

'Tourette's Doesn't Have Me'

By Rich Harbert
MPG Newspapers

Dawn Erickson noticed the first signs of her family's medical troubles four years ago when her middle son, Ryan, starting blinking while playing with his brothers out in the yard.

She first suspected allergies and when the blinking progressed, she feared a vision problem and made an appointment with the eye doctor.

But Ryan's eyesight tested fine. And then he started making facial grimaces along with head and shoulder shrugs. Specialists eventually diagnosed a neurological disorder.

Within a year, Ryan's big brother, Joshua, started coughing repeatedly. Then he started shrugging his shoulders.

"A familiar pattern emerged," Erickson said.

The Erickson boys are among hundreds of thousands of children in America coping with Tourette syndrome, a physical disorder of the brain that causes involuntary movements and vocalizations. Ryan and Joshua, students at Nathaniel Morton Elementary School, contend with both simple and complex motor and vocal tics.

Ryan, a third grader, blinks, grimaces, shrugs and grunts, though not all at once. Joshua, a fifth grader, snaps his wrist, jerks his neck, coughs and clicks his tongue. The tics wax and wane and change altogether over time. Sometimes they are hardly noticeable. Sometimes, they are bad enough to keep Josh from writing sentences.

Their boys' little brother, Shayne, a first grader at the school, has shown no signs yet of being affected by the disorder. But if he carries the inherited gene, he has a 99 percent chance of developing tics as well.

While the symptoms of the disorder can sometimes be managed with medications, there is no cure for Tourette syndrome. The Ericksons focus more on education.

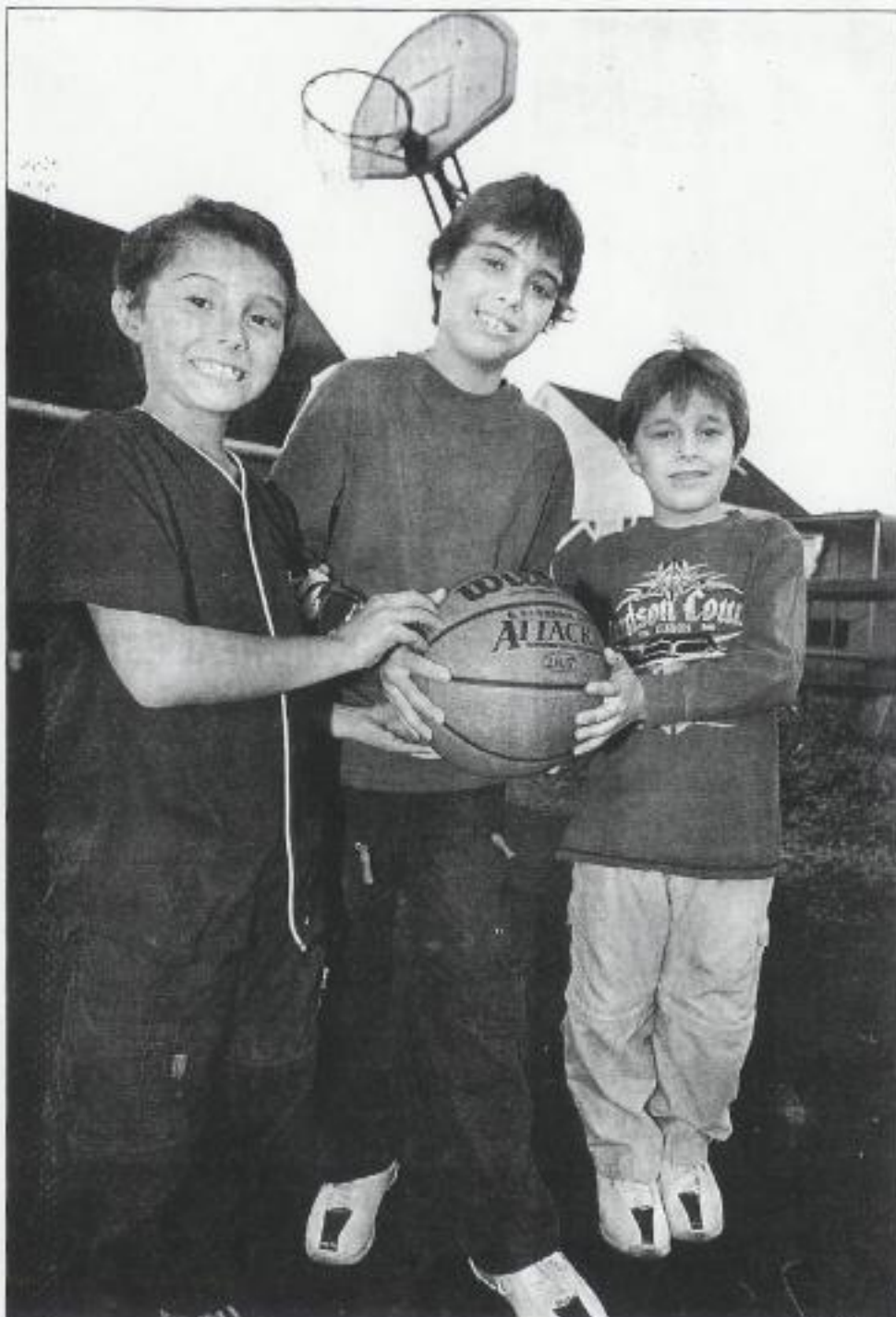
Students in Nathaniel Morton Elementary School may be among the most knowledgeable children in American when it comes to Tourette syndrome. That's because Dawn Erickson presents programs on the disorder to her sons' classes every

