

## Son's rare neurological disorder prompts family to launch group

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**W**hat would you do if your healthy, happy toddler suddenly started crying, jerking, couldn't eat, frequently fell and their eyes twitched?

When these symptoms happened to Chase Brosnan, then 18 months old, parents Brenda and Brendan Brosnan took him to the hospital.

"We knew something was wrong, we just didn't know what," said Brenda, 40, of Rochester Hills and a partner at Golden Mortgage Corporation in Bloomfield Hills.

"We took our son Chase to a local emergency room seven times in two weeks. The neurologist ran many tests, but couldn't discover what was wrong. He wanted to start running tests again, but we decided to take Chase for a second opinion."

After a physical exam and history discussion with Chase's parents, Dr. P. Harold Finkle, a partner at the Michigan Institute of Neurological Disorders (MIND) and a detective with the Warren Police Department, diagnosed Chase with Opsoclonus Myoclonus Syndrome (OMS).

"It was scary and a relief at the same time," Brenda said. "It was great to finally discover what was wrong, but the disease sounded terrible."

Since this is such a rare disease — approximately 100 children and 100 adults are diagnosed annually — doctors don't fully understand or agree on treatment and many cases are misdiagnosed, leading to possible permanent brain injury.

Its name describes the disease: "opsoclonus" refers to jiggling eye movements, "myoclonus" is a term for muscle jerks. This is where the name "dancing eyes, dancing feet" originated.

Chase Dakota Brosnan, along with his identical twin brother, Dylan Lake, who does not have OMS, were born healthy babies on Oct. 25, 1999. They began walking at 12 months and were talking dancing, twirling and what Brenda calls their "baby run" like normal toddlers.

"Easter 2001 we noticed Chase's eye started to flicker, right to left," Brenda said. "We almost missed it, it happened so fast. At the same time he started losing his balance."

"Comparing him to his brother Dylan and to what he could do before, we knew something was very wrong."

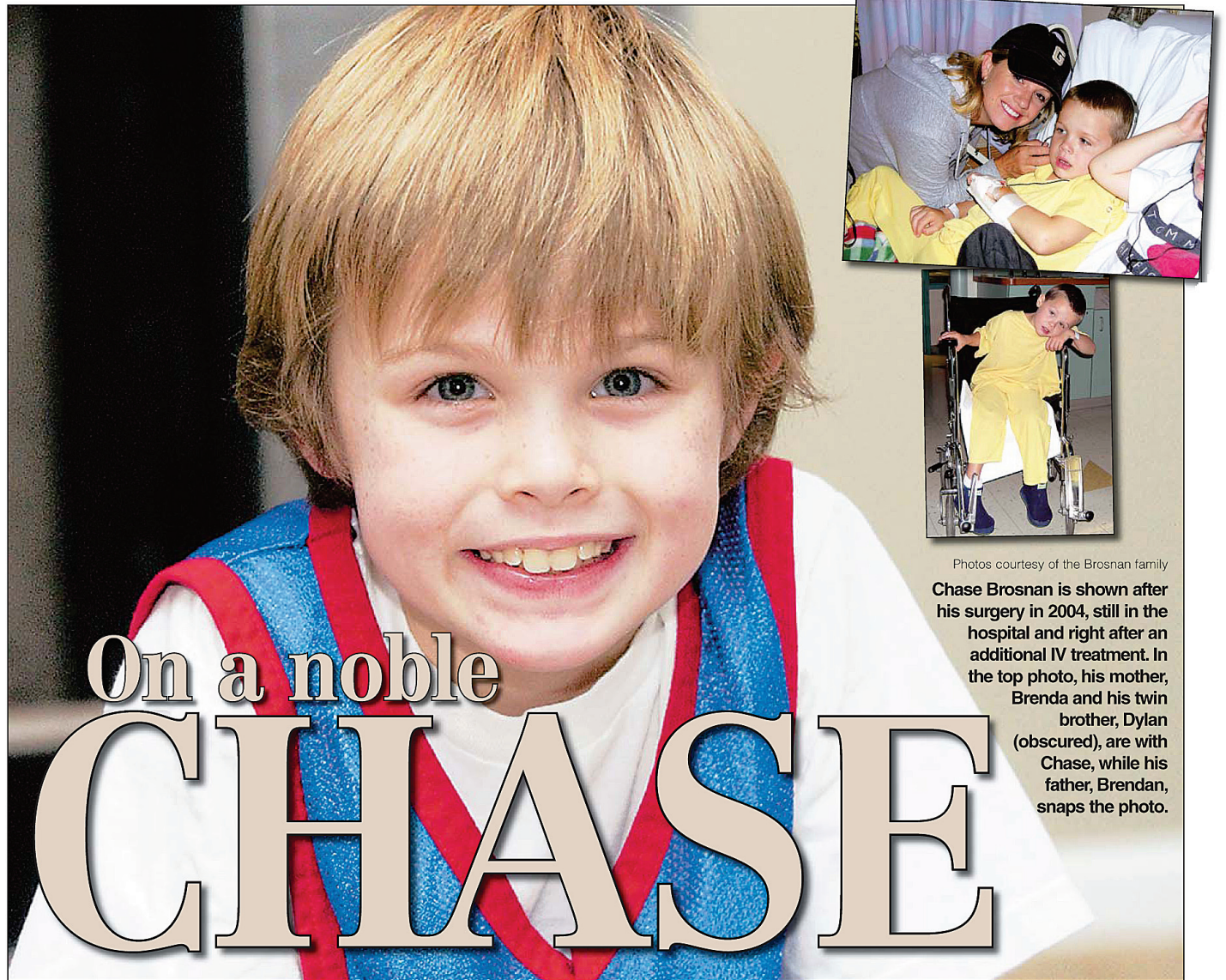
Finally, after 212 weeks of tests and a referral to Finkle, Chase was diagnosed with OMS and referred to Children's Hospital of Detroit, where they drove that same day.

