father received a compassionate military reassignment to Baltimore so Megan can once again receive the expert care she needs from Kennedy Krieger.

The Schneider family from New York has a top-notch behavioral team to help care for their son Jamie, who has severe autism, but when they noticed his troubling and out-of-character behavior, they turned to Kennedy Krieger. Our experts diagnosed catatonia, which was quickly treated. Now, Jamie is back doing what he loves best—running.

And for fifteen-year-old Kokayi Thomas, Kennedy Krieger offered the right combination of motivational therapists and evidence-based rehabilitation therapies to help get his life back after a brain tumor.

We are proud to offer the care that has helped unlock the potential of so many children and young adults, enabling them to live productive, purposeful lives.

Sincerely,
Gary W. Goldstein, MD

On the cover: Six-year-old patient Megan Miceli with her mom, Amie Miceli, at Fort McHenry in Baltimore, MD.
The year my son was in the third grade, I didn’t eat. I never left my phone, even to take a shower. Jake, who has autism, was scared to go to school and totally unhinged once he got there—running in circles, biting his hand, melting down. Desks would fly if one thing went wrong. He would return home from school exhausted, with fingernails chewed to the quick and tear-stained cheeks. It was torture seeing him so miserable. Jake was so overwhelmed, I honestly don’t know how I was able to keep my sanity and our family together.

The last straw in the public school system was when Jake broke a window with his bare hands, sending him to the hospital in an ambulance. My husband, Chris, and I raced to meet him as soon as we got the call from his school. I had no idea what to expect as that ambulance pulled up with lights flashing. I could feel my heart beating in my temples and sweat pouring down my face. Jake’s teacher, whom we adore, met me at the door with the school psychologist. I was instructed to not react when I saw Jake because that would give him too much feedback and attention. As I saw the stretcher, the tears came. I had to turn my back on my baby so he wouldn’t see me crying.

This was our breaking point. We needed a new school for Jake and we needed it now.

After all our other options were exhausted, we waited in agony to hear back from Kennedy Krieger Schools. It was our only hope. The day before spring break, my stomach had grown a giant ulcer, my lip huge cold sores—we still had not heard from any school that would accept Jake.

At 4 p.m. that last day before break, my phone rang. “Mrs. Lynn, I’m calling to tell you that Jake has been accepted into our program at Kennedy Krieger.” I burst into tears, and Chris and Jake started to dance around the driveway. For the first time in three years, there was hope.

I haven’t written about this experience before and tears are rolling down my face again as I type. I can feel my heart beating and that exact feeling of relief that our son would be saved. Since being enrolled in school at Kennedy Krieger, Jake has stabilized. He has gone up an entire grade level. He has earned 98 percent of his behavior points and is flourishing. No aggressions, no self-injury. Our son is learning tolerance along with social skills, patience, self-regulation, and coping strategies, as well as basic manners and life skills. We adore the staff at the school. Everyone from the headmaster to the friends that keep the school clean for our kids puts more than 100 percent into every encounter with the students. Kennedy Krieger has renewed our hope.

Visit potentialmag.kennedykrieger.org/Jake to learn more about Jake’s story and Kennedy Krieger School Programs.
Jamie Schneider has profound autism and cannot speak. The 23-year-old from New York cannot cross the street alone and requires constant supervision. But when he’s running, he is free. Jamie can’t communicate how it feels to hear friends and family cheer him on during a race or to cross the finish line of a marathon. But you need only see his smile and the pride shining in his face to imagine what he might be thinking.

Jamie has run 7 marathons and 150 races, along with his identical twin brother, Alex, who also has autism. The boys have been running since age 15, when the family discovered a running club that pairs volunteers with kids with disabilities. It quickly became clear that running was a natural fit for Jamie. It was a way to focus his energy, and his parents could see the sense of freedom he felt when running.

It was a turning point in their lives, opening the door to a new world where the boys could participate in activities alongside typically developing peers. The twins joined their high school cross country team, and began running competitively. The boys inspired their parents, Robyn and Allan, to begin running, and it quickly became a favorite family activity. “It’s something we can do together,” explains Robyn. “Even though the boys can’t talk, it’s a way of spending family time together and bonding.”

From the start, Jamie loved running, and could go for hours. During races, he would often slow down to shake hands with bystanders, enjoying the social aspect as much as running itself. Jamie, who had always been even-tempered, sociable, and happy-go-lucky, was in his true element.

