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# Marisa

A little  
girl's fight  
to live

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NEWSDAY PHOTO / ALEXANDRA VILA

**MARISA**

A little girl's fight to live

# Saving their child, every night

BY CANDICE FERRETTE | [candice.ferrette@newsday.com](mailto:candice.ferrette@newsday.com)

NEWSDAY PHOTOS BY ALEJANDRA VILLA

**N**estled under a plush gray comforter, Marisa's heart-shaped lips are pursed, her chubby cheeks rosy and moist with sweat. The Bayport 5-year-old is sleeping on one side of her parents' bed. Her mother, also asleep, lies beside her. On the other side, doing his best to stay awake at 3:08 a.m., is Marisa's father.

A ghostly glow fills the master bedroom as he clicks the TV remote with his thumb, listlessly flipping channels. The two-story, pale-yellow suburban home, set back on a neatly mowed lawn, is still.

BEEP! BEEP! BEEP!

When the piercing alarm sounds and red lights flash, Bill Carney isn't startled. >>





Marisa's father, Bill, suctions her breathing tube.



# MARISA

## A little girl's fight to live

» BEEP! BEEP! BEEP!

"Wh-what is it?" asks his wife, Danielle. She lifts her head off the pillow, but her eyes are still closed.

"Relax," Bill murmurs as he walks around the bed and presses a button on a machine to end the racket. He's not surprised that the lights and siren failed to rouse his daughter. The alarm, sometimes triggered a dozen times a night, has lost its shock value.

"Marisa honey, wake up. C'mon baby, you have to wake up," he says, shaking her leg.

Half-asleep, Marisa, wearing a pink Tinkerbell nightgown, pushes herself into a sitting position.

She's in danger — again. There's too little oxygen in her body; too much poisonous carbon dioxide. The monitor hanging from the bed's wrought-iron headboard says the CO2 level is 69 percent — about twice what it should be.

"It's weird," says Danielle, now on alert. "Did the tube get knocked out or something?"

Bill disconnects his daughter's lifeline, the 4-foot-long plastic breathing tube that runs from the hospital-grade ventilator on the nightstand to the hole in Marisa's throat. He cleans out the moisture inside the tube, then reattaches it, covering the connection with a leopard-print ribbon — Marisa's favorite — that he ties into a neat bow.

"I'm going to bump it up," Bill tells his wife.

"Put it on 18," Danielle advises.

"I know, I know."

He pushes more buttons on the machine, increasing the number of "breaths" that fill Marisa's lungs from 16 to 18 per minute.

The parents hover over their daughter. The blue light coming off the monitor shines on their worried, weary faces.

"Forty-seven," Bill says, reciting the CO2 number.

A few more tense minutes pass. Marisa has already fallen back into a deep slumber.

"It's going down to 43," her father says finally. "Good call."

Relieved, Danielle settles back under the covers. She's supposed to take the next shift, starting in a few hours. She needs her sleep — to get her daughter off to her pre-K class and herself to work — but she can't shut her eyes. The anxiety is too great.

Marisa is one of only 75 chil-

dren worldwide to be diagnosed with a childhood disease that triggers uncontrollable obesity and extreme sleep apnea. By choking off the supply of oxygen to vital organs, the condition puts kids at serious risk of permanent brain damage — or death.

Discovered by researchers only a few years ago, the disorder is a mystery. Little is known about how it wreaks havoc on the body, and even less is known about how the disease progresses past childhood.

There's no cure, only constant pressure to manage unpredictable symptoms before it's too late. Every night becomes a well-practiced, lifesaving ritual.

Danielle, 42, a labor lawyer, and Bill, 43, a golf instructor, have turned their home into a makeshift clinic laden with medical equipment and supplies — even a just-in-case power generator.

They haven't had a full night's sleep in a year, and they have no idea when relief will come. Or if it ever will.

For the Long Island couple, the future is uncertain and the present has become an exhausting, endless vigil.

"My biggest fear," Danielle says, "is that she won't wake up in the morning."

### A medical mystery

The home is adorned with framed photographs of a little girl — petite, blonde with blue-green eyes, glowing with a summer tan.

In one picture, she's captured in mid-twirl, thin arms high in the air. She's smiling and care-free, prancing in a field of reeds in a pink-and-gray sundress.

She looks like a model, friends — even strangers at the mall — used to say.

That was two years ago, before Marisa doubled her weight in a matter of months. At 3½ feet tall, she now carries 67 pounds — the average weight of a 9-year-old girl.

The diagnosis came 10 months ago, after the Carneys saw more than two dozen doctors at five hospitals in New York, Pennsylvania and Illinois.

"We didn't believe it in the beginning," Danielle says. "Who has ever heard of such a disease?"

The name of the disorder is a mouthful: Rapid-onset Obesity with Hypothalamic Dysfunc-

Experience the family's story in an emotional video and more photos at [newsday.com](http://newsday.com)

**Before**  
At 3 years old, Marisa showed no signs of the illness to come.

PHOTO BY NYDARGOSE VARIO

# Today

Marisa doubled in weight in a matter of months and now uses a ventilator 24 hours a day.



tion, Hypoventilation and Autonomic Dysregulation. ROHHAD for short.

No one knows what causes it.

What's known is this: The disease strikes the hypothalamus — a pearl-sized part of the brain that controls body temperature, hunger, thirst and fatigue. It also regulates metabolism and activities of the body's autonomic nervous system, which controls vital involuntary functions such as breathing, blood pressure and the beating of the heart.

In healthy people, this system keeps everything in balance and makes sure the brain, organs and other parts of the body have their needs met automatically.

But like most kids with ROHHAD, Marisa's fingers and toes are often cold, her breathing shallow. Her metabolism has gone haywire. She can eat

and eat without ever feeling full. Despite a healthy diet built around lean chicken and fish — controlled down to the ounce by her parents — the pounds pile on because she can't burn off calories normally.

