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GABRIEL'S WORLD

NEWSDAY/ALEANDRA VILLA

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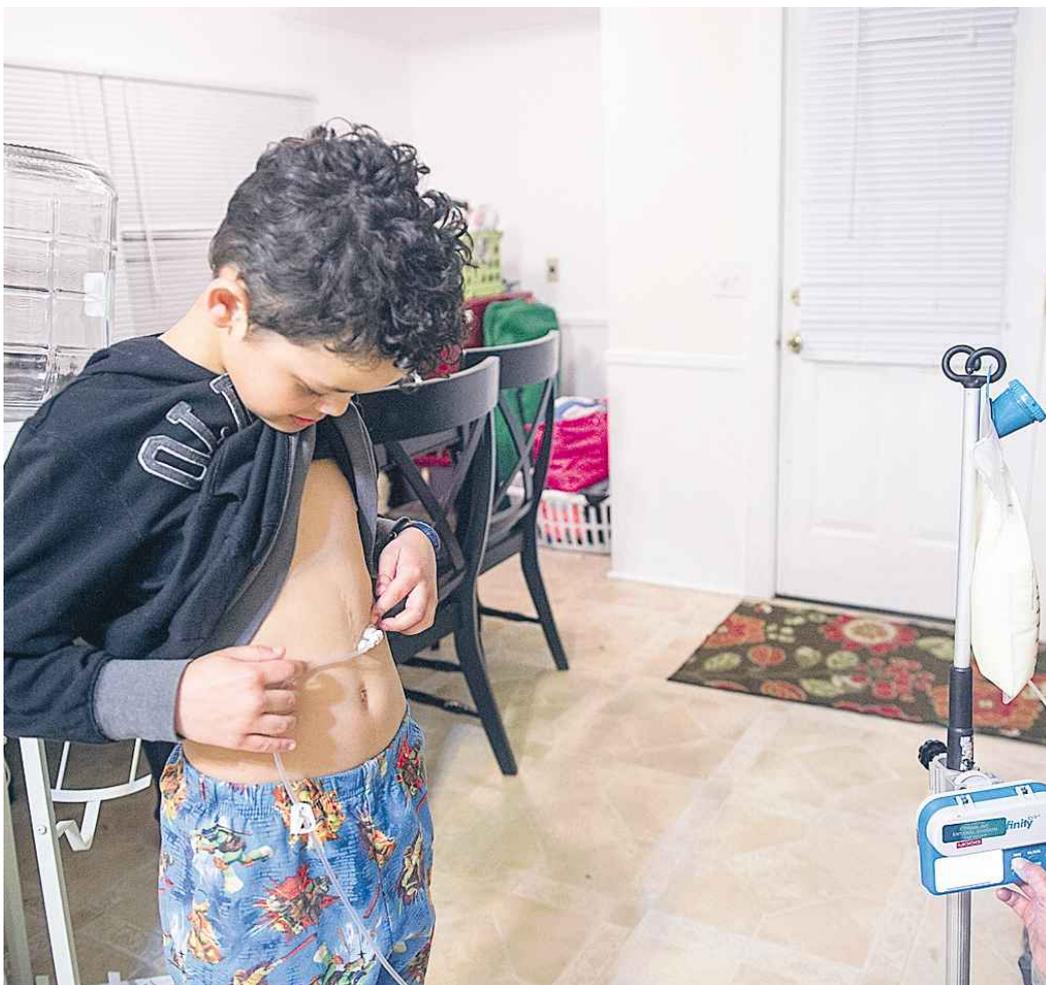
Ellen Coven's cooldown

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Thrilled to be a classmate

A boy isolated due to severe allergies to all foods blossoms with a special connection to school



Gabriel hooks himself up to a feeding tube that will provide him sustenance during the night. While he sleeps, a machine beside his bed pumps a formula of amino acids into his system.