A Bump in the Road

But inexplicably, in late 2011, Jamie’s behavior began to change dramatically. He began having self-injurious behaviors, biting himself and slamming his feet on the floor to the point of breaking bones in his foot. “This was something we had never experienced with Jamie,” notes Robyn.

Jamie also began slowing down—Robyn describes him as moving in slow motion. He needed prompting to eat a meal, and getting dressed was a lesson in patience—when putting a sock on, he might be stuck with his foot in the air for several minutes. If rushed, he would blow up, banging his fist on the computer, for instance. “His personality really changed,” recalls Robyn. “He wasn’t happy the way he was before.” He became very sensitive to loud noises and disruptions in routine.

When Jamie ran in the Boston Marathon in 2013, he was deeply traumatized during the aftermath of the bombing. Jamie was taken off course and wasn’t able to finish. People were crying and taken to lockdown, and Jamie was upset by the emotional turmoil surrounding him. “For him to see others crying, it’s like the world is crashing down,” says Robyn. “It affects him 1,000 times more than it would you or me.”

Despite severe autism and catatonia, Jamie Schneider’s triumphs have been far greater than his disability.
**A Second Wind**

At his worst, Jamie could no longer run. Distressed, Robyn reached out to Dr. Lee Wachtel, medical director of the Neurobehavioral Unit at Kennedy Krieger Institute, on the advice of a friend. After Robyn described Jamie’s symptoms and showed videos of his behavior, Dr. Wachtel immediately suspected catatonia, a neurological condition with motor, behavioral, and vocal symptoms. The diagnosis was confirmed during a later visit.

“We’ve seen this frequently in patients with autism,” says Dr. Wachtel, who notes that 12-18 percent of adolescents and young adults with autism meet the criteria for catatonia. “One of the first things parents notice is that their kids slow down, and become amotivated and disinterested. Sometimes parents assume their child is misbehaving, or they chalk it up to being a teenager. Parents see their child deteriorating.”

Catatonia can show in many forms. Individuals may become rigid in posture, and may be “stuck” in the same position for hours. They may maintain what is called “waxy flexibility,” meaning that if you lift an arm and position it a certain way, it will stay in that position. In other cases, parents may notice physical agitation and pointless, repetitive movements. Some of the symptoms overlap with symptoms of autism, but the key distinctions of catatonia are a marked change in behavior and no operant cause for the self-injurious behavior.

If catatonia is not recognized early, the condition can worsen and become increasingly difficult to treat. In severe cases, electroconvulsive therapy (ECT) is required. In Jamie’s case, Dr. Wachtel was able to quickly treat him with lorazepam, a benzodiazepine that acts on the gamma-aminobutyric acid (GABA) neurotransmitter, typically the first line of treatment for catatonia.

**Going the Extra Mile**

To complement the medical treatment, consulting psychologist Dosia Paclawskyj traveled to New York to observe Jamie in his environment and consult with his behavioral team, Dr. Mary McDonald and Jamie O’Brien of the Genesis Program. Dr. Paclawskyj offered recommendations to reduce Jamie’s anxiety and obsessive compulsive behavior.

Since beginning treatment at Kennedy Krieger, Jamie has improved dramatically, says Robyn. He’s not hurting himself like before. He tolerates more. He’s happier and more social. And he’s running again.

Most recently, Jamie completed the New York marathon. “For him to come out of where he was and to accomplish that…it’s just off the charts beyond wonderful,” Robyn says. “I’m just so thankful that we’re able to offer him this opportunity and to experience this joy with him.”

Robyn hopes Jamie’s story will help others who are struggling. “I’d love to know that others who read his story would feel hopeful and inspired to find different ways to keep forging ahead,” she says. “Our message is to persevere, regardless of how difficult the situation may be. Your child needs you more than ever.”

Visit potentialmag.kennedykrieger.org/Jamie to learn more about Jamie’s story and Kennedy Krieger’s neurobehavioral program.
Fifteen-year-old Kokayi Thomas had always been healthy and athletic, until last November when he started complaining of weakness in his right arm and leg. After a visit to the pediatrician, a battery of tests, and an MRI, Kokayi and his parents were shocked to hear the diagnosis: Kokayi had a brain tumor. Although considered low-grade, the tumor—pilocytic astrocytoma—was located on his brain stem. “In that one moment, with those few words, our world turned upside down,” recalls Kokayi’s mother, Debra Jeter-Thomas.