On most days, there's little indication anything's wrong, and that in itself is troubling. Marisa feels little pain. Her lungs work fine, but the brain signals that tell her body to breathe are on the fritz.

When her body needs oxygen, she doesn't gasp, giving no one around her any warning. Because of that, her doctors say, Marisa is at serious risk of slipping into cardiac arrest.

"It's not just a breathing problem . . . It's not just a weight problem. It's so much more complex than that," says Dr. Pallavi Patwari, one of the world's few ROHHAD specialists.

Patwari, who has been treat-

ing Marisa, works in the Center for Autonomic Medicine in Pediatrics, or CAMP, at Children's Memorial Hospital in Chicago. The center, headed by Dr. Debra Weese-Mayer, focuses on disorders that affect breathing and the autonomic nervous system. Sixty documented ROHHAD cases have been treated there, making Weese-Mayer and Patwari two of the foremost experts on the disorder.

They named the disease in

2007 after evaluating 23 children. Three of those patients have since died. Many of the others have become neurologically impaired or brain-damaged, Weese-Mayer says.

The oldest known ROHHAD patient is a 21-year-old man from Colorado who was diagnosed late and is now developmentally disabled after being deprived of oxygen as a toddler. But a 15-year-old girl from Maine gives the Carneys reason to hope. Despite her reli-

ance on a pacemaker, and a ventilator when she sleeps, the teen is a high school honor student.

There are no specially engineered drugs for ROHHAD, no viable surgical options. Marisa had the good fortune of being diagnosed early so her parents could at least be coached on what to look for and how best to respond.

The first clue that something was wrong came when Bill and Danielle noticed their daughter getting chubby.

"It was sort of like a little beer belly," Bill recalls.

Then, one day in preschool, Marisa wet her pants three times in a few hours.

"She never did anything like that before. She had been potty-trained at a very young age," Danielle says.

Concerned, Bill and Danielle brought her to their pediatrician. Marisa, they discov- >>>

## ABOUT THIS STORY



**Candice Ferrette**  
Reporter

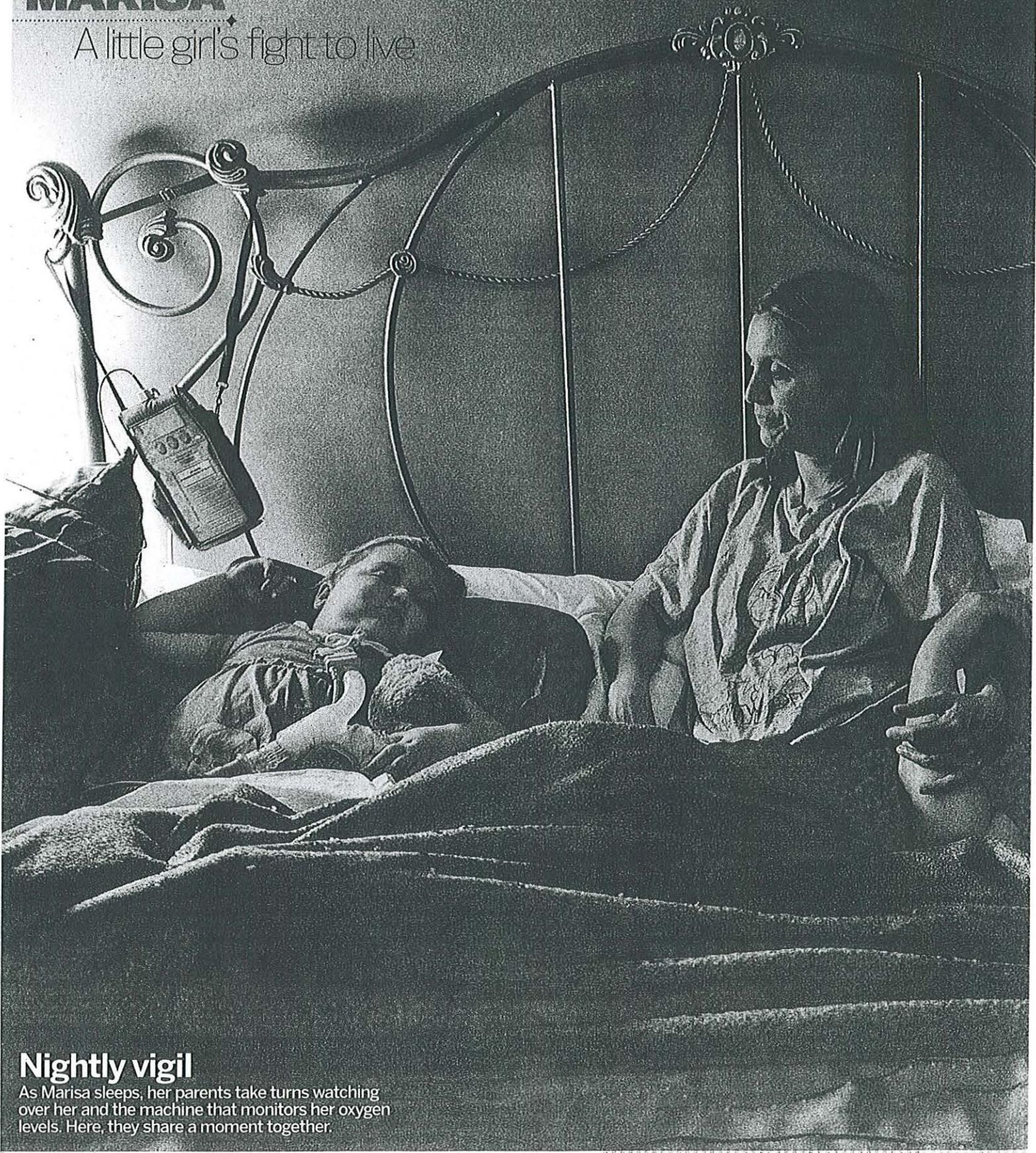
To chronicle Marisa's struggle, reporter Candice Ferrette and photographer Alejandra Villa followed the Carney family for four months. Ferrette and Villa spent days and nights inside the Carneys' Bayport home, visited Marisa's school and accompanied the family to Chicago for medical tests.



