

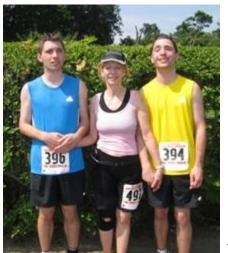
Organization for Autism Research Monthly E-Newsletter

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On the Run It Takes a Village to Keep Up with the Schneiders

Alex (Alie) and Jamie Schneider are identical twins, 21 years old and severely autistic. Neither one of them communicates verbally with the exception of simple words, which can be hard to understand for those who don't know them well. They have found common ground, however, with their peers and others through running. "Through the many years of learning in an intensive, structured ABA program, the idea of inclusion with their peers was only a dream. Running has made that dream a reality," their mother, Robyn Schneider, happily exclaims.



Jamie (left) and Alex (right) Schneider relax with their mom, Robyn Schneider, after a 5K run.

The Schneider family lives on Long Island, N.Y., and was fortunate to find a running club for people with autism, Rolling Thunder. Today, the Schneider sons are celebrities in the running community, notes Robyn who is the coordinator of external and legislative coordinator at Eden II Programs, where the boys go to school. "They have been featured on the front page of the New York Times, Newsday, and the Southampton Press as well as other publications. Placing first or second in their age group is very common and our home is overflowing with the more than 80 trophies, plaques, and medals that adorn every room." Jamie and Alex gained entry and ran in the 2011 Boston Marathon, where Alex finished in four hours and Jamie in six.

Their father, Allan Schneider, a semi-retired real estate broker, used to take them running on the beach and when they were about 13, they began easily surpassing him. "The very first day at Running Thunder, the coaches came to us and told us we must concentrate on their training, because they are very gifted. The boys always loved running and it's become the focal point of their lives," he says.



Alex, Jamie, and Allan Schneider celebrate the completion of the Boston Marathon with volunteer coach Katie Raab-Reed. "Running has changed our family life dramatically. Running is the number one activity for the boys and for us as a family," Robyn adds. She often runs or rides her bike with the boys. "This is so exhilarating for me, as I can share the experience with them."

Robyn and Allan say that Alex and Jamie would not be able to maintain the training and running schedule they do without the help of their volunteer coaches. Alie relies on long-time coach Kevin McDermott and a newer coach, Stephen Dalton, while Jamie trains with his dad and, more recently, Katie Raab-Reed.

They have always been physically active and gifted athletes, Allan says. They began running in races and marathons when they were 15, depending on volunteer coaches to run with them for support and guidance. Jamie and Alex and their coaches will have completed three marathons, once they complete the upcoming Marine Corps Marathon in Washington, D.C., on October 30, which marks their first marathon for OAR. "We're coming up on 100 competitive races that they have done," Allan notes.

For Alie and Jamie, these workouts are not so much work as a lot of fun, says Robyn. "Jamie can run long distances with very little effort, usually singing or vocalizing along the way. He can easily run over six hours and does so with plenty of energy to spare! His happiest runs are when there is a pretty girl (preferably blond, with a swishing ponytail), running near him. He will quickly speed up to run beside her! Alie follows Kevin's instructions precisely. And because running is such a potent reinforcer, he is on his very best behavior."

Kindred Spirits

"Alie came in to Running Thunder with some talent," says McDermott. "After a few months, he was running faster than many of our coaches. They were getting injured trying to stay with Alie. I was the fastest coach in the club at the time so we got paired up."

"We are kindred spirits, both obsessed with running," he explains. He is delighted by Alie's willingness and enthusiasm. "He never balks at a workout, never wants to stop at halfway, even when I ask." In fact, McDermott admits he sneaks in runs between his training sessions with Alex so that he can to stay up with or ahead of him.



Alex Schneider is a step or two ahead of Kevin McDermott, his

McDermott had begun volunteering with Rolling Thunder not too long before the Schneiders brought Alex and Jamie. "The head coach is a character. He saw me at a few races. At one, he pointed at me and said

volunteer coach, during one of their many runs.

you run with her. I ended up running with a young girl in a 5K race." And he's been training and volunteering with Rolling Thunder ever since.

A self-employed floor installer and former missionary, McDermott makes time to train with Alex three days a week. "Alie is not very verbal but he's very smart and understands what I say. I talk to him during runs. He listens to me bellyache but he doesn't do it. When I ask him how he feels, he says 'I feel good."

Dalton, who is originally from Ireland and now works as a bartender in New York City, started coaching Alie with McDermott in 2010. He and his wife, Danielle, have been close friends with the Schneiders for years. "Danielle worked with the twins in their home from the time they were 8 years old until they were 16, providing ABA therapy and subsequently speech therapy for Alex and Jamie. Our families have remained close since then." In fact, his children, Oscar, 4, and Amelia, 2, love coming to races to cheer on Alex and Jamie with homemade signs.

After he ran the Blazing Trails 4-Autism Four-Mile Race, which Robyn coordinates to raise money for the school Alex and Jamie attend, and the Hamptons Half Marathon in 2010, Robyn asked if Dalton would coach Alex and run the Boston Marathon with him. "Training for Boston with Alex and Kevin was such a rewarding experience," Dalton explains. "Over that time, the three of us became such a cohesive unit that running and training together for the future seemed like a natural progression."