Kokayi underwent a suboccipital craniotomy to remove the tumor. The surgery was successful, but because the cerebellum was affected, Kokayi experienced a lack of muscle coordination and could not walk. He had increased weakness on his right side, and tremors. On top of that, he lost the ability to swallow effectively, had difficulty speaking, and experienced blurry vision.
The View from the Top

At Kennedy Krieger’s inpatient rehabilitation unit, Kokayi underwent intense therapy, including physical, occupational, and speech, and steadily made progress. Soon, he was stable enough to be transferred to the Specialized Transition Program, the Institute’s day hospital program.

When physical therapist Katlyn Recchia first began working with Kokayi, he couldn’t walk without assistance or navigate his wheelchair, but he was determined to recover. Recchia told Kokayi that eventually, he would be able to walk to the top of the stairs at Kennedy Krieger and see the harbor. Two weeks later, they tried two flights of stairs, but Kokayi surprised her by saying, “We’re doing all four. I’m going to look at that water.”

“Kokayi has a great attitude, which is half the battle,” says Recchia. “He’ll say, ‘I don’t necessarily want to do this today, but I know I have to. I want to get better.’ You can’t ask for more out of a patient.”

Each day, Kokayi worked with the therapists on his short-term goals, and when he met those, they set new ones.

Buoyed by Aquatic Therapy

A key part of his regimen was intense therapy in the Institute’s state-of-the-art aquatic therapy pools, equipped with underwater treadmills, video systems, temperature controls, and hydraulic lifts that allow the floors to be raised and lowered for easy access by patients in wheelchairs.

Perhaps what’s best about aquatic therapy is the independence and freedom that comes from escaping the limitations of gravity, allowing patients to do more in the pool than is possible on land and achieve their therapeutic goals more quickly.

“With the underwater treadmill, Kokayi gets thirty minutes of cardiovascular activity using the natural resistance and buoyancy of water,” says Recchia. The pool’s multiple jets can increase this resistance, helping build muscle strength and coordination. And a video screen shows patients a view of their leg and foot placement from the underwater cameras as they walk, helping retrain a proper gait pattern while maintaining good posture alignment.

“When you combine all that, it’s a very efficient therapy session,” explains Recchia.

The Art of Rehabilitation

These days, Kokayi is able to walk short distances and climb stairs, and is much more independent with his wheelchair. His parents attribute his success to Kennedy Krieger’s ability to bring together the science of rehabilitation technology with therapists who know how to motivate patients. As Kokayi’s father explains, “It’s sheer art plus science.”

Kokayi’s parents credit the staff for helping him stay motivated. “Kokayi had a very talented and skilled group of inpatient and outpatient therapists who worked with him,” says his father, Dr. Duane Thomas. “The staff made Kennedy Krieger a home away from home. I can’t even put into words all the things they did on his behalf. Without their encouragement and dedication, he could not have made the progress he made.”

With the assistance of educational specialists at the Institute, Kokayi returned to school in the fall with all the needed services in place.

“I’m just so proud of him,” says his mom, Debra Jeter-Thomas. “I don’t know too many people who can go through a trauma like this and maintain that motivation. He never gave up.”

Kokayi still has goals he would like to achieve and will continue to work hard in outpatient therapy to achieve his potential. “He’s fought his way back, and he’s still fighting,” says his father. For Kokayi, the challenges he has faced from his brain tumor are mere stepping stones. —Kristina Rolfes

Visit potentialmag.kennedykrieger.org/Kokayi to learn more about Kokayi’s story and Kennedy Krieger’s brain injury program.

“This is not going to be my life. This is not going to be the new normal. This is temporary.”

—Kokayi Thomas
OPERATION

SAVE MEGAN

A MILITARY FAMILY’S QUEST FOR THEIR DAUGHTER’S CARE
With her big bright eyes, auburn curls, and contagious giggle, 6-year-old Megan Miceli is truly one in a million. You could even say she’s one in a billion—Megan has a genetic disorder so rare that only a handful of cases have been reported in the world. Since she was a baby, she has been under the care of neurologists at Kennedy Krieger who, after extensive genomic testing, diagnosed her with gene microdeletion 15q13.3.

This tiny piece of chromosome missing from her DNA affects nearly every aspect of her life. Megan’s medical problems are complex—aside from having low muscle tone, needing a feeding tube, and being unable to talk, she has suffered frequent seizure-like episodes that cause temporary paralysis on the left side of her body.