**Alejandra Villa**  
Photographer

# MARISA

A little girl's fight to live



## Nightly vigil

As Marisa sleeps, her parents take turns watching over her and the machine that monitors her oxygen levels. Here, they share a moment together.

# “Do we feel overwhelmed? All the time.”

— Bill Carney

ered, had gained six pounds in six weeks. Her stomach was bloated. Her swollen feet had quickly outgrown her shoes. Something was clearly wrong.

A CT scan found a benign tumor in Marisa's abdomen. Surgeons at Cohen's Children's Medical Center of New York in New Hyde Park removed the one-centimeter tumor as a team of doctors, puzzled by the symptoms, pored over research on rare disorders.

The breakthrough came when they found an academic paper on ROHHAD authored by the Chicago doctors that detailed many of Marisa's woes: rapid-onset obesity, noncancerous tumors, bloating, difficulty regulating body temperature.

The frequent urination, the doctors speculated, was probably linked to fluctuations in Marisa's sodium levels also caused by the disease. The mineral helps regulate fluids in the body and plays a key role in keeping nerves and muscles working properly.

Before long, the Carneys were packing for Chicago in a desperate search for answers.

While ROHHAD typically strikes children between the ages of 1 and 4, and on occasion up to age 10, the official diagnosis doesn't come easy. Parents must submit medical records, blood and genetic tests, along with growth charts going back to birth. Sometimes, the most telling evidence can be the simplest: photos or videos from the previous year.

"A 3-year-old who gains 30 pounds over six months is pretty obvious," says Weese-Mayer, a University of Chicago graduate and mother of four.

The nation's childhood obesity epidemic, though, has made it even more difficult to diagnose ROHHAD. It's easy for pediatricians to dismiss rapid weight gain as the result of a poor diet or lack of exercise, says Weese-Mayer, who believes there are many undiagnosed ROHHAD cases out there, putting young kids at risk.

The Chicago specialists hope to find the gene that causes ROHHAD, convinced it could lead to broader discoveries on what makes certain children more

prone to obesity. They have built detailed files on each of their 60 cases, bringing in as many children as they can for follow-up testing. The Carneys and other parents do it willingly, hoping to contribute to greater understanding of the disorder.

But CAMP has been unable to complete one of the first major steps toward a breakthrough: assembling a database of DNA taken from all known ROHHAD cases around the globe.

It's a quest that, like research into most rare diseases, suffers from a chronic lack of funding.

## Sleep is precious and scarce

The digital clock on the cable box reads 5:21 a.m.

Danielle drags herself out of bed. Bill, out cold, is face down in his pillow, hanging off the edge of the mattress.

Last night was another bad one. The alarm sounded almost every hour.

Marisa's breathing tube was clogged with more mucus than usual. Could it be allergies, Danielle wonders. Is she getting a cold?

The mother pads to the bathroom, returning to wake her daughter. Minutes later, they're in Marisa's room for the start of the morning ritual.

"What time is Chris coming, Mommy?" Marisa asks. Since January, the Carneys have been paying more than a \$1,000 out of pocket a week for a private nurse to stay at the house two nights and one morning, giving the couple a sorely needed respite.

"Seven o'clock, baby," Danielle replies. "Lay down."

She turns on the suction machine, removes the red cap that covers Marisa's tracheostomy tube and sticks a long, thin vacuum into the hole. She removes slimy, yellow mucus as her daughter coughs and shakes. The tube often becomes clogged with mucus because Marisa can't blow her nose or clear her throat like other kids.

Danielle then hooks her back up to the ventilator, the whooshing, constant compan-

ion that the little girl has nicknamed Venti.

When they're done, Marisa brightens. She's already thinking about the day's art activities.

"Are there projects for us to do?" she asks.

"I'll get that together before I leave," Danielle promises. "Did you fall back asleep again last night?"

"Yeah, a little. A little." Danielle got precious little sleep, too. She eyes her daughter's comfy bed hungrily. If she could just lie down . . .

"Mommy wants to rest her head for a few minutes," she says.

"No!"

Marisa won't allow it. There are too many fun things to do.

Danielle doesn't argue. She combs Marisa's hair as she sprays on a dry shampoo. There's no time — or strength — for a bath.

"Mommy, you know those short, black pants?" Marisa says. "I want to wear those." The elastic waistband makes the pants one of the most comfortable pieces in her wardrobe.

Minutes later, dressed and downstairs, Marisa waits at the kitchen table, eager for breakfast.

"Butter or cream cheese?" her mother asks as raisin bread pops from the toaster.

"Cream cheese!"

Danielle puts the plate of toast in front of Marisa along with a Hello Kitty glass filled with orange juice. Then she goes straight to the notebook where everything Marisa eats, drinks and deposits in the toilet is recorded.