By this time, his motor skills had completely deteriorated so he couldn't walk, talk or eat.

### Cancer, too?

At the same time, a malignant cancer tumor, called a Neuroblastoma, was discovered on Chase's adrenal gland (located on the kidney) from a magnetic resonance imaging (MRI). This tumor is the most common tumor in childhood and is the tumor most often found in OMS. It was discovered early, classified as a Stage 1 at 2.5 centimeters.

One week after OMS was diagnosed and the tumor discovered, and 3 1/2 weeks from the start of symptoms, Chase's tumor was surgically removed. By now, his condition was an absolute invalid unable to do anything except cry. He would remain in the hospital for four weeks to recover.



Photos courtesy of the Brosnan family

Chase Brosnan is shown after his surgery in 2004, still in the hospital and right after an additional IV treatment. In the top photo, his mother, Brenda and his twin brother, Dylan (obscured), are with Chase, while his father, Brendan, snaps the photo.

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**Opsoclonus Myoclonus Syndrome (OMS), also known as Dancing Eyes, Dancing Feet, is a rare and serious disease affecting the brain, involves mostly young children and can start with no warning. Chase Brosnan (above) first exhibited symptoms at 18 months old. After years of treatment, the prognosis for Chase is positive. He and his family have started Chase Away OMS Foundation to help others with their struggles.**

The tumor was gone, but what followed were years of doctor visits and a laundry list of medication, including: daily injections of Adrenocorticotropic Hormone (ACTH) administered by Brenda and Brendan, 39, for more than two years; IV injections of Intra Venous Immune Globulin (IVIg) at CHM every four to six weeks for five years; and chemotherapy and Cellcept.

Dylan also is periodically checked to ensure he remains healthy. Dr. Jeffery Taub, pediatric oncologist at CHM, sees Chase every six months.

"He is a caring doctor, quick to respond to my calls and has overseen Chase's care since we started with CHM," Brenda said.

She pointed out that Dr. Michael Nigro, neurologist and MIND partner, recently retired, was a significant asset to the team of doctors working with the family.

"We think we're done, but we never know for sure" said Brenda.

### Prognosis

Chase had a relapse in 2004 after his Mediport (device implanted under the skin for delivery of medications into the blood system) became infected.

The family travels annually to Springfield, Ill., to the National Pediatric Myoclonus Center, founded in 1985 by Dr. Michael Pranzatelli, attending staff neurologist and professor of pediatrics at Southern Illinois University of Medicine.

"Dr. Pranzatelli has devoted his career and practice to research and finding a cure for OMS," Brenda said. "The doctor performs a special spinal tap to determine if Chase's OMS is active or not. So far, so good."



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Brenda (from left), Chase, Brendan, and Dylan Brosnan playing a board game.

### OMS Foundation

In 2005, Brenda, started a charity called Chase Away OMS to assist families facing childhood cancer challenges.

"We feel so blessed because everything turned out OK for Chase we wanted to do something to give back," she said. "We kept hearing about children that haven't been as lucky. Typically, this disease is discovered later and the cancer can be a stage 3 or 4; the longer between the start of symptoms and treatment, the greater possibility of brain damage."

"Our goals are to support awareness and funds to find a cure for OMS, help support children and their families affected by childhood cancer and to support the Oncology Department at Children's Hospital of Michigan."

The charity has already helped a local Rochester Hills child with a brain stem tumor stranded in Houston after a second opinion. The family was unable to find a flight that would get them home in time for their daughter's medication and allow the child to lie down during the flight.

Brenda, through Chase Away OMS funds, was able to locate and pay for a possibly life-saving flight.

Fund-raising events have included golf outings in 2005 and 2006 at Pine Knob

Country Club and dinner with Mike Babcock, head coach of the Detroit Red Wings, also in 2006, at the Roostertail Restaurant in conjunction with the Jeffrey Thomas Foundation. A Texas Hold 'Em tournament and an annual golf outing at Pine Knob Country Club are planned events for 2007.

### Volunteers needed

The Brosnans, along with Gayle McKnight of Golden Mortgage, are new to fundraising and are doing the task with full-time jobs, no sleep and active children involved in hockey, skiing, tae kwon do, Cub Scouts and biking.

They want to be good parents first, keep their day jobs second and give back through the foundation (in the wee hours of the night, according to Brenda); but they need volunteers. They wish for an administrative (computer) assistant, event coordinator, monetary and fund-raising donations and event sponsors.

To learn more about their cause and ways to help, visit [www.chaseawayoms.org](http://www.chaseawayoms.org) for event details or to give a donation, along with [www.omsusa.org](http://www.omsusa.org) (National Pediatric Myoclonus Center).