Despite these challenges, Megan made great progress under the care of Drs. Ali Fatemi and Alec Hoon, and physical therapist Megha Patel. As a toddler, Megan began gaining skills like sitting up and cruising along furniture, and after months of physical therapy, she took her first steps unassisted. Genetic counselors at the Institute worked with the family so they could understand what to expect with this complex disorder as she got older.

The Micelis had eased into a confidence about Megan’s care, knowing that she was in good hands at Kennedy Krieger. But when Megan’s father, Nick, who is in the army, received a reassignment to Ohio, the family began to worry.

**AN UNEXPECTED SETBACK**

Nick recalls the concern they had about his military relocation to Ohio, hundreds of miles from Kennedy Krieger. “You wonder if she will get the same high quality care, attention to detail, and compassion we received at Kennedy Krieger...You know deep down that it is impossible to replicate.”

As it turned out, their fears were not unwarranted. After the family moved to Ohio, Megan acquired mastoiditis—a serious infection of a bone behind the ear—and became very sick. After that, she declined to the point where she couldn’t even sit up.

Her new doctors in Ohio had never seen a disorder like Megan’s, and since her case was so complex, they didn’t know how to treat her. To make matters worse, Amie was not able to get Megan physical therapy appointments, and she felt like the doctors weren’t listening to her. Megan was in and out of the hospital for eight months, suffering from seizures and not getting the treatment she needed. >>
Since returning to Kennedy Krieger, Megan’s seizure-like episodes have stopped, and she has learned to walk with a walker and take steps unassisted.

**OPERATION SAVE MEGAN**

Through it all, Dr. Fatemi stayed in touch with the Micelis about Megan’s care. Amie had a hard time getting Megan’s new doctors to talk to her, but when she called Dr. Fatemi, he always made time to listen and offer medical advice.

“One of the most important things we can offer, aside from expertise, is being readily available for our patients and families,” says Dr. Fatemi. “That’s one of the main things that makes a difference.”

Worried about Megan’s failing health and determined to get their daughter the care she needed, the Micelis filed a request to the military for a compassionate relocation back to Baltimore so they could be near Kennedy Krieger. Drs. Fatemi and Hoon filled out stacks of paperwork about Megan’s condition as part of the application process. The request went up the military chain of command, and after weeks of waiting, Nick received orders to report back to Baltimore.

“When I got the final approval, I was excited…pumped, really,” says Nick. “Then we emailed Dr. Fatemi and Dr. Hoon and thanked them over and over for what they did for us.”

Back at Kennedy Krieger, Megan was once again under the care of expert neurologists who knew how to treat her. Dr. Fatemi started her on new medications and supplements, and with the help of physical therapy, Megan slowly began progressing again. When she was reunited with her therapist Megha, Megan immediately smiled, grabbed her, and gave her the biggest hug. There was no doubt that Megan was relieved to be back.

“You can see in Megan’s face how comfortable she feels at Kennedy Krieger,” says Patel. “She’s been coming here since she was 6 months old—she knows all the staff here. It’s really great to know that we can work together again to help her progress.”

Megan relearned how to pull up to a stand and walk with a walker, and in September, she took her first steps again during a physical therapy session—six steps, to be exact.

“We were in total shock,” says Amie. “Just out of nowhere she took off!”

She began trying foods for the first time—ice cream is her current favorite—and most importantly, her major seizure episodes stopped.

The Micelis are thrilled with Megan’s progress and grateful to be back at Kennedy Krieger. “Her doctors and therapist are amazing—they are the best of the best!” says Amie. “Without them, I don’t know where we would be.” —Kristina Rolles

Visit potentialmag.kennedykrieger.org/Megan to learn more about Megan’s story and Kennedy Krieger’s neurogenetics program.
Patients with a group of rare degenerative brain diseases known as leukodystrophies have few places to turn for expertise in their medical care. Neurologist Dr. Ali Fatemi and his colleagues hope to change that with the new Moser Center for Leukodystrophies, launched this past December.

Following in the footsteps of the late Kennedy Krieger neurologist Hugo W. Moser, one of the world’s foremost leaders in the field of leukodystrophies, the new center carrying his name offers comprehensive treatment, research, and hope for families struggling with these disorders.