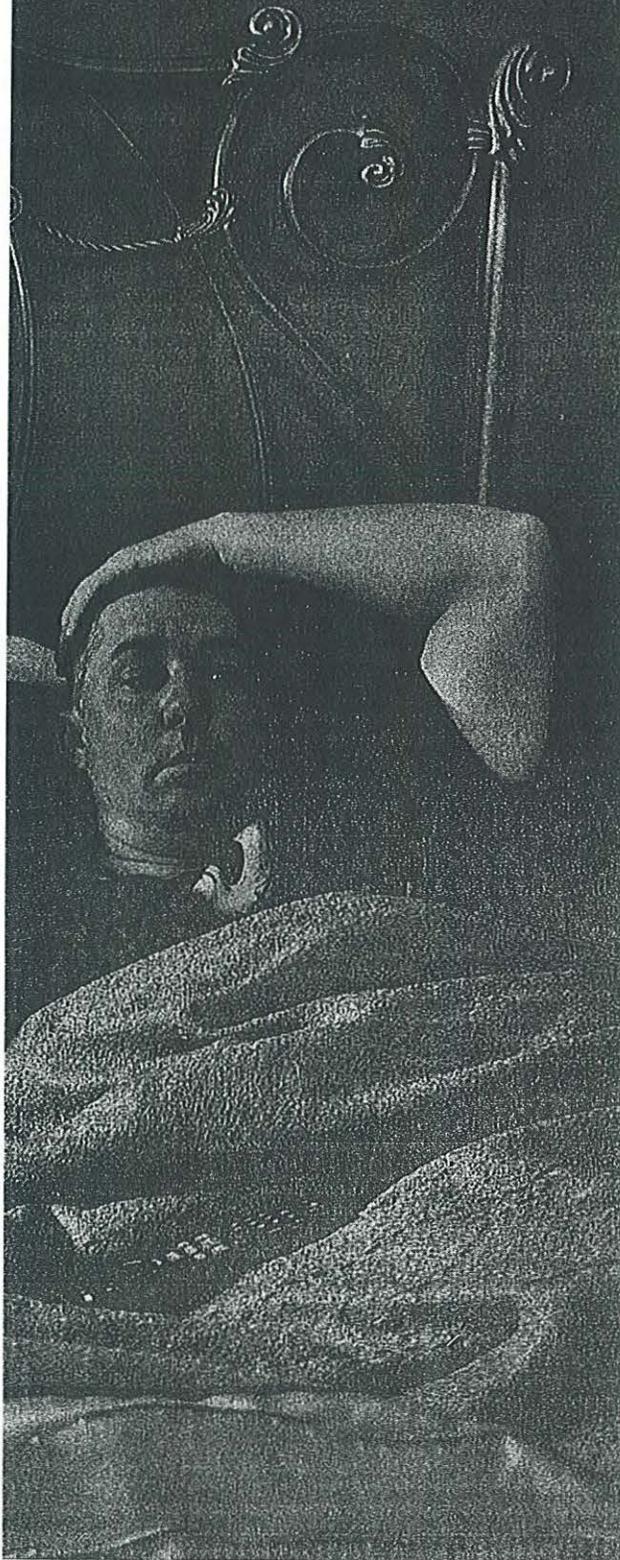
*Breakfast: 2 slices of raisin toast. 6 oz of OJ.*

At 6:12 a.m., Danielle heads back upstairs to take a shower. Marisa wants to play in her room, but her mother rejects the notion.

"Why not?" Marisa asks.

"Because I can't hear you breathing from the bathroom," Danielle answers.

Plugged into her portable ventilator, the preschooler sits outside the bathroom until the shower ends and Danielle steps out looking refreshed. >>> Soon, she's ready for work, >>>



# MARISA A little girl's fight to live



**A GIRL PARTY** Marisa's 5th birthday party drew friends and family to their Bayport home. "We live much more for these memories now because we honestly don't know what tomorrow will bring," her mom says.



**ORIGINAL QUEKID** Dr. Pallavi Patwari is a specialist in ROHHAD at Children's Memorial Hospital in Chicago.

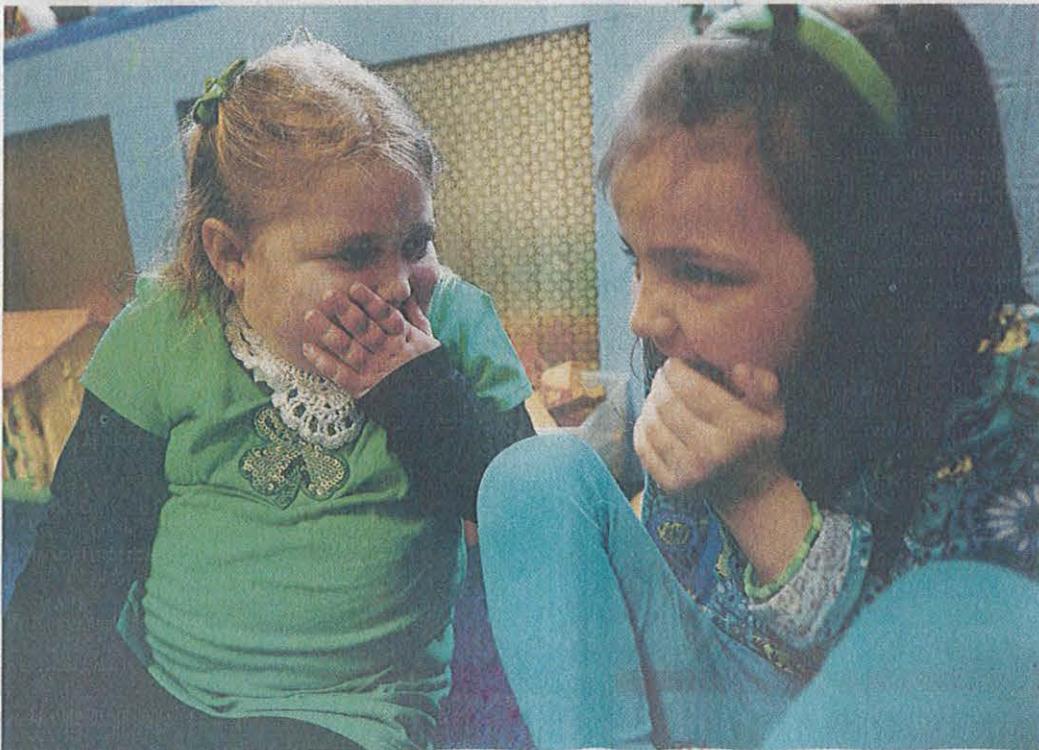
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Watch them tell their story and see n7



**DADDY TIME** Marisa's father, Bill, took time away from his career as a country club golf pro to be a caregiver to his daughter during the day. Her quick wit and sharp intellect keep him on his toes.



