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Expressing Themselves, Step by Step

On Marathon day, this family of autistic twin runners deserves cheers



Alex Schneider does everything fast. Hear him pounding on the stairs in his family's New York home and you might fear an earthquake. Watch him wolf down breakfast and you might wonder if he tasted anything. Hear the morning alarm and give him all of 20 minutes to be up, fed, and dressed.

Alex's twin brother, Jamie, is his polar opposite, as deliberate as his sibling is hurried, intent on making things perfect before departing for anywhere.

Yet connected by the biology of shared DNA, they can be so similar, too, deeply aware of each other, feeling the other's presence in a way an outsider could never understand. They are brothers. They are runners. They are brothers who run. They are runners who happen to be brothers. One who runs so hard and so fast he will be at the starting line in Hopkinton Monday for his fifth Boston Marathon, 18th marathon overall. One who has done eight marathons of his own but will be in Boston this time as a spectator. Both under the constant, watchful eyes of their parents, Allan and Robyn.

They are also profoundly autistic.

And from the moment those diagnoses were delivered, when these 27-year-old young men were but 21½-month-old boys, this family of four was thrust into a world of complete unknowns, of deep-dive research and countless doctors, of mounting questions and elusive answers, of the search for anything in the effort to connect two nonverbal, uncommunicative boys to the world around them. That running would emerge as the primary path wasn't something Robyn and Allan Schneider could have predicted, not after trying everything from karate to gymnastics to swimming to piano. But as the devoted, loving, invested parents they vowed to be, they found it to be an activity they have embraced with their hearts, their minds, and yes, even their lungs and their legs.

So as yet another remarkable day of long-distance running takes over the streets of Boston, meet one of the most inspiring families making its way to New England for Patriots Day, and go ahead and save one of your heartiest cheers for them. Because what this family has built around running represents the best of what we can be for our kids, a reminder of the power between physical activity and mental health, a window into a life that might seem so unlike your own, but whose core can be a model for anyone.

"We always introduced them to many other things, karate, gymnastics, and from an early age, we always loved to go to the beach," Allan recalled in a late-evening phone call from their Long Island home, after Alex and Jamie were

asleep, Robyn by his side on speakerphone. “From the time they were very small, we would run with them on the beach. They would chase me. Until their early teens, when they would run past me. That was our first introduction to running, them chasing their parents on the beach. That segued into a special-needs running club.”

Alex was a natural. From the first speedy step, it was apparent he had a gift, one his parents have nurtured with individualized coaching (current coaches are top Long Island runners Boyd Carrington and Sal Nastasi), specially designed training, and specific help with everything from injury checks and road crossings to bathroom stops and nose blowing. As the introduction on their website www.autismrunners.com describes it, “They are both severely autistic. Neither can communicate verbally. They cannot cross the street alone, or be alone at any time. They have very challenging, and at times, self injurious behaviors. They need 24/7 supervision. THEY ARE RUNNERS. And have run in 25 marathons and over 350 races collectively.”

Reading emotions in severely autistic individuals can be nearly impossible, but in running, these parents are certain about what they see.

“We can honestly and comfortably say that for Alex, especially Alex in particular, he really enters a state of Zen,” Robyn said. “He’s completely focused, just has a euphoric look on his face. We love seeing that because we don’t see it very often. We see it when he’s running. Going to a race, sitting so quietly and peacefully in the car — he’s normally high-strung, hyper, his typical state is high anxiety. But on the way to a race, he’s different.”

Jamie benefits in a similar way, even if he took to running in a different fashion, preferring outdoor trails and slower-paced runs with Allan. For the Schneiders, running has truly become a family affair. Allan has used it to stay ahead of a decades-plus diagnosis of multiple sclerosis, bonding with his son while also confounding doctors who expect the debilitating attack on the central nervous system to have affected him much more than it has. Robyn has used it to cope with difficult, painful radiation and chemotherapy treatments for breast cancer, bonding with her sons (she’s known to hop on her bike to keep pace with Alex) while thankfully reaching remission.

“As his father, because of the profoundness of his autism, there’s really very little we can share together,” Allan said. “We can’t share going to baseball games, or doing things that fathers normally do with their sons. Running is probably the only time, I mean I take him shopping and we do things together, but when we’re running, it’s a physical act we’re doing together. It’s probably

the only thing I can do with him [where] we have that camaraderie as doing it as father and son. There's not a lot of talking, but some one-word answers, we share some food. It's like an unspoken thing going on between us that's very hard to put it into words. It's the only aspect of his life that I have any closeness."

A return trip to Boston recalls how that closeness helped Allan guide Jamie through one of the toughest moments of their lives, when the tragic 2013 bombing at the race's finish line split the family in two, keeping them separated for hours. Robyn, who'd met Alex and his running coaches/guides when they'd finished running, was back at the hotel and preparing to meet Allan and Jamie, who was still running. But when the bombs exploded, they were stopped at Mile 22, holed up in a church for hours, cold, hungry, and doing anything imaginable to keep Jamie calm. They got through the day, though a later diagnosis of catatonia necessitated further treatment for Jamie. Running would eventually return, while for Alex, it just kept getting better. A recent personal best (by nearly six minutes) of 2:50:05 at the New York City Marathon has the family excited for what can happen in Boston.

"He's really developed into an amazing runner," Robyn said.

Lucky for him, he's always been part of an amazing family.