

# An honor for Marisa

■ **Assembly to recognize** LI girl with rare disorder

■ **Family hopes to bring** more awareness to disease

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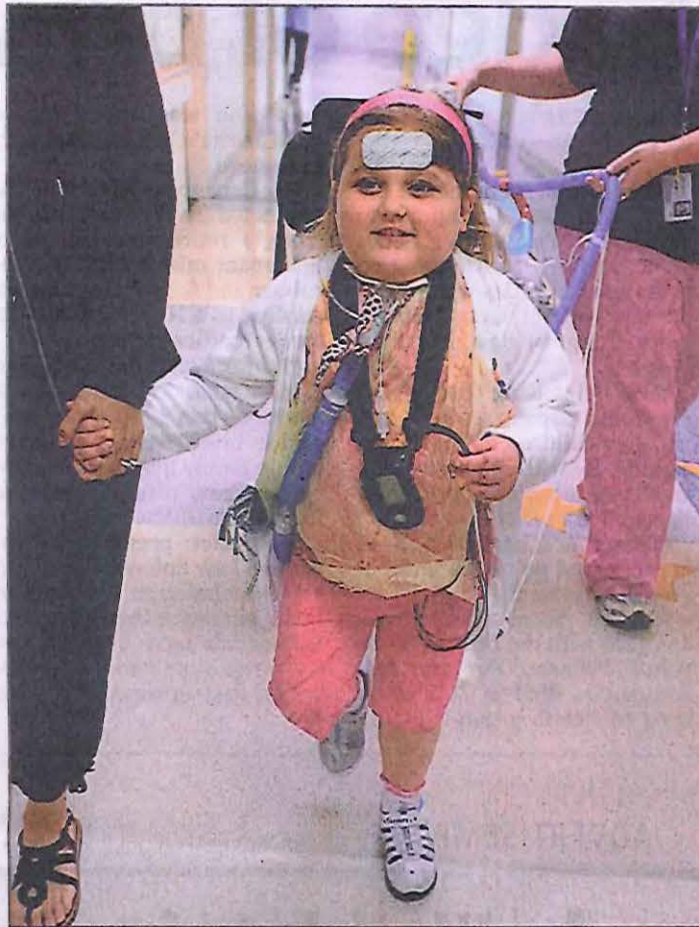
State lawmakers are expected to pass a resolution this week declaring May 2013 ROHHAD Awareness month, honoring a 7-year-old Long Island girl diagnosed with the rare obesity disorder.

Two Suffolk assemblymen, Andrew Garbarino (R-Sayville) and Al Graf (R-Holbrook), are scheduled to present a copy of the resolution to the girl, Marisa Carney of Bayport, this afternoon on the floor of the state Assembly.

"This is something small I can do right now," said Garbarino, who as a political candidate met Carney and her mother last summer at a Bayport library reading event. "Maybe someday it will be one of those rare diseases that will be tested at birth. At least this is a way I can help them bring awareness. You got to start somewhere."

The resolution has the backing of at least 60 of the 150 Assembly members. Sponsors are confident it will have the needed majority to pass.

Carney, a first-grader at the Sylvan Avenue Elementary School, was diagnosed in 2010 with ROHHAD, short for Rapid-onset Obesity with Hypothalamic Dysfunction, Hy-



Marisa Carney said she's "nervous" about visiting the Assembly.

poventilation and Autonomic Dysregulation. The extremely rare and incurable childhood disorder attacks the hypothalamus, the part of the brain that controls bodily functions such as breathing, heartbeat and body temperature.

In 2011, Newsday covered

the disorder and Carney's plight in a three-part series.

"It's a big deal for us to be able to get this kind of recognition and political involvement," said Marisa's mother, Danielle Carney, 43, a lawyer. "Although the disease is rare in itself, if more people understood the



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How Newsday covered the story

cause, it could perhaps give clues into other health issues, like childhood obesity or other breathing problems."

Marisa Carney was 4 when she began rapidly gaining weight. Her breathing began to shut down, and her sodium levels spiked. Since March 2011, she has been using a portable ventilator to help her breathe. She is one of 75 diagnosed cases worldwide.

In a moment of shyness, Marisa Carney said she was "nervous" about going to the state Assembly but glad to bring awareness to ROHHAD.

Friends of the Carney family formed a nonprofit organization, ROHHAD Fight Inc., to raise money for research and to help other families affected by the disorder.

The group's major fundraising event, a golf outing, is scheduled for June 15 at the West Sayville Golf Course. More information is available at rohhadfight.org.

NEWSDAY PHOTO, 2011 / ALEJANDRA VILA



## In her honor

Marisa Carney, 7, of Bayport, and her family, including dad Bill, left, visited the State Assembly, which passed a resolution yesterday declaring May 2013 ROHHAD Awareness Month. Marisa suffers from the rare and incurable childhood disorder that causes breathing problems and rapid weight gain. Suffolk Assemb. Andrew Garbarino, right, and