BY CARL CORRY

Special to Newsday

It's probably safe to say you've never met a child like Gabriel Dispenziere. He's cute and smart and loves school. Typical.

But Gabriel, who will turn 9 on June 21, is allergic to food.

All food.

Two drops of pear juice is one drop too many — he was sick for days afterward. A sample of chicken caused a 20 percent drop in his body weight. Tastings of mango and quinoa landed him in the ER.

Gabriel has eosinophilic esophagitis, or EoE, a condition in which allergic reactions to food cause inflammation of the esophagus. The condition affects about one in 2,000 people in the United States, according to the American Partnership for Eosinophilic Disorders. Less than 1



ON THE COVER Gabriel Dispenziere looks out from inside his mother's Riverhead beauty salon, where he keeps up with his schoolwork.

percent of those with the condition have as severe a case as Gabriel, and it's left the Riverhead boy virtually homebound because he must avoid food and people with food on their hands or breath.

Up until this school year, that meant never having a classroom teacher or class-



Gabriel via his VGo system, far left, with its audio capabilities and a webcam, sings along with other fourth-graders during the spring concert at Aquebogue Elementary School earlier this month. ■ More photos at newsday.com/lilife

Gabriel, at his computer screen in his mother's beauty salon, is jubilant at his participation in his first school production. Chelsea Dispenziere, his aunt, is with him.

RANDEE DADDONA

mates or being in a school setting. But thanks to his mother Raquel Dispenziere's determination and sacrifice, and cooperation from a cadre of local educators, Gabriel is a fourth-grader at Aquebogue Elementary School in Riverhead.

When Gabriel started school this year, tutoring for two hours a day began immediately. But the school was also putting into motion the videoconferencing program FaceTime so Gabriel could be a part of the classroom instruction.

The first time was in late September with a science lesson.

"I really don't know if I can find the words for that," Dispenziere, 29, said, recalling the experience.

They added reading. And to allow Gabriel to come along virtually on a class trip, teacher Robert Shilling brought in his own iPad, because it had a data plan, whereas the school's

would only work with Wi-Fi at the time.

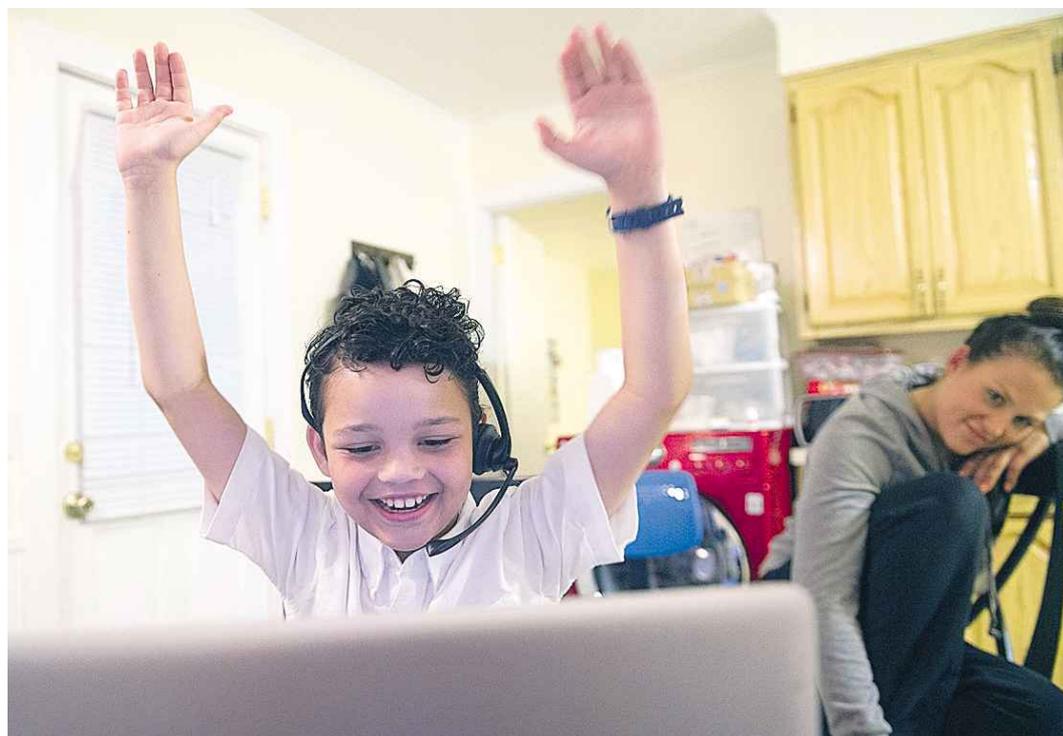
"And that was Gabriel's first school bus ride," his mother said. "He talked about it for weeks."