Leukodystrophies, which destroy the protective myelin sheath surrounding the brain’s nerve cells, can affect multiple organ systems, leading to an array of debilitating symptoms such as blindness, deafness, seizures, loss of muscle control, and cognitive decline.

Some leukodystrophies strike in childhood, and many children die within one to ten years of onset of symptoms. Other leukodystrophies have an adult onset. All are progressive diseases, meaning they worsen over time, and there is no cure.

“We want families to know that just because there is no cure doesn’t mean there is no care,” says Dr. Fatemi, who heads the Moser Center. “These patients have a neurological disease, but it also often involves other organ systems,” he says. “We recognize that we need to address all aspects of their care.”

To accomplish this, the center has a team of interdisciplinary specialists—including neurologists, physical therapists, social workers, physical medicine and rehabilitation physicians, urologists, and endocrinologists. Genetic counselors are also on hand to counsel patients and their families about inheritance, prognosis, family planning, and other questions they may have about the disorder. For patients with unknown leukodystrophies, the center also offers an individualized medicine approach using advanced genomic techniques, in addition to the standard tests and MRIs.

Investigators at the Moser Center are actively researching new therapies and drugs aimed at preventing and treating leukodystrophies. >>

“The Center collaborates with other leukodystrophy centers across the country and around the world, helping patients get the treatment they need and seeking funding for the most promising therapies.

“The patients have a neurological disease, but it also often involves other organ systems. We recognize that we need to address all aspects of their care.”

–Dr. Ali Fatemi, Director of the Moser Center for Leukodystrophies
Scientists are exploring cell therapy and stem cell research, brain imaging, and treatment models in mice to search for drugs that reduce very long chain fatty acids, the biomarker for leukodystrophies. If the drugs show improvement in mouse models, permission for clinical trials is sought.

The Center works collaboratively with other leukodystrophy centers across the country and around the world. Working together, leukodystrophy experts can share information that will help patients get the treatment they need and seek funding for the most promising treatments to help those in the leukodystrophy community.

The Lorenzo’s Oil trial, championed by Dr. Moser and made famous by the 1992 movie “Lorenzo’s Oil,” was an encouraging clinical research study conducted at Kennedy Krieger. This trial showed that three-quarters of the presymptomatic boys with adrenoleukodystrophy (ALD) treated with the oil did not develop the devastating neurological symptoms of this disease during childhood.

Scientist Ann Moser, Hugo Moser’s widow, has focused much of her research over the past several years on refining newborn screening that can identify babies with X-linked ALD, which mainly affects boys, and implementing newborn screening for ALD nationally. “The only way to save these boys is to identify them early, before they have the first symptoms of brain disease,” she says.

This past December, the state of New York added ALD newborn screening, resulting in the identification of two positive screens in the first weeks of implementation. With the help of lobbying efforts by parent ALD groups, Moser is hopeful that other states will follow suit.

Asked what her late husband would think of the new center, Moser replied, “I think he would be pleased. He believed strongly not only in providing care to people with leukodystrophies, but in developing new therapies and using the best treatments available for these patients.”

“We know that somewhere there is an answer to this and other disorders—there is hope. We want to see that each child gets the best chance for a healthy, happy, productive life. We want every child’s parents to be able to say... ‘I have a lot of hope—now.’”

—Hugo W. Moser, 1983
How soon should kids return to play after sustaining a concussion? Are they now more vulnerable to future injury or long-term effects on memory, mood, or behavior?

These are the kinds of questions Kennedy Krieger researchers are trying to answer with a new study on traumatic brain injury funded by the National Institutes of Health in partnership with the National Football League (NFL).

With the NFL acknowledging a connection between concussion and long-term neurological problems, more patients are seeking treatment for head injuries that may once have been brushed off. The problem that remains, though, is the lack of an objective tool or test to reliably diagnose a concussion and then also evaluate recovery.

Currently, physicians rely partly on the patient and parents to describe the onset and resolution of symptoms, such as headache, dizziness, feeling off balance, and difficulty thinking or remembering. Doctors also can give a physical exam and cognitive testing immediately after the concussion and during a later follow-up visit, but these results may be misleading.

“Research shows that, even if the child seems back to his active self and is performing at the same level as prior to injury, he may be using more brain resources to do that,” explains Stacy Suskauer, MD, director of Brain Injury Rehabilitation Programs at Kennedy Krieger.

The new study, led by Dr. Suskauer, will investigate whether the body’s own somatosensory system information processing (SSIP) is sensitive to concussion, and whether SSIP can be used as a biomarker for concussion and recovery in youth aged 13-17.

