

SCITUATE

Teen with Tourette's eager to inform

By **KAITLIN KEANE**
THE PATRIOT LEDGER

At the start of each school year, Alex Parenteau, now a seventh-grader, stands before classmates and teachers to talking about living with Tourette syndrome, a disorder he was diagnosed with when he was 6.

Standing before his peers, Alex debunks myths, answers questions – no, he can't control it and, no, it doesn't hurt – and tries to change perceptions about a disorder that few people fully understand.

He explains that his tics – sudden, repetitive movements or sounds – are caused by a neurobiological disorder.

Alex said being upfront about the disorder has always meant a smoother school year – for him and his peers. Now

he's ready for a bigger audience.

Alex, 14, has been named a youth ambassador for the National Tourette Syndrome Association. The program, started several years ago by a teenager from Long Island, is based on a theory Alex

Learn more

■ For more information about getting a youth ambassador or to watch a sample presentation, visit the National Tourette Syndrome Association Web site.

discovered long ago: kids will listen to kids.

"It's a real person talking about their own life," said his mother, Liliane Larsen. "He can be a help to as many kids as possible and really just remove the

stigma."

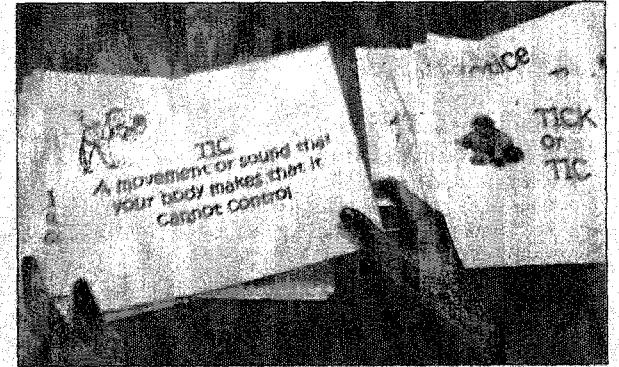
For Alex, who likes to skateboard and wrestle, speaking publicly about his disorder is now second nature.

"Sometimes it's new (information) and sometimes people have heard about it," said Alex, who stresses the need for compassion in his presentations.



AMELIA KUNHARDT PHOTOS/THE PATRIOT LEDGER

■ Alex Parenteau, 14, has been named a youth ambassador for the National Tourette Syndrome Association.



■ Alex shows some of the flash cards he uses in presentations.

"If someone had asthma, you wouldn't laugh because they have to use an inhaler," he said. "It's no different."

Last week, Alex completed a three-day training session in the nation's capital, where he met with lawmakers, including U.S. Sen. John Kerry, to discuss living with Tourette syndrome.

The trip gave the ambassadors the tools to give presentations in classrooms and to community groups, and it prepared them to raise awareness for fundraising

and research opportunities.

Alex said he hopes to talk to kids all over the South Shore. His family said the information Alex gives to fellow students could find its way to parents, many of whom know little, if anything, about Tourette syndrome.

"People are really starting to understand what this is," said Jim Larsen, Alex's stepfather. "The sooner you get the answers out there and everyone understands, the sooner everyone can get over it."

Reach Kaitlin Keane at kkeane@ledger.com.