

# GOING THE DISTANCE

*For these young adult twins on the spectrum, distance running has become a passion and a lifestyle...*

INTERVIEW BY POLLY TOMMEY, AUTISM FILE EDITOR-IN-CHIEF

**R**obyn Schneider is mother to Alex and Jamie, identical twins with autism who are making headlines because of their passion for running. Now 23, the twins have demonstrated remarkable abilities, completing more than 120 races, including six marathons and nine half-marathons. Robyn and her husband Allan got their sons involved in distance running seven years ago as a way to participate in something they seemed naturally suited for that would give them real-world experience and stimulation. Polly Tommey recently had the opportunity to ask Robyn about the inspirational story of her sons' accomplishments.



▲ **THE SCHNEIDER FAMILY**—Left to right, Alex, Allan, Jamie, and Robyn getting ready for a run.

- ▶ **POLLY TOMMEY:** *When did you find out your two boys had autism?*
- ▶ **ROBYN SCHNEIDER:** Alex and Jamie were 21½ months old when we received the “official” diagnosis.
- ▶ **PT:** *Do you believe that they were born with autism, or were they developing typically followed by regression?*
- ▶ **RS:** Both Alex and Jamie were developing normally. By 17 months, we became concerned because of their lack of language, but their pediatrician felt it was due to their premature birth.
- ▶ **PT:** *Can you describe Alex and Jamie? How do they differ from each other?*

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▶ **RS:** Alex and Jamie are identical twins, but they do have differences. Alex is lean and fast at everything he does—especially running. He is more serious and focused on his activities. He is loving and affectionate and loves to keep busy, constantly moving and needing to complete tasks. Jamie is slower and very meticulous. He is very affectionate and loves to hang out and relax, but also loves to do many activities and be active. They both take weekly horseback riding lessons and piano lessons as well.

- ▶ **PT:** *When did they first become interested in running?*
- ▶ **RS:** Alex and Jamie had always been extremely active as young boys. They would run anywhere they could—at the beach and in gym at school. When they were 15, we found out about a running club for children and adults with developmental disabilities called the Rolling Thunder Special Needs Program and that's when we realized not only did they love to run, but it came very naturally to them. They quickly began to run competitively.
- ▶ **PT:** *Besides the health benefits, what do Alex and Jamie get out of*

running and participating in these kinds of events?

- **RS:** The benefits of running are many! Alex and Jamie run three to four times a week, and we run with them. Alex has a running coach because he is so fast, and Jamie runs with his dad and/or me, so we are all enjoying a family activity together.

Running allows my husband and me to have a one-to-one bonding experience with Jamie. We get to cross the finish line together when competing in races and that's a truly beautiful experience that we share with him.

The race events are an exciting and fun experience; it's like a party every time because we're all so exhilarated and high after a race. We're surrounded by feelings of happiness and accomplishment. It also affords all of us the opportunity for socialization with other runners and those in the running community. Alex and Jamie have earned the respect and admiration of so many runners. And they have inspired hundreds of other young adults with autism and developmental disabilities along the way.



With Alex, running has become an obsession. He loves to run more than anything else, and he has become a true competitive athlete, beating his personal record time after time, race after race. For Jamie, he loves the freedom of running as well as the social aspect; running near pretty girls, stopping at the water stops, sipping the water and throwing his cup in the air. And that running has enabled them to be included with their peers.

- **PT:** *People watching the news clips may think you have autism sorted, but parents with children on the spectrum will know the everyday struggles we have. Can you describe what these may be for your family?*

- **RS:** Oh no. We are far from having autism sorted. Both Alex and Jamie have severe anxiety and OCD, they are both non-verbal, and have some very challenging behaviors. We deal with all of this on a daily basis.

Alex has extreme anxiety concerning his ritualistic and obsessive-compulsive behaviors, and the interruption of those behaviors. Examples of these associated behaviors include lining items in a row, straightening and then re-straightening the same items, doing tasks in the same order multiple times, darting, tapping, and stomping. When interrupted during these rituals, he can become self-injurious and aggressive. Alex presents anxiety in many daily situations.

We've successfully ignored some of these behaviors altogether, and then later found further success in replacing those activities or environments in which OCD would be

- ◀ **PART OF THE TEAM**—Mother to twins Alex and Jamie, Robyn enjoys the time she spends with her sons in training for events throughout the year.