**BEST BUDDIES** Marisa shares a giggle with her best friend, Kayla Vazquez, during recess at the Prince of Peace School in Sawville. It was during Field Day at school last year when her symptoms first appeared.



**THEY'RE A TEAM** Bad news during a March trip to Chicago crushed Marisa's mother, Danielle. But Marisa's resiliency has helped her mom bounce back. "I have to be strong for her," Danielle says.



**DAILY RITUAL** Each night before bedtime, Marisa's father pricks her finger and draws blood to test her sodium, cholesterol and sugar levels. They use a portable testing machine that gives them instant results.

# MARISA

A little girl's fight to live

## Time to dance

Marisa and her mother take to the floor, dancing and exercising to keep her weight under control. Despite her healthy diet, Marisa gains weight because she can't burn off calories normally.



PHOTOGRAPH BY JEFFREY M. HARRIS FOR EW.COM



» wearing a short-sleeved silk top, slacks and black-heeled sandals.

She has 10 minutes to give Marisa her medicine before hopping in her blue Volkswagen Routan for the hour-long commute to Barnes, Iaccarino & Shepherd LLP in Hempstead, where she's been a lawyer for 14 years, specializing in pension funds.

"Here," Danielle says, handing Marisa a Dixie cup filled with water and a large, golden fish oil pill. The 5-year-old, who also takes a pill to control her sodium level, is getting the same cholesterol-reducing therapy as her father.

"Don't forget, Daddy needs his pill, too," the girl says.

Even at the office, Danielle squeezes in phone time with the family's local Medicaid case worker, trying to nail down approval for insurance-paid nursing care.

Marisa is entitled to the benefit because she's technically disabled, but the application process has dragged for months. With kindergarten looming in the fall finding a full-time health aide who can tend to Marisa at school and home is the family's next big hurdle. Bill and Danielle's health plans already cover the bulk of their medical costs.

To spend more time with her daughter, Danielle has been working one day a week at home. Bill, who helps run the pro shop at the West Sayville Country Club, had much of the winter off.

But summer is here and he needs to return to work. He missed the first six weeks of the golf season and feels guilty about it.

Bill and Danielle have tried to split the enormous responsibilities posed by Marisa's condition. Besides their late-night and early-morning shifts, there's a constant battery of calls to make, from consulting with insurance companies to scheduling doctor appointments and reordering home medical supplies.

"It's exhausting," Danielle says.

Adds Bill: "Do we feel overwhelmed? All the time."

### Mature beyond her years

Life before the diagnosis has become a golden memory. Their marriage was the second for them both, and Bill and Danielle didn't waste time trying to become parents for the first time.

On March 31, 2006, Marisa was born.

Everything seemed perfect after that. They would give

their new daughter, and only child, trips to Disney World, a room full of toys, a nice house with a yard, pool and playset — all the things they never had as kids. The couple came from New York working-class roots: Bill's father was a cop; Danielle's an Argentine immigrant who worked as an airline dispatcher.

As a baby and toddler, Marisa met all her developmental milestones on time, and some of them early. Her parents never had to deal with anything more than the occasional cold or ear infection.

"She was like the Energizer Bunny, dancing, climbing on everything. She'd literally be bouncing off the walls," says Margaret Vario, 41, a neighbor who did some of the baby-sitting. "It was hard to keep track of her. One minute she was doing one thing, then she was on to something else and next thing you know, she comes to you and says 'I'm bored.'"

Her vocabulary and diction have always been advanced for her age. She has a quick wit that makes her as comfortable around adults as children.

When others called the older boy next door Lenny, Marisa addressed him formally as "Leonard." When a classmate showed her a Lego helicopter, Marisa pointed out: "It doesn't have enough propellers."

When the conversation in school one day last year turned to sneezing and allergies, Marisa piped up with the reason.

"It's just funny to hear a 3-year-old say, 'The pollen count is high today,'" says Tricia Parahaus, a preschool teacher at Marisa's school, Prince of Peace School in Sayville. "She's an adult in a little girl's body."

Even during the grueling bedtime routine, Marisa shows her inner strength.

A couple of hours after dinner, Bill lifts Marisa onto the kitchen counter and runs the tap until the water warms. She wets her abnormally cold fingers, prepping for the blood draw.

Many kids her age would put up a fight — a tantrum or tears — but Marisa remains calm. She opens her little fist and obligingly offers an index finger. Her father pricks it, squeezing drops of blood into a 2-inch-long vial.

Bill, who once got queasy at the sight of blood, has been trained to take daily samples from his daughter and record the results. He drops the blood into a machine that gives instant readings on his daughter's sodium, sugar and cholesterol levels. Then they head up stairs. »

## ROHHAD Q&A

### A MYSTERIOUS DISEASE

#### What is ROHHAD?

Rapid-onset Obesity with Hypothalamic Dysfunction, Hypoventilation and Autonomic Dysregulation is an extremely rare childhood disorder that's difficult to diagnose and treat. There are 75 known cases worldwide. Most patients begin life as healthy babies but in early childhood start to rapidly gain weight. All develop serious breathing problems.

#### How does the disorder affect the body?

The disease strikes the part of the brain called the hypothalamus, which sends signals to the rest of the body to regulate automatic functions such as breathing, heartbeat, body temperature and digestion.