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Staff photo/Wesley Ennis

Meeting the challenge – Ryan Erickson and his older brother, Josh, both of whom suffer from Tourette syndrome, ride their bikes in the backyard.



Brothers - Ryan and Josh Erickson, who suffer from Tourette syndrome, pose with their younger brother, Shayne, under their basketball hoop.

'It doesn't make you any different'

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year. Josh helped present the program to his class this year. It starts with a comparison to hiccups.

"You don't plan to have them, you don't want them, you can't really stop them, and they go away when they are good and ready to and not until then," Erickson tells the children.

The boys' ties are the same—unwanted and uncontrollable. And until the boys grow into men, they will likely only get worse.

French neurologist Georges Gilles de la Tourette first described the condition more than a century ago. Roman emperor Claudius, composer Wolfgang Amadeus Mozart and literary scholar Samuel Johnson are thought to have been challenged by tics long before the disorder had its modern name.

Jazz musician Michael Wolff, soccer goalie Tim Howard and baseball players Jim Eisenreich and Mike Johnson are among the more than 200,000 diagnosed with the disorder.

But medical experts believe the number would be considerably higher if people with mild forms of the disorder were tested.

Like many with Tourette syndrome, Jeff Swift only learned that he had the disease as an adult.

An emergency room nurse at Jordan Hospital, Swift noticed he occasionally twitches his head from side to side. He recognized himself in reading about tics associated with the disorder and had his concerns confirmed by visiting a specialist.

"It was kind of a relief, to say that this thing had a name to it and was a benign condition," Swift said.

Swift has since become chairman of the Massachusetts chapter of the Tourette Syndrome Association. He runs bimonthly support groups at the hospital and has found many people learn they have the disorder late in life. Many more will never learn.

"You walk down the street and see people blinking or grimacing but people are embarrassed to talk about it," Swift said.

With his two sons, Swift and Dan and Mark Erickson hope to dispel stereotypes of people with Tourette syndrome. Hollywood has similar, likes to portray an extreme form of the disorder known as coprolalia—people uttering inappropriate words.

Only about 15 percent of people with Tourette syndrome have coprolalia.

The most typical form involves twitches

tics.

Erickson's first Aha Moment came with Ryan's doctor connecting the boy's blinking (a motor tic) with his habit of clearing his throat (a vocal tic). The boy had been driving his family nuts by constantly clearing his throat in the months leading up to his diagnosis.

The Aha Moment for Josh came with the realization the boy's coughs had nothing to do with a cold. Laura Finkel, Josh's second-grade teacher, started noticing facial contortions at the same time. She wondered if fatigue or stress might not be bothering the boy.

Together, mother and teacher arrived at the real problem, long before the actual diagnosis, and set in motion a plan that has seen both Erickson boys through elementary school.

Finkel and Erickson devised a strategy first for Josh and later Ryan in case their tics ever became overwhelming during class. The boys would simply ask to get a drink or use the restroom and then let their bodies loosen up in the hallway.

It helped that the other children in the class had an understanding of what was happening and why. "They noticed it, but once they knew what it was it almost gave them permission not to worry about it," Finkel said. "I think the kids in the class became very educated about it. And as an educator, I learned there is nothing you can do about it. He's got to express those tics. If it's disruptive, we have a system."

The Ericksons helped host a reception last weekend at the New England Aquarium in Boston celebrating the release of the HBO documentary, "I Have Tourette's, But Tourette's Doesn't Have Me." The 30-minute program presents a candid look at children growing up with the condition and explores what it is like to live with the disorder. About 200 people, including two of the children featured in the documentary, attended.

For the boys, the reception offered an opportunity to get together with others coping with tics. They shared laughs—they shared stories. They shared strategies.

