

Family PORTRAIT

Evan Trost graduated from Brandeis University and the Pennsylvania State College of Medicine. He is now a resident in Family Practice at Scottsdale Healthcare, in Arizona.

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

Evan Trost: I think it gave me direction in my career. Part of what I want to do is take care of patients with TS, but not just the disorder, my concern is the well being of the entire person. TS became a model of how I want to approach medicine, that a cough or diabetes or cancer or a broken leg is only one piece of the puzzle. TS gave me the ability to understand the person as a whole and not as a medical condition. That's what led me to family medicine. My experience with having TS gave me a way of looking at all illnesses in general. A person is made up of a lot of things: medical, spiritual, ethical, their job, their morale. It's a holistic approach.

A lot of what it comes down to about how it affects you is who notices it. Diagnosis leads to identification and a lot of people are reluctant to diagnose TS. I guess they're afraid to put a name on something, that there'll be a stigma. But the physician is obligated to identify it. And identification is not really bad. We identify and classify all the time, people's conditions, their ethnicity, etc. All those things just make you who you are.

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

ET: I think doctors were my role models. I saw six or seven of them even before I got my diagnosis. The ability to diagnose was pretty cool. Once I saw that I loved science and math, and that I was terrible at reading and English, I knew medicine was for me. I also looked at my father's work ethic. He's the CEO of the Yankees. The combination of the work ethic and science was medicine.

I didn't know any adults with TS—or at least diagnosed TS. My grandfather probably has it worse than I do but was never diagnosed. I knew of Jim Eisenreich

but I didn't know anyone else with TS personally until my sister met someone at summer camp.

TSA: How did your family cope?

ET: We used a lot of humor. When I was in a bad stage we'd up the medicine, in a good stage we'd lower it. Most of the time we'd try to laugh it off. And TS can be funny—as long as the person who is suffering with it can take it with a grain of salt. It doesn't work for everyone, but it worked for me. My sister called me 'tic tock the clock.'

I'd say that my tics were moderate, and I didn't have coprolalia. But I was getting made fun of in school and there were secondary effects—reactive depression and anxiety in school and about going to school. As a kid I didn't realize that kids make fun of everyone—not just me with my tics. So I tried to conceal them.

TSA: Has TS had an impact on other important relationships, and on your education and work?

ET: It has. I have to go about things differently. I have pretty severe OCD as well as TS. I know what affects me and the best way for me to study, to relax, and the best way for me to get things done. Being on call every fourth night means being sleep deprived. I've had to learn to cope with the stress and deal with the tics that come out of that stress.

Part of that is admitting to myself and others that I have TS. People have been understanding and extremely supportive. My roommate in college was a slob and I have OCD. I used to stack his mess! I've gone through medical school and a residency, with facial tics coming out. Sometimes people ask. Other physicians can be very inquisitive. They're curious. It's not negative. I just wind up saying, "Gosh, I'm having a bad night tonight." But I'm better off letting them out, as opposed to suppressing my tics.

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?

ET: Overall the media is doing poorly. After I met a nine-year-old with tics who'd come into the emergency room for a sinus infection, and who's mother had been told by pediatricians and neurologists that he'd "outgrow" them, I was telling another physician that I had TS. And he asked, "Which curses do you shout?" I explained that not everyone has coprolalia, just a minority, he acknowledged that he knew it, but it was his initial comment. It's the most shocking, so it's what the media looks to.

Esquire was planning a story on a person with TS. We were setting it up but they decided against me because I don't have coprolalia. The story was on ten people facing challenges of various conditions. I thought they'd want someone with the most common presentation but coprolalia was part of their criteria. The media overplays the most severe cases. If they actually wanted to do some good, they would have brought out the average, most common TS case and someone might say,—"that looks like my child" and not be afraid of the stigma around it.

TSA: Do you have any advice for kids with TS?

ET: The sky is the limit. You can do whatever you want, be whatever you want, find the different path. The goals and expectations should be no different.

TSA: Tell us about your involvement with TSA.

ET: I'm getting involved with the Arizona Chapter, but once you become a physician other members of a support group no longer look at you the same way. I don't want to step on other physicians' toes. It's a balancing act. I want to do clinical research on kids with TS and why some do well in school, to learn how to predict it.

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2006 Update: Dr. Trost is now a Family Physician practicing in Scottsdale, AZ. He completed his Family Medicine Residency at Scottsdale Healthcare, where in his last year of residency, he served as Chief Resident. He was the 2005 Grobe Award recipient for outstanding 3rd year Family Medicine Resident in Arizona. Currently, Dr. Trost serves as Medical Director for Westchester Care Center and Hospice Inspiris. Additionally, he is on the Tourette Syndrome Association Arizona chapter board and the team physician for Coronado High School. His private practice sees numerous patients with Tourette Syndrome. In his free time, he flies the skies overhead in his Cessna 152.