

Boston Marathon offers a 'freedom' trail for autistic Schneider brothers

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Challenges can't slow down New York siblings and their family

Marathon

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OLD BETHPAGE, N.Y. — Robyn Schneider will be in Copley Square next Monday at the finish line of the Boston Marathon.

As she waits for her twin sons, Alex and Jamie, to arrive, many thoughts will be racing through her head.

Did they get lost? Did they get hurt? Did they remember to use the bathroom?

Robyn has lived with those types of concerns every day for the past 22 years as the mother of profoundly autistic sons. But those fears are outweighed by her sons' love of running.

So Robyn will wait for Alex, accompanied by coaches Kevin McDermott and Stephen Dalton, and later Jamie, joined by her husband Allan, to cross the finish line, just as they've done in more than 100 races over the past seven years.

"When I'm at the finish line, my heart is pounding because I worry," Robyn said. "I don't want to think the worst, but you can't help but worry."

Born to run

When Alex and Jamie were 17 months old, Robyn was alarmed because they weren't talking.

"My doctor told me, 'Don't worry about it. They were premature and they're boys, so they're a little bit slower,'" Robyn said.

Four months later, Robyn knew something was wrong and asked to see a neurologist.

"It took her about five minutes of observing them and asking me questions, and that's how they were diagnosed," Robyn said. "I didn't even know what autism was. I knew it was bad, but I didn't know what it was. I just said, 'What do I have to do to fix it?'"

The twins received home care as preschoolers. One person who came to their home in Great Neck, N.Y., was Joanne Gerenser, a speech therapist from the autism organization Eden II Programs.

Eden II Programs was based on Staten Island, and when it came time to go to school, the Schneiders were uncomfortable sending their 5-year-old sons on daily hour-long bus rides. Gerenser, who is now the executive director of Eden II Programs, suggested the Schneiders and four other families meet with the board of directors to propose a satellite program on Long Island.

That led to the founding of the Eden II Genesis School in Plainview, N.Y., which provides the necessary care for children with severe autism.

“My boys are really low on the spectrum,” Robyn said. “They are profoundly autistic. They can barely speak and their communication is extremely limited. They’ve had some very severe behaviors, including self-injury and aggression. Managing their behaviors is beyond a full-time job.”

The twins always had boundless levels of energy. They loved running around the beach as toddlers and enthusiastically participate in physical activities, such as horseback riding or basketball.

But nothing captured their attention like running.

Seven years ago, the Schneiders discovered the Rolling Thunder Special Needs Program, a running club based on Long Island. When the twins, then 15, met with a pair of Rolling Thunder coaches at a local park, Robyn feared they might run away during the lap around the park.

“It turned out that they had the talent from the beginning,” Robyn said. “They both loved it. It was just freedom, because they need 24-hour supervision. Just the fact that they could go out and really experience that feeling, they loved it.”

There was only one catch.

“They said they were not able to keep up with Alex,” Robyn said. “So if we wanted to pursue running, we’d have to find somebody that could run fast enough to be with him. That’s when we met Kevin.”

Helping hands (and feet)

McDermott didn’t seriously begin running until 10 years ago when he and his wife, Leslie, were on a mission teaching at a school in Thailand. McDermott decided to join another teacher who was training for the Bangkok Marathon.

McDermott quickly became hooked, running the Bangkok Marathon in 2003 and 2004 before returning to America to raise his two nieces after his sister and her husband died.

While participating in a local 5K road race in 2006, McDermott noticed a group of 40-50 kids from Rolling Thunder running in matching singlets.

“I was amazed at these kids,” McDermott said. “I just got sucked in.”

McDermott began volunteering for Rolling Thunder, and was quickly paired with Alex when the Schneiders joined.

“He went through a bunch of our coaches in the beginning,” McDermott said. “These coaches would try to stay with him and they couldn’t. It just wasn’t working out. I was younger then and in better shape so I got paired up with Alie.”

Before long, McDermott began training Alex individually. McDermott has a flooring business and works his schedule around their three weekly training sessions at Bethpage State Park.

Alex’s speed proved to be a challenge initially.

“I got a sports hernia from literally holding onto him with one hand and trying to run seven-minute miles for 10 miles,” McDermott said.

Alex now follows on McDermott’s heels, which keeps the 54-year-old motivated.

