By KATLIN KEANE
THE PATRIOT LEDGER

Teen with Tourette’s eager to inform

Alex Parmesan, 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 discovered long ago: kids will listen to kids.

“Alex is a real person talking about their own life,” said his mother, Liliane Lamia. “He can be a help to as many kids as possible and really just 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 made a smoother school year for him and his peers.

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.

“Anyone can be informed,” he said. 

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

"If someone had autism, 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 Lamia, Alex's stepfather. "The sooner you get the answers out there and everyone understands, the sooner everyone can get over it."