

# Family PORTRAIT

Jon Schwartz works in corporate communications for a consumer products company in Connecticut. He coaches high school hockey and is involved in a program open to children with a variety of disabilities. He is married to Danielle, and has a golden retriever named Sofia.

**TSA:** The impact of TS varies from person to person. What has been the biggest impact of TS on your life?

**Jon Schwartz:** I think I've been able to take quite a bit away from my experience with TS. Up until recently, I hadn't talked about it, even to people who are close to me. I've been thankful that I did have it, thankful that it made me stronger, more tolerant and more patient. I think you are automatically more tolerant when you've been through something—now I can relate to the kids with disabilities and their parents who I meet as a coach.

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Socially, I think there was an impact. It was a confidence issue. Everybody struggles with self confidence. The plus side is what I've taken away from the experience. I use what I learned as a kid with TS to deal with situations as an adult.

**TSA:** What was it like when you were a child? Did you have any role models?

**JS:** I was diagnosed at eight when I was in the third grade. By the end of high school, it subsided. I had it pretty good, considering . . . We were at a different point in understanding TS then, still learning about it. Then there was only one doctor in this area who was recognizing TS and diagnosing it. I had no role models at all. And, just like now, the way TS was portrayed in the media was limited.

**TSA:** How did your family cope?

**JS:** They were very supportive and active in getting my diagnosis. In fact, they were very proactive, documenting all of my tics (two dozen tics verbal and physical), keeping journals and doing research. My parents subscribed to all sorts of publications and monitored my behavior. That certainly helped me really understand what we were dealing with. I have a brother who is five years younger than me, he didn't do much teasing. I'm the older brother—teasing was my job.

**TSA:** Some kids withdraw, some discover a special outlet, others have symptoms that require medication—what worked for you?

**JS:** I tried medication, therapy, hypnosis, bio-feedback, even a mood ring. Then I found hockey—or hockey found me. I think it helped me overcome TS. It was something to focus on, something that I was good at. I wasn't outstanding at the other things I tried. I played baseball too, but I was the guy benched during practice. They put me in right field! My defining baseball moment was when I begged to try out for pitcher. I pitched to the catcher and, in the middle of my tic rotation, the catcher sends the ball back to me and hits me in the nose. I kept it up as

long as I could, but . . .

At that point in northern New Jersey hockey wasn't on anybody's radar screen. Only one or two people in my town played the game. It was something unique that I could call my own. I was different and the sport was different. Hockey was something I was good at.

I played hockey in high school and in college too. I'm 29 and I still play. And I coach high school and in a special hockey program. The athletes range in age from five to sixteen. We're approaching 30 players now and we began the year with six. The disabilities range in severity from highly functioning players who also do conventional hockey programs to new ones that are just learning to skate and are non-verbal. There's autism, Aspergers, a couple of kids with Down Syndrome, ADD, and ADHD seems to be a common denominator.

Everybody plays, everybody participates. If they can't communicate, we figure out a way to make it work. We get them out there and moving, even in the right direction! I knew I wanted to get involved with this as soon as I heard about it.

**TSA:** Stress has a big impact on people with TS. Do you do anything to help alleviate your stress?

**JS:** Hockey. Outside of hockey it's racquetball.

**TSA:** TS is in the media a great deal lately. Some of the presentations are more realistic and more positive than others. What do you think of the role of the media in increasing awareness?

**JS:** Awareness has not evolved in the media. I'm frustrated. Every time you see TS in the media it's associated with cursing. A couple of made for TV movies have addressed it, but I'm shocked by the amount of research and education in the last 20 years and that's made no difference to the media. Autism is portrayed very differently than it was when *Rain Man* was made, TS has not really caught up yet.

At this point I'm not sure that the general media feels responsibility for educating the masses about TS. There's too much else on their plate. I think that if it was ever done right, TS would get its fifteen minutes—but to date, there's no significant progress.

I also coach a regular high school hockey team and a good percentage of those players would not be interested in learning about TS or any other disability. It's a great reality check to go from that practice to the special hockey program and get an appreciation of how lucky they (the high school players) are.

It would be easier if they came out to a special practice or two. I've invited a couple of them, but not formally. I don't want to be perceived as pushy. They need to volunteer. But everybody's attention span is so short. Everything is about after school activities—me, me, me.

I've noticed a few kids on my regular teams that might have TS. My major concern is that a person is undiagnosed and is being given a hard time, but I don't want to put a kid on the spot or embarrass him.

**TSA:** Do you have any advice for the parents of kids with TS? And for the kids themselves?

**JS:** I'm not in a position of giving people advice, but I'd say find something that you're good at, OK at, or could get good at. Something that keeps your attention and that you find interesting. Get your attention off TS and onto that activity. The other thing would be to set little goals for yourself.