The experiments use a small, portable device that delivers painless vibrations to the fingertips, and the child responds based on what he senses. The child’s perception of the vibrations reflects activity of sensory neurons in the brain, thereby providing a measure of SSIP. Teens are tested within a week of the concussion, and again 3-4 weeks later. The study will also investigate whether changes in SSIP are related to differences in certain brain chemicals after head injury.

“If we have a tool that we can use clinically to better understand when functioning of the brain has actually returned to baseline, it would help to prevent sending a child back to play when the brain is still recovering from concussion and very vulnerable to a second injury,” Dr. Suskauer says.

Researchers also hope that the tool can predict who will recover quickly from concussion and who is at risk for developing late-appearing problems or long-term issues such as progressive brain degeneration.

For more information about this and other research studies at Kennedy Krieger Institute, visit kennedykrieger.org/research.
I remember the moment I knew I would be the first person in my family to attend college. When I was 16, a doctor recommended that I apply to a technical school instead of a four-year college because of my Asperger’s syndrome. I was crushed and broke down in tears. I took red permanent marker and made a giant “X” on his report and threw it away. I decided then and there that I wanted to go to college. I wanted to do better.

I am now a college freshman on scholarship at Bowie State University. I attended high school at Kennedy Krieger, and many teachers helped me get to where I am today. So many teachers made an impact on me. These were not ordinary, everyday teachers. These were teachers who wanted you to make a difference in this world; they wanted you to be unique and to be known on this earth for your true purpose.

Kennedy Krieger improved my work ethic, and taught me how to work smarter. They taught me how to go above and beyond and do the best job I could, to strive for greatness no matter what. They taught me that I had to really work in order to be successful—even if I had to work day and night, work my fingers to the bone. I worked hard, and it paid off. The proudest moment of my life was walking across that stage getting my high school diploma.

When I found out I had won a college scholarship, I was amazed. It showed me that if you really want to make a change and people see that, they will open up their hands and help you. I believe I am continuing to prove that you can achieve anything if you keep going and work hard for it.

Being the first person in my family to attend college means a lot. I believe that by getting a college degree, I will have a better shot of doing great things in my life. For me, it means victory over my circumstances, financial stability, and the ability to give back to my community. Giving back is very important to me, because so many people have given to me.

My advice to others with Asperger’s who may be struggling is to find what you want to do in life and go after it. My dream is to be an entrepreneur and design my own T-shirt line. If your gift is dancing, be the first person with Asperger’s to make it to Broadway. If you’re an artist, be the first person with Asperger’s who designs things for Nike. Even if you want to be the president of the United States—somebody with Asperger’s can be a doctor, a Supreme Court judge, a lawyer, the CEO of Apple, anything. The sky is the limit.

Visit potentialmag.kennedykrieger.org/Makaile to learn more about Makaile’s story and Kennedy Krieger School Programs.
Join the Kennedy Krieger Institute Charity Team in the 2014 Baltimore Running Festival! Whether it’s the Kids Fun Run, 5k, Team Relay, or half or full marathon, we’ve got a space for you! And if you can’t join us in person, you can join the team as a “virtual racer.”

As a member of the Kennedy Krieger team, you can register for free by committing to raise funds for the Institute and our spinal cord injury program. You will also receive additional perks, such as a team Under Armour shirt, breakfast, and access to the hospitality tent.

For more information or to register to join the Kennedy Krieger team, visit kennedykrieger.org/BaltimoreMarathon.

$8 Million Weinberg Gift Will Fund New Outpatient Center

The Harry and Jeanette Weinberg Foundation has chosen to support Kennedy Krieger Institute’s efforts to expand critical services for children with disabilities with a gift of $8 million over five years. The gift will support the construction of a new outpatient facility serving children with neurodevelopmental disorders, and will include group therapy rooms and exam and treatment rooms, and provide a controlled multisensory environment for children with autism. Groundbreaking is planned for next year.

Festival of Trees

NOVEMBER 28 — 30, 2014
MARYLAND STATE FAIRGROUNDS

Celebrating its 25th year, Kennedy Krieger Institute’s Festival of Trees is an exciting three-day, holiday-themed extravaganza that raises funds for research, treatment, education, and community programs at Kennedy Krieger Institute. Event features include more than 700 spectacular holiday trees, wreaths, and gingerbread houses; live entertainment and holiday readings; the SantaLand fun zone for kids; holiday shopping; a silent auction; and much more!