#### How does ROHHAD put children at risk?

Children with ROHHAD typically have shallow breathing that, if not addressed, deprives the brain of oxygen. That can lead to neurological disabilities, seizures or cardiac arrest. Rapid obesity can also cause heart disease.

#### What are other symptoms?

Sudden weight gain of more than 20 pounds in six to 12 months is the most noticeable symptom. Some patients plateau in weight years later. Other common signs are benign tumors, trouble metabolizing food, gastrointestinal problems, excessive or diminished thirst, decreased sensitivity to pain and poor circulation, leading to abnormally cold hands and feet.

#### Is it preventable?

No one knows what causes ROHHAD, and there's currently no way to prevent it. There's no cure.

#### Does any other disorder resemble ROHHAD?

ROHHAD is a disease of the autonomic nervous system and is similar in some aspects to Congenital Central Hypoventilation Syndrome, a genetic condition that appears at birth and causes breathing problems.

SOURCE: CENTER FOR AUTONOMIC MEDICINE IN PEDIATRICS AT CHILDREN'S MEMORIAL HOSPITAL

# MARISA

## A little girl's fight to live

» Marisa's bedroom, girly pink and purple with a "Princess" banner hanging on one wall and stuffed animals covering half the bed, has become a hospital suite with frills.

Standing bedside, Bill snaps on blue surgical gloves and turns on a suction machine perched on an antique nightstand. The familiar routine to clean out Marisa's breathing tube isn't easy to watch. The little girl's face reddens as she coughs violently.

Danielle comforts her daughter by rubbing her thigh.

The entire evening ritual can take up to an hour, and Bill can't help but be moved by his daughter's acceptance of it all.

"It breaks your heart to hear your child say, 'Daddy, it's OK, you can take my blood,'" he says.

There are times, though, when maturity as a shield isn't enough.

One afternoon, at home after school, Marisa's friends were running circles around her, chasing one another. Marisa, realizing her limitations, became frustrated by the 50-pound ventilator she was lugging around in her pink, wheeled suitcase.

She sat down on the living room floor and cried.

"I wish I could be reborn," the girl blurted out the next day. It was Easter week and Marisa had hit a rare low point. She had balked at leaving the house to get her picture taken with the Easter bunny. She didn't want strangers staring at her.

"Baby, why would you want to be reborn?" Danielle asked, taken aback. "You are perfect just the way you are."

Marisa seemed comforted by the mother-daughter moment.

Later, in private, it was Bill and Danielle's turn to cry.

### A new prognosis

Lap No. 8 and she's showing no signs of tiring.

Marisa is smiling, unfazed by the wires creeping out from under her snug, bubblegum-pink top. A matching headband covers the brain monitor stuck to her forehead. Another device is clipped to the nail of her right index finger — the only one not polished a sparkly pink.

She rounds the hospital hallway pushing a wheeled cart holding her ventilator, refusing to let it slow her down.

"Forty-seven-point-ninety-four!"

Speed-walking behind the 4-year-old, a respiratory therapist calls out the number. Their sneakers squeak in unison along the buffed tile floor.

To Marisa, the exercise is like recess — a break in two days of testing and probing, blood draws and brain scans. To the specialists at Children's Memorial Hospital of Chicago, it's all business as they search terabytes of data for clues in a mystery disease.

"Fifty-two-point-ninety-one!"

Hustling to keep pace with Marisa, the therapist — a friendly woman in her late 30s — watches the electronic monitor wired to the girl. The preschooler doesn't know what the numbers being shouted out mean, and that's a good thing.

The pair dashes past the open door to an office where two other specialists are taking notes and scanning computer screens. They're checking Marisa's carbon dioxide levels to see if she's expelling enough of the gas and getting the right amount of oxygen to her brain.

In a healthy child, the numbers are in the 30 to 45 percent range. Marisa's numbers are too high, putting her at serious risk of a seizure or cardiac arrest.

Bill steps in to walk with his daughter for the final laps. Excited, Marisa forgets to push the cart, nearly yanking out her breathing tube. The smile on her round face fades as she looks up at her dad in frustration.

"Come on, you know you need to push it," he says.

In silence, father and daughter complete the exercise in the bland, utilitarian corridor. Unlike other wings of the hospital, there are no elaborate murals or fish tanks or big toys. The lone concession to childlike imagination is the ceiling in one of the sleep-study observation rooms, featuring stars that twinkle as the lights dim. Marisa sleeps there.

A team of therapists and doctors view much of the data on computers in a separate room. They test her heart rate, and oxygen and CO2 levels while she is asleep, awake and active.

There's never a moment when she isn't being studied. The staff, though, has learned to trust Marisa's parents with some of the basics.

"You want to suction her or do you want me to?" a nurse

asks Bill.

"I'll do it," he says, rising from a blue armchair. He steps over to his daughter, who's sunk deep in her own cushioned chair, fettered by the usual array of wires and monitors.

He pulls on a pair of latex gloves and starts the familiar breathing tube cleaning ritual.

"Let's try talking, Marisa," Bill urges. "Please. C'mon, say something. Let's do our ABCs."

The normally chatty Marisa has her lips shut tight. It's difficult for her to speak over the air rushing down her throat, filling her lungs. She'd only been using a ventilator when she slept. Now, forced to speak through the device, the words tumble out with a strange robotic tone.

In the doorway, Danielle is chatting with one of the doctors, having just reviewed the notes written in her daughter's medical chart.

"If it's as easy as eating more fish — maybe doing a fish for lunch or dinner more often — we can do that," she tells the doctor.