Technological helper

After reading aloud a passage of "Matilda" by Roald Dahl, bringing the story to life with impressions of the accents of its working-class English characters — including Matilda's father, whom he made sound akin to Dick Van Dyke's Bert in "Mary Poppins" — Shilling opened the reading to discussion.

Why did Matilda's family always eat TV dinners? Did Matilda's father know she was going to the library to read books? For the last question, some students raised their hands to respond yes, others to respond no.

See COVER STORY on G6



The boy who can't eat



Gabriel sits in a room in back of his mother's hair salon. There, he connects with his fourth-grade class and enjoys games such as Minecraft.



Gabriel, on the VGo, center, poses with his friends Mikayla Scott and Sean Donohue after the concert.



On a day when he was fighting the effects of allergy medicine that made him drowsy, Gabriel works with his tutor, Tanya McGowan.

COVER STORY from G4

Gabriel chimed in with “no” by prompting a flash of lights from the sleek, white VGo robot system that he controls remotely from a special room set up in the back of his mother’s hair salon in Riverhead. A delayed audio response also came from the system, which featured a video stream of Gabriel’s face.

Reading is Gabriel’s favorite subject. He has read the whole “Diary of a Wimpy Kid” series and is looking to pre-order the next book in the line. He also likes chorus, music and history, subjects he couldn’t focus on in the past. But what he most appreciates about school this year is that “it’s been a lot easier to make friends” because of the VGo system and the use of FaceTime. Shilling visits Gabriel regularly to drop off notes.

“This experience has been wonderful,” Shilling said. “He’s made me a better teacher, without a doubt.”

He added that he is proud of the district’s efforts on Gabriel’s behalf, from the technology department to the administration. “It’s been a learning curve for us all,” Shilling said.

It’s the kind of interaction Gabriel and his mother had only dreamed about before moving in May from California to Long Island.

Dispenziere was born in Manorville and spent time as a child both with her mother in California and her father on Long Island. She attended Riverhead High School but completed high school in California. She then returned to Long Island and graduated from Long Island Beauty School in Hauppauge. While pregnant with Gabriel in 2005, she moved back to California. Soon after, she parted ways with Gabriel’s father, and with the support of family she has raised him on her own.

Dispenziere said that after his birth, it was immediately apparent that Gabriel had health issues. Her son had severe trouble breathing at times and had pneumonia nine times before his first birthday.

“We had no idea he couldn’t eat foods, but at that time he was having allergic-type reactions,” Dispenziere said.

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Gabriel joins in the class activities at Aqueboque Elementary School in Riverhead through the VGo system, which features a video stream of his face.

EoE causes white blood cells to attack the esophagus, resulting in severe stomach, leg and head pains or gastrointestinal issues.

In addition to EoE, Gabriel also has many allergies. "Not all kids with EoE have the allergies as well," his mother said. "So he would get all those symptoms — wheezing, coughing, rashes, puffy eyes, itchy eyes, runny nose."

As time went on, Dispenziere tried different meats, fruits and vegetables to see whether Gabriel could tolerate them. They included mango, chicken, turkey, squash, grapes, broccoli, artichoke and sweet potato.

