

Touring with Tourette's

By Carol Stuart | Posted: Sunday, April 22, 2012 8:00 am

Late last month, during the busiest part of the Orlando theme park season, the Rivere family of Walker toured Disney's Magic Kingdom, Sea World and Legoland, and they never stood in a single line.

"We got some angry looks because none of us are in a wheelchair," Leslie Rivere said. "But we saw everything we wanted to see and I'm so glad they gave us that button."

The button that granted the Riveres that preferential treatment was given by the Sunshine Foundation to Leslie Rivere's youngest son, Brendon, 6, who has Tourette Syndrome.

Other better known foundations grant similar wishes to terminally ill patients, but Tourette Syndrome is not life-threatening. However, unlike many other foundations, the Sunshine Foundation doesn't grant wishes only to children with terminal illnesses, but to any child between the ages of 3 and 18 who is chronically ill, seriously ill, physically challenged or abused.

Tourette Syndrome is chronic and genetic with symptoms of the disorder usually appearing between the ages of 5 and 7. However, Brendon's parents, Leslie and her husband Scott, saw his problems earlier than that because his older brother Mason, 7, had previously been diagnosed with a mild form of autism, so they were more alert to possible problems.

"Brendon started rapid eye blinking when he was 4, and his eyes would kind of roll," Leslie said. "Originally they thought it was a form of autism, but then when he started having jerking tics with his head he was finally diagnosed with Tourette Syndrome."

People with Tourette's cycle through a variety of motor and vocal tics. Brendon has also had his hands flap or shake and has recently started mumbling words over and over while watching television. The tics are more common when he is nervous or even pleasantly excited.

While she was online last year looking for anything that might help Brendon, Leslie came across the Sunshine Foundation and realized that Brendon qualified for a dream wish, so she filled out an application. In response she was asked for a letter from his doctor and a copy of their tax return to demonstrate that Brendon qualified medically and they qualified financially. Shortly after she sent them in, Brendon got a call asking what he wanted.

Brendon's dream was the most commonly requested, a trip to Disney World.

The Sunshine Foundation pays the way for not only the child involved and the child's parents, but for any family members living in the household, so Mason got just as much of a treat as his

brother, undercutting any complaints he might otherwise have made about Brendon getting the lion's share of attention in that family.

Based in New Jersey, the Sunshine Foundation has 14 volunteer chapters, most of them in that state, but some in Colorado, Delaware, Florida, Maryland, Minnesota, Pennsylvania and West Virginia. The chapters hold fundraisers directed to helping specific children. On Sept. 11, the Joan and Jake Miller Memorial Chapter in Williamstown, N.J., held a 33-mile bike-a-thon to raise the money for Brendon's dream.

The Sunshine went beyond his dream of Disney World and paid for airfare, car rental and fuel, lodging, tickets to three major Central Florida attractions and \$500 of spending money.

Because Brendon's dream is so common, The Sunshine Foundation has built a Dream Village in Davenport, a small community 15 miles west of the Orlando parks. A residential resort complex, the Dream Village is equipped with a swimming pool, a handicapped equipped playground, a miniature golf course and nine unique cottages, each with its own childhood theme, from a windmill to the seaside.

The Riveres arrived on Thursday, March 22. Brendon chose the space-themed cottage, because he has become fascinated by space. After a tour of the Houston Space Center at Christmas, he got a space kit with astronaut figures and a space shuttle. At the Dream Village, he and Mason slept in a bed shaped like a rocket ship in a room painted with stars.

"They had putt putt golf, pretty houses, basketball and our bed was a rocket ship," Mason enthused.

"The spaceship bed made a noise like blasting off," Brendon said, "and they gave us a dolphin pillow pet, snacks and a Mickey Mouse."

And that was just the beginning of the fun. The Sunshine Foundation paid for all of the tickets at all three theme parks, and the Riveres spent Friday at Legoland, Saturday in the Magic Kingdom and Sunday at Sea World.

Mason liked all of the parks equally and couldn't decide what he liked best, but Brendon had no problem with that question.

"I liked the Magic Kingdom best," Brendon said, "especially the race cars and the Haunted Mansion."

He also had favorites at the other parks: a boat that "went around and around that I rode with my dad" at Legoland and the Shamu rollercoaster at Sea World.

"I wasn't scared on any ride," he stated with considerable pride.

Both Mason and Brendon are doing fine. They attend Levi Milton Elementary where Mason is in 1st grade and Brendon is in kindergarten.

“Brendon’s teacher, Krista Rippel, is very good with him. She watched a video about Tourette’s and it helped her understand. She is a really good friend,” Leslie said.

Brendon has an IP that accommodates his difficulties to some extent, and they are working on a 504 plan that will allow him other exceptions, including taking extra time on a timed test.

Brendon’s motor tics can interfere with his writing, especially under the stressful conditions of a test.

Brendon plays soccer. Last year he played with the ARC Association at BREC in Baton Rouge for players both with and without disabilities. This year he’s playing with the Livingston Parish Soccer Association on Team U6 with Josie David.

Mason is a year older and is looking forward to playing flag football in October of this year.

“They are for the most part inseparable,” Leslie said. “But they are brothers and you know the brother thing.”

To see Brendon in action, visit <http://watch.thirteen.org/video/2135738235>, a documentary called “Different is the New Normal,” about a teen living with Tourette Syndrome. It includes clips of children living with Tourette’s, including a couple of clips of Brendon and an interview with James Durbin, 22, a finalist in the 10th season of American Idol who has Tourette’s.

To learn more about the Sunshine Foundation, visit sunshinefoundation.org. For more about Tourette Syndrome, call 888-4-TOURET or visit tsa-usa.org.

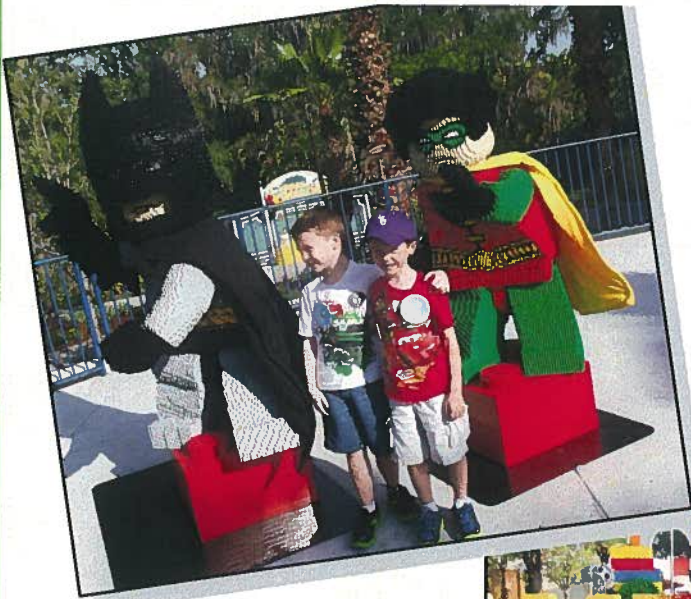


All Volunteer Joan 'Jake' Miller Memorial Chapter's Annual Bike-A-Thon Answers Brendon's Dream!



Sponsored by:
Library IV

Sunshine Foundation
Love, Brendon River Jon



Brendon is 6 years old and has Tourette's syndrome.