Dalton explains that he and McDermott coordinate the training, with "a specific goal in mind, normally choosing our next race and then training with that race date and distance in mind. Whether it's a three-hour plus long-distance run or intense one-milespeed workouts, Alex is a serious athlete almost always placing in the top three of his age group in the races he runs.

"The beginning of the race is the most challenging when running together. The crowded starting line is typically filled with runners focused on getting out in front and getting a good start to their race. This can be distracting for Alex and it is the coach's job to make sure he does not get jostled around or trips. Other responsibilities in general when running with Alex include, keeping him aware of his surroundings, such as avoiding large water puddles, ice patches, snow, etc.; being mindful of crowding on the course; and reminding him to watch where he is going," Dalton explains.



Volunteer coaches James Kennedy (left) and Stephen Dalton (right) join Alex Schneider in a happy grin after the Boston Marathon.

"Alex is a very talented runner with a seemingly unlimited resource of untapped potential," he says. "It is exciting and challenging to run with him and to help him reach his full potential."

Gifted with Athleticism

Allan and Raab-Reed are Jamie's coaches. "I was in good shape, but I was never a runner, until a pivotal race that Jamie was in," says Allan. "I was on the sidelines at the finish line and saw Jamie fall over the finish line, with his knees skinned up and bleeding. He had thrown himself to the ground during the race because something upset him. That's when I decided I needed to get involved. He had great coaches but I felt as his parent, I could address the behavioral issues."

Even then, it didn't immediately get better, Allan notes. "Right off the bat, I had issues. He was still very erratic, but I learned how to sense and deflect any difficult behavior. Now, we've had three years of pretty well-managed behavior. He's had to slow down a little so I could keep up with him, but he is also a happier runner. He still gets nervous sometimes, but generally he does just fine." Allan has run a couple of marathons with Jamie since he first began coaching him.

Raab-Reed, who also runs with Jamie, was placed in the twins' classroom in December 2005 at the Genesis school as a teacher's assistant and shortly after began working in their home program as a behavior

specialist. "It is an absolute pleasure to work with the boys and both Allan and Robyn are very welcoming to all of their teachers."

"Not only is Jamie athletic," notes Raab-Reed, "but he has a love for art and projects that involve intricate shapes and patterns. He sees colors differently than I do and I'm always amazed how he pairs colors together and just makes it work. Jamie also has a love for music and will sometimes break out into song and dance to express how happy it makes him. Working with him can bring a smile to your face in an instant."

About a month and a half before the Boston Marathon, the Schneiders asked Raab-Reed to run with Jamie and Allan during the second half of the marathon. "I began training with Allan and Jamie the following weekend. The Schneider family had inspired me to take up running again after many years of absence to the sport so I was ecstatic to be a part of Jamie's second marathon. I am so proud of these boys; running is hard work and their love for the sport shines through the second they start moving."

Jamie's needs determine the coaching methods, Allan says. "I'm not a coach I'm a parent who took up running. I throw in everything but the kitchen sink. Jamie's behavior can be erratic so I make decisions as we go. For instance, if his behavior starts to become difficult, I will change our pace or shoot off on a different trail or start a conversation to get his attention onto something else."

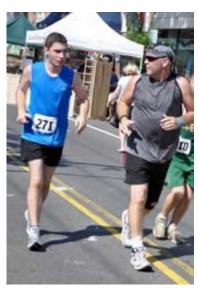
Raab-Reed follows Allan's lead since he and Jamie have established a working routine. "I only get to join in on the weekends for the long runs so I am lucky to spend several hours running on the trails with them. Basically I feel out Jamie's mood, sometimes he wants to be the leader and other times he'd rather run next to you. There's been a few times when both have us have been pushing each other's pace, making the other one work hard to keep up, and it almost turns into a game of tag. Jamie is definitely tuned into his body and knows when to turn down the heat for a walk break."

Gifted with athleticism, running the Boston Marathon was a breeze for Jamie, Raab-Reed notes with a smile. "He sailed through the entire Boston Marathon as if it were only a 5k. He has an incredible amount of energy in his stride and when he hit those hills in Newton, he charged up them without breaking a sweat."

On the Go

While it's meant sacrifice for Allan and Robyn, overall, it's been a great gift for the boys to have running to concentrate on. They are almost constantly on the go, no matter the weather, meaning that Allan or one of their volunteer coaches has to be ready to go with them. "We've can't just sit them in front of the television. If they aren't running, they are walking or biking in any weather under any conditions," says Allan. The Schneiders set up a gym in their basement to give themselves and boys a place indoors to train. Even so, Allan notes, it's a lot of work for him to coach Jamie and for his wife to manage their volunteer coaches and training schedule.

"We haven't imposed any of this on them," he notes, "They have such a love for it and we just feed that." In fact, he says that he and Robyn would not be able to keep up with the boys' love for physical activity if it weren't for the volunteers who run with the boys. "So many people have helped us, the volunteers and other club members and runners. It's become our social life."



Jamie Schneider keeps pace with his dad, Allan Schneider, as they start a run.

"It's good for them and good for us and we've had incredible health benefits and the opportunity to get to know an incredible group of people who support the boys," says Allan.