"Eventually, it all came down to rice and potatoes, but then those were taken away," Gabriel said, when he developed reactions after eating them for more than a year.

Promoting interaction

EoE has not hampered Gabriel's academic performance. When he lived in Ante-

lope, California, testing revealed a high IQ, and Gabriel skipped first grade.

Dispenziere said she struggled to find educational opportunities and support for Gabriel in the California school system. His previous schooling was limited to two hours of in-house tutoring a day, she said.

"After a lot of fighting, they brought in iPads and let me FaceTime with two kids during recess," Dispenziere recalled. "So he got to play a board game. One time. That was the most they were willing to do. They weren't willing to involve the teachers."

Still, his mother was insistent that Gabriel get beyond the walls of his home and interact with classmates.

"I wanted him to have every part of learning," she said. "And I know a lot of what we learn is from our peers. I know that's really important. So when he was in kindergarten, I saw on 'Good Morning America' another

kid in another state was using something called a VGo. I kind of knew then that this was something we needed."

A car accident in 2013 that required Dispenziere to have back surgery in 2014 amped up the pressure to get Gabriel in a school environment.

"I knew I needed to make some changes, because I had to find a new line of work and I was determined to change the way he attended school," she said.

Dispenziere had been a learning leader adviser at Paul Mitchell Schools, "teaching classes, hiring, a little bit of everything," she said of the cosmetology school. It was a job she loved, but it required too much time on her feet. So she sold her house in California and used the profits to renovate a 1,400-square-foot former coin laundry that she leases. She only does about one appointment a day herself to stay off her feet, but has a staff of

See COVER STORY on G8

Forwarding the kindness

When most everyone else in the United States is fixated on preparing or enjoying a Thanksgiving feast, Raquel Dispenziere focuses her attention elsewhere.

"My sister is really good at random acts of kindness," Chelsea Dispenziere, 27, said of her older sister. Chelsea, who also lives in Riverhead, will join her sister and her highly allergic nephew Gabriel and "go tape dollars on vending machines or gas pumps or bus stops. We went to the fire department and gave them a pie. That was risky, but it was sealed. We left an umbrella at a bus stop and got a kit together for someone who was homeless.

"We've also gone through

a drive-thru and not gotten anything, but paid for the person behind us," she said.

Gabriel keeps his distance from the food while fulfilling his special role: "He'll hold out the money," his mother said.

Nice to meet you

Before meeting Gabriel, certain steps must be taken:

1 DO wash your hands.

2 DON'T eat before you come.

3 DO make sure you've removed any animal hair if you've been around the furry set.

— CARL CORRY

Connecting with his class

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COVER STORY from G6

four for the eight-seat salon.

Gabriel studies in a bright-orange room in the rear of the salon, which is across the street from Town Hall in Riverhead and has a window so his mother can peek in on him. He spends six days a week there studying and playing games, especially Minecraft.

"I wish I could walk around the whole building, but sometimes there is food, so I'm in this 5-by-5 area," Gabriel said.

Since the start of the school year, Mattituck resident Tanya McGowan has tutored Gabriel daily for two hours a day. Though she said he has his down days, McGowan, 53, describes him as "awesome," among other descriptives.

"He's bubbly," she said. "He's mostly positive, he's very intelligent, very outgoing, very eager to learn. And he doesn't get easily frustrated. When I go in there, every day I go out smiling or laughing."

Gabriel has a feeding tube in his stomach and is solely fed a formula made from amino acids that contains no food proteins.

"Most kids don't fail every food, so we're always on this mission to try and find that there's some crazy food out there that he wouldn't react to — that maybe he could actually eat," his mother said.

Gabriel goes to Stony Brook University Hospital about twice a year for in-hospital trials of foods. In September, he tried quinoa. Before that, bison. There is the Center for Pediatric Eosinophilic Disorders at The Children's Hospital of Philadelphia, but Dispenziere said more regular visits there are "hard because of insurance."