For more event information, call 443-923-7300 or visit festivaloftrees.kennedykrieger.org.

Zombie Run Partnership Helps Kids with Brain Injuries & Disorders at 25 Runs Nationwide

Kennedy Krieger is the national charitable partner of The Zombie Run—a unique series of 5k obstacle races held around the country from March through November.

Participants and teams can support research and care for kids battling brain injuries and disorders nationwide. There are lots of ways you can help, no matter where you live. You can register for a race, build your own fundraising team, sponsor another runner, make a donation, or volunteer. For more information, visit kennedykrieger.org/BRAIN.

Another ROARing Success

Spirits were high at Oregon Ridge Park in Cockeysville, Maryland, where an enthusiastic group of more than 1,000 participants joined together for Kennedy Krieger Institute’s ROAR for Autism event on Sunday, April 27. In its ten years, the annual bike ride, run, walk, and family festival has raised more than $2.3 million to support autism programs at Kennedy Krieger. To learn more, visit ROARforAutism.org.

To learn more, get involved, and stay connected, visit kennedykrieger.org/connect.
We are all born with great potential. 
Shouldn’t we all have the chance to achieve it?

Kennedy Krieger Institute is dedicated to helping children and young adults with disorders of the brain, spinal cord, and musculoskeletal system unlock their potential through:

**Patient Care** – Highly trained professionals from various fields and departments collaborate to evaluate patients and create treatment plans tailored to their individual needs throughout all stages of care.

**Research and Professional Training** – Our investigators are leading the way in the prevention and treatment of a wide range of developmental disorders and injuries, and are committed to sharing our knowledge to help others worldwide.

**Special Education** – We offer a number of school, hospital-based, and recreational programs designed to unlock the promise inside our students.

**Community Initiatives** – We are committed to helping individuals with developmental disabilities achieve their potential and enjoy success in community life.

For more information, call **888-554-2080** or visit [kennedykrieger.org](http://kennedykrieger.org).
Successful Regeneration of Human Skeletal Muscle in Mice Enables Accelerated Research in Muscular Dystrophy

Researchers at the Kennedy Krieger Institute recently announced study findings showing the successful development of a humanized preclinical model for facioscapulohumeral muscular dystrophy (FSHD), providing scientists with a much-needed tool to accelerate novel therapeutic research and development.

Published in Human Molecular Genetics, the study outlines the validity of a unique model that, for the first time, mirrors the gene expression and biomarker profile of human FSHD tissue. Previously, there was no accepted preclinical model for FSHD, a complex and rare neuromuscular disorder that affects approximately 4-7 per 100,000 individuals. As a result, therapeutic development for the disorder has been stymied.

Inspired by cancer preclinical models developed with human tumor tissue, Dr. Kathryn Wagner and her research team leveraged both basic science and clinical research resources available at Kennedy Krieger to successfully regenerate grafted muscle within the models. Human biceps muscle biopsies transplanted into models survived for over 41 weeks and retained features of normal and diseased tissue.

To learn more, visit kennedykrieger.org/muscledisorders.

NIH Awards NFL Funds to Institute to Study Concussion Biomarkers

The National Institutes of Health (NIH) announced that a research study at Kennedy Krieger Institute is among eight projects to receive financial support to answer some of the most fundamental questions about traumatic brain injury. Under the direction of principal investigator Stacy Suskauer, MD, director of the Brain Injury Rehabilitation Program at Kennedy Krieger, this new research study will focus on assessing youth sport-related concussion and recovery using a portable device that measures somatosensory system information processing (SSIP) as a possible biomarker. Researchers will also investigate whether changes in SSIP are related to differences in certain brain chemicals after head injury.

Currently, there is no objective tool or test to reliably identify concussions, or to predict who will recover quickly, who will suffer long-term symptoms, and who will develop progressive brain degeneration, called chronic traumatic encephalopathy (CTE).

The study is funded by the NIH in partnership with the National Football League (NFL), which donated $30 million toward research studies on injuries affecting athletes, especially traumatic brain injuries.

For more information about the study, email clarkke@kennedykrieger.org or call 443-923-7987.

