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EDITION

Newsday

THE LONG ISLAND NEWSPAPER



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CLOUDY WITH RAIN



Good Job, Marisa!

Rare disease can't
keep her from
kindergarten, ballet

A12-15

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NEWSDAY PHOTO / ALEANDRA VILLA

RADING THE TEACHERS

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TOP STORIES



Attached to a ventilator
stop Marisa Carney, 5, in
class at Sylvan Avenue
Elementary School in Bayport.



One of the Gang,

Battling a rare & dangerous disease,

Marisa goes everywhere with a breathing tube & a 50-pound ventilator.

And she fits right in at kindergarten & ballet class.

BY CANDICE FERRETTE | candice.ferrette@newsday.com

Ten little girls in pale-blue leotards and tulle skirts line up by the balance bar, waiting for ballet class to begin.

Some fidget with their soft pink slippers. Others dance with their reflection in the wall-length mirror.

Marisa Carney stands still at the end of the line, her round face a mask of concentration.

The Bayport 5-year-old is eager to fit in, to be like the other girls, but it's hard to ignore the machine humming beside her. Or the plastic tube snaking from the device to her throat.

"And one-two-three . . . one-two-three," the instructor chants as the music starts and the class launches into a short routine. With each twirl,

See **MARISA** on A14



Marisa looks to fit in

MARISA from A13

Marisa must take care to avoid getting tangled in her breathing tube. The ventilator, stuffed inside a pink-and-black wheeled suitcase, follows like a faithful servant, rolling along the gleaming hardwood floor at the Relevé dance studio in Blue Point.

Minutes later, the girls are asked to execute a series of graceful leaps. Marisa waits her turn, her blond hair already wet with sweat. When the time comes, chatty parents suddenly stop to peer through the studio's glass doors. The pressure is on, but she surprises everyone with her athleticism, leaping and skipping like the others. "Good job, Marisa," instructor Jessica Snyder Hambley says.

For an hour one afternoon, Marisa feels like a normal kid, and that's what her parents, Bill and Danielle, are hoping for. Years filled with days like this.

Fourteen months ago, their only child was lithe and petite — a miniature ballerina. Her life changed in an instant. Stricken by an extraordinarily rare childhood brain disorder, she ballooned in weight, suddenly becoming obese. She struggled to breathe, especially at night.

Her condition baffled doctor after doctor until she was tested by experts in Chicago. They confirmed that she suffers from rapid-onset obesity with hypothalamic dysfunction, hypoventilation and autonomic dysregulation. Worldwide, there are 75 documented cases.

No one knows what causes ROHHAD and there is no cure, just testing and constant monitoring. Nearly every night, alarms on the ventilator sound, warning that Marisa's breathing is dangerously shallow. And almost every night, Bill and Danielle lose sleep.

But this afternoon in September is brimming with optimism. This is much more than an after-school activity, Danielle knows. This is a chance for her daughter to prove she can resume an interrupted life.

Marisa began ballet and tap lessons at the studio when she was 3, never missing a class. She was ready for the end-of-



the-year recital a few months after her fourth birthday. Then she became ill. When she should have been dancing on stage, she was in a hospital.

Now, despite the setbacks, she is picking up where she left off.

"It will be so exciting to see what this year's recital outfit will be," Marisa says after class, rubbing her sore feet.

"I'm definitely going to be there this year."

A new beginning

Looking cute and girlie in a pink dress, Marisa stands in the living room posing for first-day-of-kindergarten photos.

"Smile! No, wait! Stand over there and put this on."

Marisa obliges her mother, shifting to another spot. She dons her homemade name-tag necklace, a string of yarn deco-

rated with a paper owl, and resumes her pose.

Danielle, buzzing excitedly about the house, returns with a video camera.

"Say something, Marisa. Tell us how you're feeling today. This isn't for anyone else but you and me to watch when you're older."

For Bill, 43, a golf pro, and Danielle, 42, a labor lawyer, it's a rare moment of faith that their only child will have a future.

Not long ago, they feared their daughter might not make it to kindergarten, but in July, following another round of tests, the couple got some good news. After a year of uncontrollable weight gain, the pace has slowed, Dr. Debra Weese-Mayer, the Chicago specialist in charge of her care, told them.

While Marisa is still consid-

ered obese at 68 pounds and will probably need to maintain a strict diet for the rest of her life, the disorder's most visible symptom is under control.

The breathing difficulties, though, show no signs of easing. Danielle told Weese-Mayer she's worried about her daughter's "psyche" as she lugs around a ventilator in school. How different will she feel?

