

# Girl's nonprofit gets \$100G

■ **Auto Group helps**  
fight rare obesity disorder

■ **ROHHAD Fight Inc. to**  
use gift to promote research

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The nonprofit organization founded for a Bayport girl with a rare obesity disorder will receive its largest single donation today — more than \$100,000 — from Atlantic Auto Group.

ROHHAD Fight Inc., started by the family and friends of Marisa Carney to promote awareness and fund research into the disorder, will be presented with a check at Atlantic Auto Mall in West Islip at 4 p.m.

Marisa, 8, has been living on a portable ventilator since 2011. She is the only person on Long Island to be diagnosed with ROHHAD, an acronym for Rapid-onset Obesity with Hypothalamic Dysfunction, Hypoventilation and Autonomic Dysregulation. She and her family were the subjects of a Newsday three-part series and multimedia project in 2011.

There are about 75 known cases of the incurable, life-threatening condition worldwide. As with many rare diseases and disorders, research is limited and funding is scarce.

"There are research breakthroughs coming and we want to support those breakthroughs," said Michael Brown, co-owner



Marisa Carney, 8, must use a ventilator.

## MARISA'S RARE DISORDER

- Rapid-onset Obesity with Hypothalamic Dysfunction, Hypoventilation and Autonomic Dysregulation, or ROHHAD, is a little-understood childhood brain disorder.
- Extremely rare, with about 75 documented cases worldwide.
- Currently there is no treatment or cure.
- Disorder strikes the hypothalamus, which regulates the activities of the autonomic nervous system, including breathing, body temperature and digestion.

of Atlantic Auto Group. "For us, it is a great way to do something where you can impact someone you can see and touch."

The exact amount of today's donation is \$103,250, representing a portion of the proceeds from November sales of vehicles at the group's 23 Long Island-based dealerships.

Brown, a resident of Fort Salonga, has twin daughters who are Marisa's age. He and his company have supported ROHHAD Fight Inc. since its inception through car shows and silent auction donations. The nonprofit typically raises about \$100,000 annually, mostly from a yearly golf fundraiser.

"This kid is a true inspiration," he said. "To be able to do the things that Marisa does is nothing short of amazing."

Marisa, a third-grader at the Sylvan Avenue School in the Bayport-Blue Point school district, remains active despite her physical disability. She takes dance lessons, is a member of the cheerleading squad at her school and is active in Girl Scouts.

Her disorder affects the hypothalamus — known as the control center of the brain and responsible for regulating the autonomic nervous system, metabolism, breathing, temperature and other involuntary functions.

She is unable to live without the assistance of a ventilator, which she uses to breathe for about 15 to 20 hours each day. Her breathing is particularly threatened when she is asleep.

Her parents bring her to see medical specialists at the Ann & Robert H. Lurie Children's Hospital of Chicago, where Dr. Debra E. Weese-Mayer, a physician who named the disease, is conducting research into the genetic origins of ROHHAD.

More research into the disorder could provide information on conditions such as obesity and Sudden Infant Death Syndrome, or SIDS, which affect the broader population, researchers have said.

"We are so thankful that we at least have a chance to start to begin significant research into this disease," said Marisa's mother, Danielle Carney, 45.