

# BORN TO RUN

Despite severe autism and catatonia, Jamie Schneider's triumphs have been far greater than his disability.

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."



## 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.



For the Schneider family (above), running has been a way to overcome the difficulties of autism, which affects both Jamie and Alex. "Running is the focus of our lives," says their mother, Robyn. "It's not autism, it's running."

## 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." ■ Kristina Rolfe

Visit [potentialmag.kennedykrieger.org/Jamie](http://potentialmag.kennedykrieger.org/Jamie) to learn more about Jamie's story and Kennedy Krieger's neurobehavioral program.



Jamie (left) and Alex (right) ran their first half marathon in 2009.



(PICTURES LEFT TO RIGHT) 1. Jamie shows off his marathon medals next to his mother, Robyn (left), behavioral intervention specialist Jamie O'Brien (far left), and his Kennedy Krieger team—psychiatrist Dr. Lee Wachtel (right) and consulting psychologist Dr. Dosia Paclawskyj (far right). 2. Jamie (left) and Alex (right) with their running coach Kevin McDermott. 3. Jamie's father, Allan, and marathon coach Katie Raab-Reed ran the Boston 2014 race with Jamie.