Marisa needs to believe that one day she will be able to live without the device, the mother said. "I don't want her to think she can't because, eventually, she will."

"We hope so," the doctor replied.

Now, the morning after Labor Day, fears of an uncertain future have been put aside. The Carneys' two-story house is filled with anticipation. A major mile-

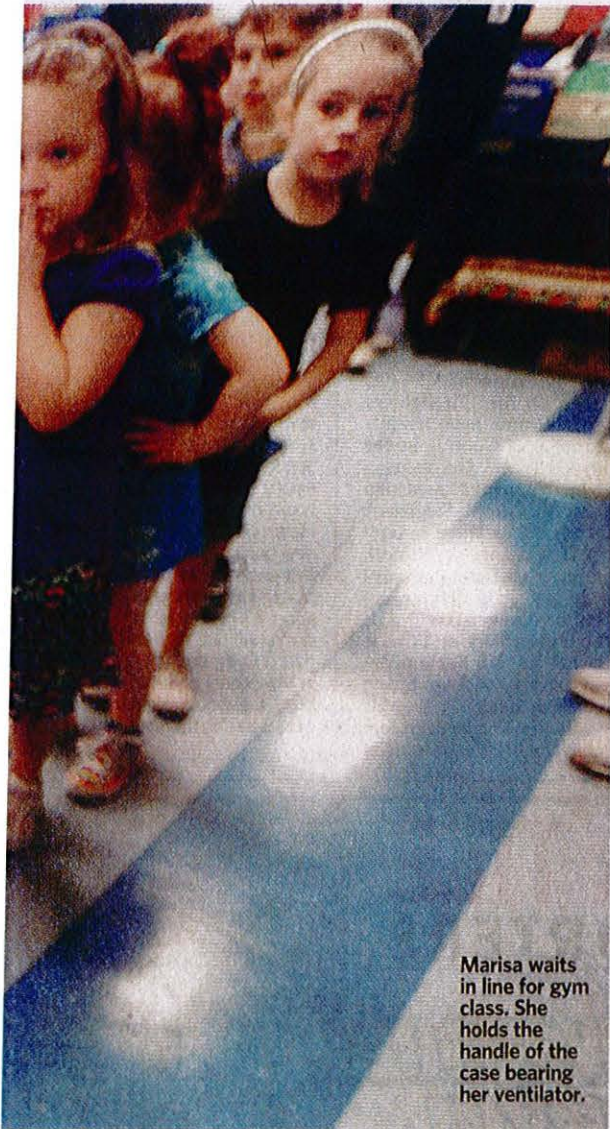
stone is within reach.

Marisa is headed to a mainstream classroom at Sylvan Avenue Elementary, a public school a few blocks from home. The 50-pound ventilator she's nicknamed Venti will accompany her. So will a full-time nurse.

As Danielle shoots video, Bill is in the kitchen briefing the nurse, Chris Hedley, on the breathing machine's power supply. "You got four hours on the one battery, and then you have another four hours on the other battery in the pouch," Bill says.

Sipping coffee from a paper cup, Hedley nods, taking mental notes. The nurse from South Shore Home Health Services is in her uniform: blue pants and a pastel print top.

While Marisa often looks vibrant and happy, she requires skilled care. Her parents have



Marisa waits in line for gym class. She holds the handle of the case bearing her ventilator.

About this series

To chronicle Marisa's struggle, reporter Candice Ferrette and photographer Alejandra Villa have been following the Carney family since March.