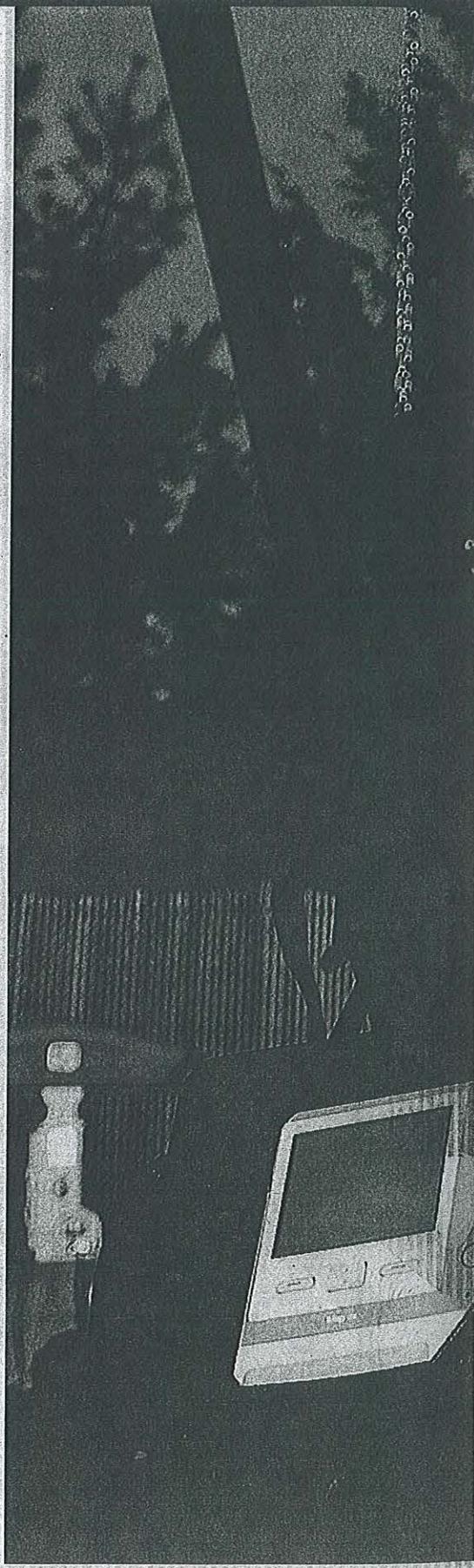
She's eager for solutions. Three months earlier, the family was here for more testing. They were crushed to learn the disease had progressed. Marisa's vital blood-oxygen levels had dropped dramatically while she slept, doctors found. She'd need to use a ventilator at night.

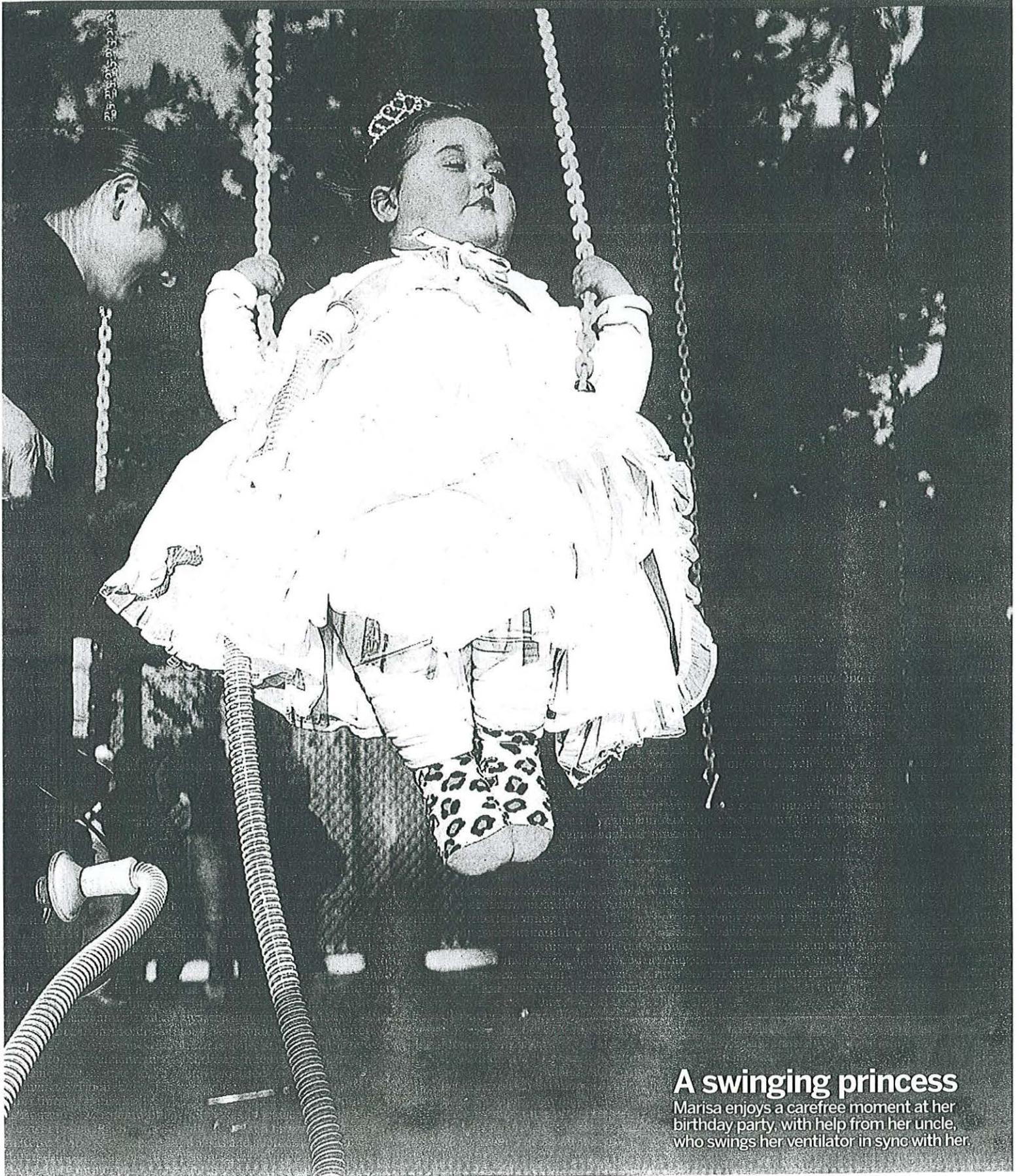
Danielle remembers the heartbreak of that week in January. She stared at her child, lying in her hospital bed. Surgeons had put a hole in Marisa's throat.

