Shayne, 6, left, Joshua, 10, and Ryan Erickson, 9, of Plymouth, play last summer on Plymouth Beach. Joshua and Ryan have been diagnosed with Tourette’s syndrome, a neurological disorder involving recurrent involuntary body movements and vocalizations.

Show on Tourette’s features Sharon boy

By STEPHANIE PETERS
The Patriot Ledger

BOSTON – When Sheri Rader received an e-mail from the Tourette Syndrome Association seeking afflicted children to speak candidly about the disorder, she suggested it to her son Jacob.

The 11-year-old, a fifth-grader at Heights Elementary School in Sharon, was eager to raise awareness about the disorder he’d been living with since age 5.

He had just spoken to his classmates about Tourette’s — why he sometimes made noises or had tics, and how he couldn’t control the behavior — and had received positive, understanding responses.

Being involved with HBO’s documentary “I Have Tourette’s But Tourette’s Doesn’t Have Me” was a way to further national understanding of the disorder, which affects about 200,000 people in the United States alone, Rader said.

“I’m so very proud of him. I thought I was proud just when he would speak to his class,” Rader said. “This got him out of his shell and helped him embrace (Tourette’s).”

Jacob is one of about a dozen children living with Tourette’s who were interviewed for the HBO documentary, which premieres Saturday at 7 p.m.

To celebrate the documentary, the Massachusetts Tourette Syndrome Association will host a special documentary screening from 7 to 11 p.m. at New England Aquarium on Central Wharf in Boston.

Jacob is one of two Massachusetts children featured in the documentary. He will be joined at the screening by 12-year-old Michael D’Ortenzio of Wellesley.

The national attention the documentary is receiving marks the largest awareness campaign by either the national or Massachusetts chapter of the Tourette Syndrome Association, said Dawn Erickson, events coordinator for the Massachusetts chapter and the mother of two boys diagnosed with Tourette’s.

“It’s an awesome documentary because it demystifies and humanizes what it’s like to live Tourette’s,” Erickson said. “It gives voice to them. . . . It features the kids going about their daily life and doing things normal kids do.”

Erickson, a Plymouth resident, describes her own sons, Joshua, 10, and Ryan, 9, as extremely normal — just “happy, athletic, outgoing children.” Many believe people with Tourette’s swear uncontrollably; however, that symptom appears in fewer than 15 percent of afflicted people, according to the national association.

In fact, Tourette’s takes the form of motor and vocal tics in most people, including uncontrollable blinking, head jerking, facial grimacing, throat clearing and tongue clicking.

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