Alex has run four marathons, including Boston in 2011. His personal record is 3:23:22 at the 2012 Hamptons Marathon, which earned him first place in his age group.

It’s difficult to determine Alex’s ceiling because he doesn’t understand pacing or distances.

“He’ll just keep running until you tell him to stop,” Robyn said.

Because of that, McDermott has resisted pushing Alex too hard.

“It’s not a priority for his parents,” McDermott said. “He just enjoys running.”

Dalton, the husband of the twins’ former speech therapist, also helps coach Alex. Dalton will run the entire Boston Marathon with Alex, while McDermott will jump in at West Natick for the final 18 miles.

The trio has formed a cohesive team, but there still are scares.

One day, Alex was doing conditioning runs up and down a bike trail at Bethpage, as he had many times before. For some reason, one time he got to the top and kept running. McDermott raced up the hill, but when he got to the top there was a fork in the trail. He chose the wrong path and couldn’t find Alex.

Allan was running a different route with Jamie when he got a panicked call from Robyn. He quickly herded any runners and bicyclists he passed on the way to search for Alex.

The twins run with ID tags on their wrists and sneakers, but they aren’t fully aware of many daily hazards, so every minute increased the risk of disaster.

“Stepping out in front of a car, you can’t depend that they’re not going to do that,” Allan said.

After a frantic 30-minute search, a bicyclist found Alex not far from where he was originally lost.

“It was probably the most horrific moment we’ve ever had in all the years of running with them,” Allan said.

A family affair

Finding a coach for Jamie was more difficult. The Schneiders tried a number of coaches from Rolling Thunder, but they struggled to identify the signs that a tantrum was building.

The low point came in a 2007 race when Jamie became so upset that he stopped running, jumped and landed with his knees on the pavement. He got up and completed the race, crossing the finish line with blood streaming down both legs.

“Seeing him like that,” Allan said, “I was like, ‘I’m not a runner but I have to somehow get involved here.’”

So Allan, who was diagnosed with multiple sclerosis in 1987, started running. It hasn’t always worked perfectly, but the father has learned to read Jamie’s warning signs.

“It’s like I’m putting out fires a lot of times,” Allan said. “I see him getting worked up so I kind of distract him.”

Allan believes Jamie is capable of a 4:30 marathon, but they expect to finish in about six hours next week. Unlike Alex, who is extremely focused during runs, Jamie enjoys the social aspect of being on the course. His favorite part of the 2011 Marathon was running through the screaming women at Wellesley College.

“He likes to go and shake hands with the people and before you know it, you’re not even looking at your watch anymore,” Allan said. “We’re just doing it as an enjoyable experience.”

Running takes a physical toll on Allan, who recently turned 60. He sometimes has to sleep for half a day to recover from the long runs, but it’s better than the symptoms that flare up when he’s inactive.

Tests show that Allan’s MS is progressing, but he’s coping much better than the first few years after the diagnosis when he could barely walk. Completely worn down by

extreme fatigue then, he was forced to retire as a real-estate broker and to sell his used-car business.

“It’s really been great for us both,” Allan said of running. “Our doctors always tell us, ‘Whatever you’re doing, keep doing it.’”

Robyn, 56, began running in 2008 during chemotherapy treatments for breast cancer that is now in remission.

“I thought I’m just sitting around waiting for them to finish,” Robyn said. “I might as well do something while they’re running.”

A strong finish

The Schneiders always have strived to involve their sons in mainstream activities, whether it was running on the Great Neck South High cross-country team or attending a Pink concert last month.

The twins attend the Genesis day habilitation program for adults Monday-Friday. They are trained in life skills, like grocery shopping, and work jobs that utilize their obsessive-compulsive behaviors, such as sorting packages or collating mail.

The activities provide a necessary respite from the inescapable strain caused by autism.

“It’s been our lives,” Robyn said. “Autism has been the only thing that has been important. The boys come first before anything. We just try to maintain as normal life as we can.”

For the Schneiders, that means Alex, Jamie and Allan will line up in Hopkinton next week alongside 25,000 other runners. Twenty six miles away, Robyn will be waiting.

All of the anxiety that will have built that morning will subside in a moment that is impossible to replicate in any other setting.

“When they come over the finish line? Forget it,” Robyn said. “It’s amazing.”

For more information on the Schneiders, visit www.autismrunners.com ^[1]

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