



New Jersey Center for Tourette Syndrome and Associated Disorders

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For Immediate Release

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Central Jersey Tourette's Syndrome patients educate physicians at Saint Peter's University Hospital

*Grand rounds presentation, sponsored by the New Jersey Center for Tourette Syndrome,
is first of its kind for patient-centered training*

NEW BRUNSWICK – Amanda Silvers has had a lot of experience talking to doctors in her life.

Since being diagnosed with Tourette Syndrome (TS) – an inherited neurological disorder seen in as many as 1 in 100 children, according to the Center for Disease Control – along with Attention Deficit Disorder (ADD) and Obsessive Compulsive Disorder (OCD), when she was 5, Silvers has dealt with plenty of them.



On Thursday, Silvers, 16, spoke to a packed room of 75 more, mostly pediatricians, at Saint Peter's University Hospital as part of the New Jersey Center for Tourette Syndrome & Associated Disorders' (NJCTS) first patient-centered grand rounds training seminar.

Her message, which has been delivered in the past at other, much smaller seminars at Robert Wood Johnson University Medical Center and Jersey Shore Medical Center, was clear: There is a big need for everyone, including doctors, to know more about how to diagnose, treat and react to someone with TS.

"I want the doctors to know what the patients want," said Silvers, a junior at East Brunswick High School who wants to be a physical therapist some day. "I want them to be understanding of patients and their needs. My neurologist focuses on my life, rather than my tics."

Focusing on life is key for Silvers, who told the riveted group of physicians all about how she holds in her tics – uncontrollable motor or vocal movements – while at school and then lets them out at home, causing stress for her loving, supportive family.

Suppression and relaxation techniques have helped, but they only go so far.

"I am still the same person, so I don't want to be singled out," said Silvers, whose tics include skipping, humming and – when she's at home – banging her head against a wall. "I try to make myself as normal as possible."

And that's where doctors can play a pivotal role.

At Thursday's grand rounds, physicians learned first-hand how Silvers and her seminar speaking partner, 21-year-old Steve Lindenbaum of Marlboro, dealt with the experience of initial diagnosis, on quality of life and on encounters with physicians and the health care system.

Facilitating that process was Lori Rockmore, Psy.D, clinical director for the Tourette Syndrome Program at the Graduate School of Applied and Professional Psychology and NJCTS' Tourette Syndrome Clinic, both at Rutgers University.

Following Rockmore's presentation, doctors were offered a chance to pose questions and potential situations about TS and its associated disorders.

Silvers talked at length about how the impact of TS is deep on her family. Lindenbaum, who just graduated from Rider University and is looking for a job as an art teacher, took that sentiment one step further: It's tough on everyone.

"It wasn't until the end of high school and probably college that I didn't care what other people thought and finally told everyone," Lindenbaum said. "Most people were very accepting; others, not so much, but who cares? I like teaching people about it and speaking about it. And I want them (doctors) to have the knowledge to properly diagnose their patients earlier, so they don't just brush it off and say it's something else when it's not."

Dr. William Bernstein, the pediatric residency program director at Saint Peter's, loved the seminar and believes more doctors should take note of such presentations.

"Most doctors are trained in all the different neurologic disorders, including Tourette Syndrome, but there is never enough training," Bernstein said. "There is always more knowledge, more treatments, more awareness that is always necessary."

That's why continuing medical education is important, Bernstein added, a statement with which NJCTS executive director Faith Rice wholeheartedly agrees.

"These presentations the doctor the time and the perspective in an educational setting that they don't have an opportunity to obtain in their busy practices," Rice said. "Tourette Syndrome is still underdiagnosed and early identification is crucial."

Photo Above: From left, Lori Rockmore, clinical director for the Tourette Syndrome Program at the Graduate School of Applied and Professional Psychology at Rutgers; Steven Lindenbaum of Marlboro; and the Silvers family, Barbara, Amanda and David, address a group of pediatric physicians Thursday at Saint Peter's University Hospital as part of the New Jersey Center for Tourette Syndrome's first patient-centered grand rounds training seminar.

More information on patient-centered training is available by calling NJCTS at 908-575-7350 or by visiting www.njcts.org.

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New Jersey Center for Tourette Syndrome and Associated Disorders, Inc.- Collaborative partnerships for the TS community.