- ▲ **CAUMSETT PARK CHAMPIONSHIP RACE**—Jamie competing in the 2012 25K event. He and his brother Alex have earned the respect and admiration of their fellow runners.

more likely to occur. This strategy was effective when implemented during the initial moments when OCD-type behaviors first become evident. By removing precursors or quickly transitioning into another setting, Alex's obsessions and sometimes associated self-injurious or aggressive behaviors were less likely to occur.

Jamie suffers from severe anxiety. In 2011, he was diagnosed with Catatonia-like deterioration that is associated with autism. This neurobiological syndrome is increasingly recognized in 12-17% of adolescents and young adults with autism and encompasses multiple motor, vocal and behavioral symptoms. We believe this first occurred from a stressful event at school that was too overwhelming for him.

Jamie's catatonia presents "freezing" and slowing down many aspects of his life. He engages in tensing of his body



▲ **2013 NEW YORK CITY MARATHON**—Alex beat his personal record in this event with a finish of 3:14:36.

when he is stressed, and scripting when his thoughts get stuck in whatever he is thinking about. If interrupted, Jamie can become self-injurious and aggressive. When Jamie engages in scripting and is hard to redirect, we find it most successful to put him on an activity that he has to concentrate on and then do his relax strategies that involve deep breathing, counting, squeezing his hands, and stretching.

Although Jamie needs structure, that structure needs to remain flexible. He likes to know what is coming next, so we use calendars and schedules quite often. He does well with change as long as we tell him what is happening. He's not a person who needs his life to be filled up every minute by an activity because down time is definitely preferred for him. He enjoys relaxing while listening to his iPod and watching movies.

▶ **PT:** *Are your boys on a special diet? What foods do they eat to keep their energy up with their running?*

▶ **RS:** They eat almost everything, but we stick to healthy foods and a balanced diet. Before a big race we do splurge a bit on carbs.

▶ **PT:** *How often do you all run?*

▶ **RS:** We all run as a family at least three times a week at a local park. During marathon training, we boost it up to at least four days, including running on the treadmill. Alex has a running coach because he is so fast. Jamie runs with either my husband or me.

▶ **PT:** *It is so inspiring watching the footage on the news of their extraordinary achievements. What other events do you have planned and how do you prepare for them?*

▶ **RS:** Their next marathon will be the 2014 Boston Marathon. Alex's running coach sets the training schedule and we follow it meticulously.

▶ **PT:** *The 2013 Boston Marathon must have been very traumatic for Alex and Jamie because of the horrific loss of lives and injuries from the bombings. How did they handle that and have they been able to move on?*

▶ **RS:** Neither of my sons understands what happened at the Boston Marathon. They don't have any concept of what a bomb is, nor how catastrophic the events were.

Alex crossed the finish line just under an hour before the first bomb exploded. He tied his personal record of 3:23:22. We were all ecstatic. I joined him and his running coaches at the family reunion area and stayed awhile to take pictures, and then we went back to our hotel room for a sweatshirt. That's when we heard the first explosion. Alex

wanted to go back outside to the finish line to watch the runners as we always do for every race, and obviously we couldn't, so this was very upsetting to him. However, I'm sure he could sense the tragedy in his own way.

Jamie was still on the course at mile 22 with his dad and another coach. They were taken off the course and brought to a lockdown church where they waited to get word of the events. Jamie was traumatized. He was surrounded by runners who were upset and crying, waiting to hear news of their loved ones and of the events that were unfolding. They were not able to leave that church for hours. By nighttime they were bussed back to our hotel. The events of Boston were the hardest on Jamie. So we started him back slowly, and now he is running well.

▶ **PT:** *Do you have worries about their future?*

▶ **RS:** Yes, every day and every night. It's all consuming. I am so inspired by your advocacy work and intrigued with what you have accomplished. We too are working on developing housing for our sons and others, however, it has been an uphill fight and everyday struggle; but each struggle makes me stronger and more determined.

▶ **PT:** *What advice would you give to parents just starting on the autism journey?*

▶ **RS:** Research all you can and base all your decisions on scientifically and evidence based research. Explore everything you can to make your child's life a happy and functional one. Surround yourself with inspiring, educated people who can help you pave the way on this long and emotional journey. ◀