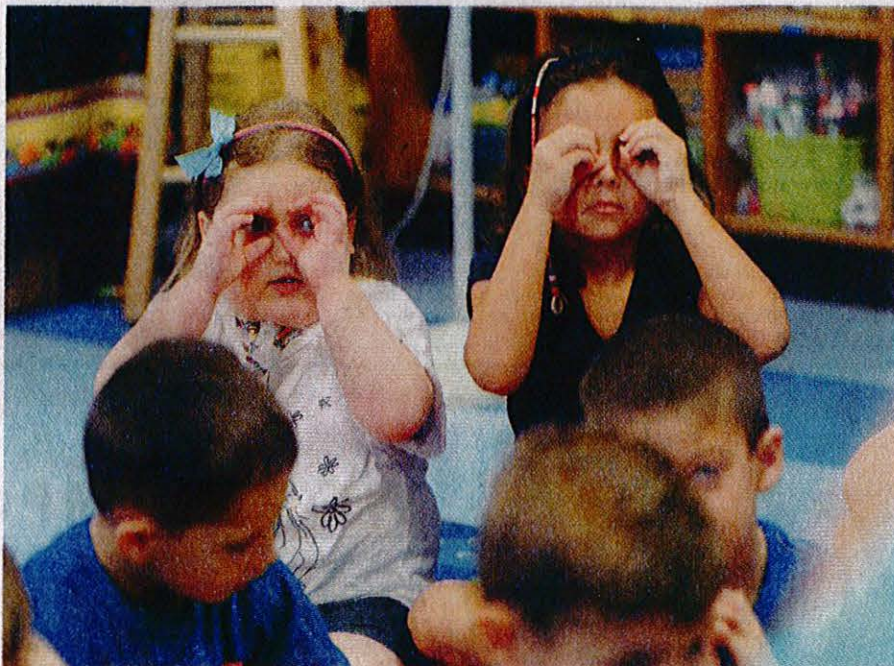


The first installment — **"Marisa: A Little Girl's Fight to Live"** — was published June 19 as a 15-page special report. Read the full story and watch the video online at newsday.com



How to help

ROHHAD Fight Inc., a nonprofit run by Bill and Danielle Carney of Bayport, is raising money for research and to support children with the disorder. To learn more, visit rohhadfight.org



Marisa is in a mainstream class at Sylvan Avenue Elementary, a public school near her home.

NEWSDAY PHOTOS / ALEJANDRA VILLA

yet to get approved for 24-hour nursing through Medicaid, forcing them to pay about \$1,000 a week out of pocket. The school district, however, will now pick up part of the tab, covering the time Marisa is in class.

"I've never done this before," the girl says nervously as she's led to the family minivan for the short drive to school.

"Neither have I," says Hedley, taking her seat.

"Well, I have," Danielle says, "but it was a very long time ago, and I don't think it was anything like this."

Moments later, they're in the school parking lot, filled with families snapping photos of neatly dressed children. Smiling teachers stand by the entrance.

As the minivan's side door slides open, Marisa hesitates, looking apprehensively at the

new world before her.

"I don't know if I can do this," she says softly.

A bag full of medical supplies slung on her shoulder, Danielle grips the ventilator in one hand, extending the other to her daughter. This is no time for doubts.

"We can do this," she says.

An alarming moment

"Boys on one side, girls on the other."

Marisa, in line behind her friend Kayla, marches quietly into Alison Purdy's kindergarten classroom.

Twenty students seat themselves around four round tables. Most seem shy. They're still getting used to being away from their parents for a full day of school.

Marisa is reserved, too. Seated eight feet away is Hedley, whose

job includes regularly recording her patient's oxygen levels and other vital information.

Something else the nurse has noted: Marisa's fierce desire to fit in.

"I can't get her to drink any water today," Hedley whispers from the side of the classroom. "Her sodium is a bit elevated, but she said she doesn't want to because no one else in the class needs to drink water."

Purdy calls the children to sit cross-legged on the mat in the front of the classroom for their morning ritual: counting the days of the week. Some students hurry, angling for a good spot.

Marisa tries to keep up, but her ventilator catches the edge of a bookcase and the breathing tube pops out, triggering a piercing alarm.

BEEP! BEEP! BEEP!

Half the students in the class turn to see where the noise is coming from, and for an instant Marisa isn't the normal kid anymore.

The stares end when Hedley jumps up and re-connects the tube, silencing the machine.

Marisa plops onto the mat, relieved. All eyes have returned to the teacher.

Unlike the others

"Is everything OK with the vent?" gym teacher Rich Campisi asks Marisa's nurse.

"Yeah, she's OK," the ever-present Hedley assures.

As the gym class does its warm-ups, Campisi keeps an eye on Marisa, making sure she isn't left out. "Looks like she's already becoming one of the gang," he tells a visitor.

Marisa joins her classmates in

a circle, everyone stretching arms. Then she musters the strength to do a push-up.

A few minutes later, though, she has trouble with a balancing exercise — standing on her left leg while bending the other back at the knee. She can't reach around her swollen body to grab her leg and hold it to her buttocks like the others.

When the students return to the classroom, Purdy launches into a lesson. She shows the youngsters a series of images: three sneakers — two purple and one pink. "Which one of these is different?" she asks.

Hands shoot up, but Marisa is glued to her work sheet.

Skipping ahead to the next line, she draws an X through a circle in a row of squares.

The one that's unlike the others.