Program Spotlight: Program Provides Assessment, Treatment, and Management of Orthopedic Conditions

The Orthopedic Outpatient Clinic at Kennedy Krieger Institute provides interdisciplinary outpatient evaluation, treatment, and comprehensive care for patients from infancy to adolescence with a wide range of developmental disorders, along with congenital, neuromuscular, and post-traumatic problems of the musculoskeletal system.

Our goal is to maximize the functional capacity of children with neuromuscular disorders, and minimize the long-term complications associated with spasticity and growth. In order to develop a customized program, we conduct an initial comprehensive evaluation. A treatment and therapy program will then be designed to maximize functional recovery. Interventions may include:

- Aquatic therapy
- Botox injections to reduce spasticity
- Evaluation of equipment and bracing needs
- Oral and intrathecal baclofen treatment for tone management
- Orthotic and brace fabrication and fitting
- Physical therapy
- Specialized state-of-the-art equipment and techniques, such as mobility training, play therapy, and gait training

Our orthopedic experts combine operative care with intensive post-operative physical therapy to maximize surgical outcomes and rehabilitation benefits. Some of the most common procedures include:

- Contractor releases
- Hand surgery
- Hip reconstructive surgery
- Single event multilevel surgery (SEMLS)
- Spine surgery for deformities

To make a referral, please call our Physician Referral Line at 443-923-9403 or visit referrals.kennedykrieger.org.
PATIENT CARE PROGRAMS & SERVICES

Inpatient Pediatric Programs
Feeding Disorders Unit
Neurobehavioral Unit (NBU)
Rehabilitation Unit—Brain Injury, Pain Rehabilitation, Post-Orthopedic Surgery, and Spinal Cord Injury

Outpatient Centers, Programs, and Services
International Adoption Clinic
Albright Clinic
Aquatic Therapy Program
Assistive Technology Clinic
Audiology Program
Center for Autism and Related Disorders
Barth Syndrome Clinic
Behavior Management Clinic
Bone Disorders Program
Botulinum Toxin Treatment Program
Brachial Plexus Clinic
Interdisciplinary Brain Injury Clinic
Brain Injury Program
 Phelps Center for Cerebral Palsy and Neurodevelopmental Medicine
Child and Family Support Program
Child and Family Therapy Clinic
Community Rehabilitation Program
Neurorehabilitation Concussion Clinic
Constraint-Induced and Bimanual Therapy Program
Cranial Cervical Clinic
Deafness-Related Evaluations Clinic
Center for Development and Learning
Developmental Cognitive Neurology Clinic
Pediatric Developmental Disorders Clinic
Down Syndrome Clinic and Research Center
Family Center
Pediatric Feeding Disorders Program
Fetal Alcohol Spectrum Disorders Program
Focused Interdisciplinary Therapy Program
Fragile X Clinic
Healthy Lifestyles Therapy Program
Center for Holoprosencephaly and Related Malformations
Intrathecal Baclofen Program

Moser Center for Leukodystrophies*
Limb Differences Clinic
Military Behavioral Health Services
Movement Disorders Program
Center for Genetic Muscle Disorders
Neurobehavioral Outpatient Program
Neurology and Developmental Medicine Program
Neurology and Neurogenetics Clinic
Clinical Neurophysiology Clinic
Clinical Neurophysiology Laboratory
Neuropsychology and Developmental Outpatient Clinics
NICU Follow-up Clinic
Nutrition Clinic
Occupational Therapy Clinic
Orthopedic Outpatient Clinic
Osteogenesis Imperfecta Clinic
Pediatric Pain Rehabilitation Program
Physical Therapy Clinic
Psychiatry Clinic
Pediatric Psychology and Consultation Clinic
Pediatric Rehabilitation Clinic
Seating Clinic
Sickle Cell Neurodevelopmental Clinic
Sleep Disorders Clinic and Laboratory
Social Work Outpatient Mental Health Clinic
Specialized Transition Program (STP)
Speech and Language Clinic
Philip A. Keelty Center for Spina Bifida and Related Conditions
International Center for Spinal Cord Injury
Hunter Nelson Sturge-Weber Center
Tuberous Sclerosis Clinic

Continuums of Care
Continuums allow patients to be seen through all stages of care, including 24-hour inpatient programs, day treatment, home- and community-based services, and outpatient programs. They include Pediatric Feeding Disorders, Neurobehavioral Disorders, and Pediatric Rehabilitation (brain injury, pain management, post-orthopedic surgery, spinal cord injury).

*Indicates new programs, clinics, and services.