She and Bill couldn't stop worrying after that. What if it became infected? What if kids at school touched the opening? What if they made fun of her?

The Carneys, sent home with detailed instructions on how to care for their daughter, did everything they were told. They did it all faithfully — every day, every night. They became nurses and dietitians, counselors and therapists. They filled notebooks with data to give to the doctors.

Now, on March 21, the week of their 7th wedding anniversary, they are back, picking at hospital cafeteria Jell-O and chicken tenders as the gauntlet of tests goes on. They don't care that they aren't keeping dinner reservations at their favorite Italian restaurant. They just hope someone will tell »





## A swinging princess

Marisa enjoys a carefree moment at her birthday party, with help from her uncle, who swings her ventilator in sync with her.

# MARISA

## A little girl's fight to live

» them their hard work as caregivers is paying off.

The moment of truth comes at the end of the second day of testing as Marisa plays a dancing game with one of the therapists. Dr. Patwari takes advantage of the distraction to usher Danielle and Bill into her office. The couple is expecting good news. Their lively daughter certainly doesn't seem sick.

The blow comes quickly, with no attempt to blunt its force. Marisa will require a ventilator 24 hours a day, the doctor says.

Patwari points to a computer monitor. The line on the graph plunges sharply, like a terrible day on the stock market. Not enough oxygen is getting to Marisa's organs.

"Her brain should be telling her body she doesn't have enough oxygen, and it isn't," Patwari says. "She's in a different place now than she was the last time she was here."

The flip side of the equation is that Marisa isn't getting rid of enough carbon dioxide. Her cholesterol level has also spiked, putting it now on par with an overweight, middle-aged man. Her heart rate is too high.

"I think maybe it has to do with nerves," Bill says, fumbling for answers.

Patwari, a Chicago native and mother of three young children, shakes her head. Her years spent as a critical-care doctor prepared her well to deliver bad news to families, but when it comes to the puzzle that is ROHHAD she shares their pain.

"What's most frustrating is that we don't have a way to stop this process from evolving," the doctor says.

"Basically, what you're telling us is that our daughter is going to be on a ventilator 24 hours a day and she won't be able to talk?" Bill says sharply.

"I can't leave here without hearing her speak," Danielle says.

Patwari shakes her head again. "I don't think it's safe for her to be off the vent for even a few minutes."

Danielle, stunned, fights back tears.

"I know I'm being selfish and I'm not going to endanger her, but — I'm sorry — next week is her birthday and if it's just for two minutes to sing 'Happy Birthday' . . . I just can't handle not hearing her voice."

Slumped in her chair, she begins to sob. The strain of

pants, waiting around in hospital rooms, has pushed her to the breaking point.

"I understand what you're saying, but it's overwhelming," she tells the doctor, struggling to collect herself. "I don't know how to wrap my head around this."

Danielle walks out of the room, wiping away tears. Bill rushes after her.

Moments later, they're embracing in the hallway, drawing strength from one another.

"This is really a nightmare," she says. "What happens when the ventilator isn't enough?"

"No one can answer the question of what comes next."

### The birthday party

For Marisa's fifth birthday, the Carney home is filled with friends and relatives. Bill's parents are up from Florida. Danielle's mother, who lives nearby and often lends a helping hand, is there, too.

Neighbors have rallied around the family in recent months, setting up a nonprofit — ROHHAD Fight Inc. — that aims to help the Carneys pay their medical bills and raise money for research.

Bill and Danielle have held a series of small neighborhood fundraisers. So far, they've collected about \$25,000, with a golf tournament slated for July 18 at Bill's course in West Sayville.

Danielle, meanwhile, has rebounded from the shock over her daughter's progressing disease, taking a cue from Marisa.

"She is much more energetic . . . She's adjusting; she always does," the mother says.

For her April 2 party, Marisa is wearing a flowing white dress and a silver crown. She deserves to be a princess for a day, Bill says.

"We have a lot of obstacles ahead of us," he says. "But we're not focusing on that right now."

As dance music kicks in, the kids rush into the yard, past the pool Marisa is unlikely to ever use again. They gather at the elaborate playset Marisa can't climb on by herself anymore.

Some of the kids hang from the monkey bars. Others hit the slide with a shriek.

Marisa, tethered to her breathing machine, watches them for a few minutes.



### HOW TO HELP

The Carney family and friends have formed a nonprofit to raise awareness and money for research. To contact the group, visit [rohhadfight.org](http://rohhadfight.org); write to ROHHAD Fight Inc., 3 Surrey Lane, Hempstead NY 11550; or call 516-459-6960.

### TO LEARN MORE

For more information about the disease, visit these websites:

#### ■ National Institutes of Health

[rarediseases.info.nih.gov/GARD/Condition/10407/ROHHAD.aspx](http://rarediseases.info.nih.gov/GARD/Condition/10407/ROHHAD.aspx)

#### ■ National Organization for Rare Disorders

[rarediseases.org/rare-disease-information/rare-diseases/byID/1216/viewAbstract](http://rarediseases.org/rare-disease-information/rare-diseases/byID/1216/viewAbstract)

#### ■ ROHHAD.net (support network for families)



## Finding their way

Toting the ventilator, Danielle leads her daughter down the slide on their backyard playset.