Back at home in Plymouth, playing basketball after school in their neighborhood park, the boys relax—the boys seem relaxed and at ease, even with the occasional tic.

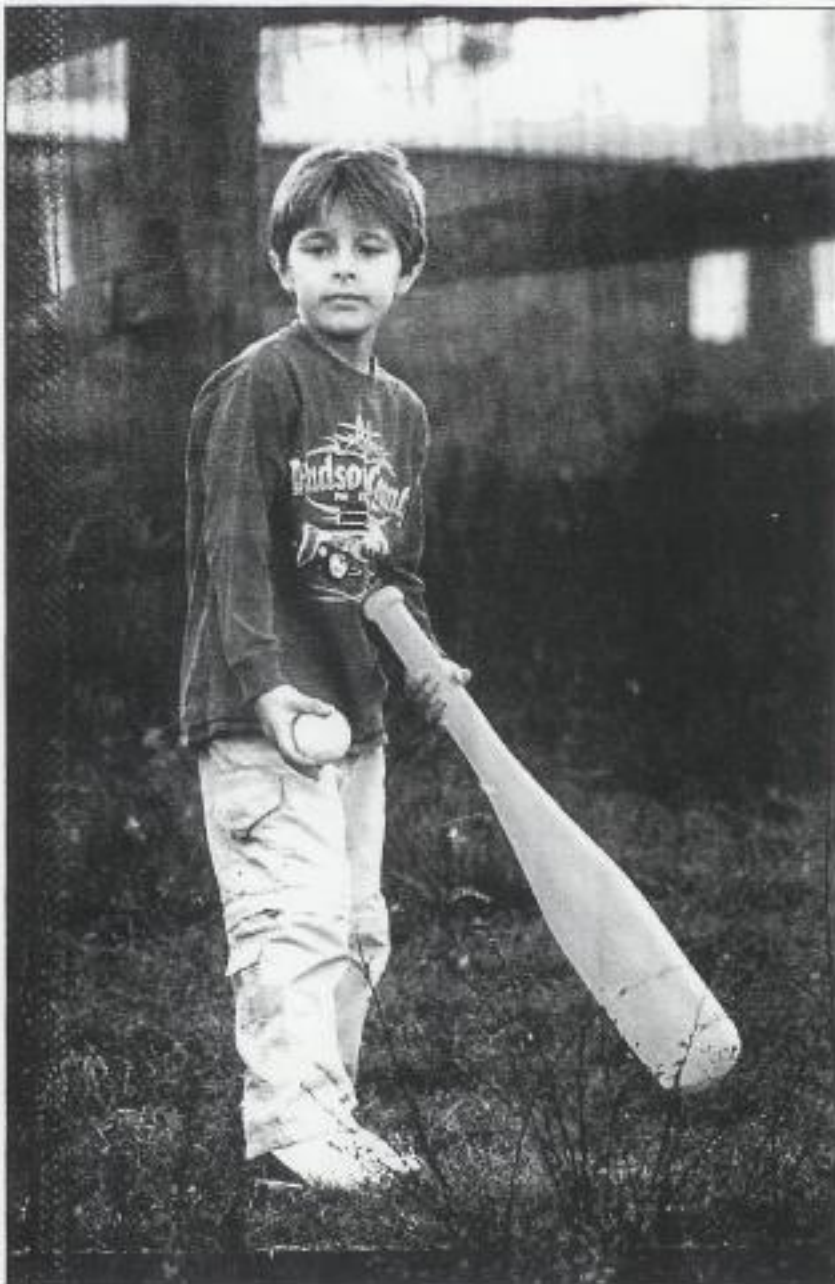
Ryan blinked repeatedly and Josh coughed—rather with a low growl—under the visible lights, but said little at the driveway basketball hoop. Having back and forth conversations with their mother, they are talking

For more information about Tourette syndrome or to learn about local support groups, contact the Massachusetts chapter of the Tourette Syndrome Association at 617-277-7589 or visit their website at www.tsamass.org.

thing there is something broken." And the Aha Moment – the split second when parents realize the annoying little things that their children sometimes do are part of a disorder in the brain, an excess of the chemical dopamine producing street cir-

cling. They want to get to know their disorder isn't contagious and, underneath all the fidgeting, they really are like everyone else.

"It doesn't make you any different," Josh said.



Don't shoot! Mike Ervin

Shayne Erickson, 6, not diagnosed with the disorder his older brothers share, plays with a Wiffle ball in the backyard.



Don't shoot! Mike Ervin

Josh Erickson, 10, shoots hoops with his brothers in their backyard.