When they're not in the salon, Gabriel and his mom spend a lot of time at doctor appointments, the beach — where there's usually no food around — or with Dispenziere's sister Chelsea, her father, Michael, and stepmother, Susan, and extended family, all of whom live in the Riverhead area.

Gabriel, a yellow belt in karate who has since stopped attending because of scheduling restrictions, said among the favorite things he has done is to go to local event spaces that have



Raquel Dispenziere, Gabriel's mom, center, proudly watches her son participate in his first school concert by use of the VGo.

trampolines. "There's all different kinds of games, like there's basketball and there's dodgeball and there's regular jumping, and I can do all different types of tricks. Sometimes we have to leave because there's a birthday party with cake going on. But it's fun while it lasts."

When it comes to her own diet, Dispenziere said she doesn't like to eat in front of Gabriel, so she'll eat late at night in her bedroom or sneak in something.

Gabriel is allowed to have cotton candy and rock candy because they are made from sugar and don't have food proteins. He can also have shaved ice.

After adding the reading class at Aquebogue Elementary, more hours of classroom interaction were included throughout the week.

The VGo arrives

Then in March, Shilling reached out to Peggie Staib, the assistant superintendent for educational services at Eastern Suffolk BOCES, who happens to be the mother of one of Shil-

ling's former students and previously was a teacher and administrator in the Riverhead school district. Shilling asked her whether she could help procure a VGo.

Eastern Suffolk BOCES didn't have one, but Western Suffolk BOCES did, and it agreed to lend the system to Aquebogue Elementary for the remainder of the year. It's another academic high point Dispenziere recalls with striking clarity.

"I remember Mr. Shilling called and said, 'April 1. We're going to be able to get to use this,'" Dispenziere said. "Mr. Shilling asked that I try to surprise Gabriel. That was the hardest secret I've ever kept in my whole life, ever. But I tricked him."

"When Mr. Shilling told me it was time to connect on the VGo, I walked back with the iPad in my hand. I said, 'Gabriel, I'm sorry, you're not going to be able to FaceTime with your class anymore.' He just looked up with the saddest face ever. I felt so mean. And he said, 'But why?' I said, 'Well, click on this.' So he unlocked the iPad and

saw the VGo app and said 'Really? Really, Mom?' I said, 'Yeah.' I cried all day."

What a difference a robot makes.

"I saw really only the class, the teacher and the desk" with FaceTime, Gabriel said. "But now I can see everything."

The current VGo is a replacement for the initial one, which had some technical glitches. It came directly from the company that manufactures the VGo. (The robot costs about \$5,600, plus a \$60-\$90 monthly subscription.) When Gabriel becomes a fifth-grader in the fall, there's no guarantee he will have access to one at Pulaski Street School. Shilling and others have been trying to make it happen, but nothing has been solidified.

"The world should know that we can do these things and should do these things now," Shilling said. "Gabriel deserves an education as much as anyone."

The VGo allows Gabriel to maneuver the camera, turn around and even roll down hallways if the Wi-Fi connec-

tion is good enough. He now goes to music and chorus. He even joined the chorus' June 1 spring performance and gave an introduction to one of the songs via VGo.

Dispenziere was in the audience for her son's latest educational triumph. She got to Aquebogue Elementary a little early and for the first time saw the VGo system Gabriel uses.

"It was just so, so amazing to see him," she said. "He said, 'Hi, Mommy,' and wheeled around."

When it came time for the performance, Gabriel remotely drove the VGo out with the rest of the class. He was given a special introduction and introduced one of the songs. When he was done, he gave a bow on the other side of the screen.

Dispenziere cried tears of joy, and she wasn't the only happy one.

Gabriel "was so proud to be up there with the rest of the kids, singing and being part of the group," she said. "He was so excited all night. He was singing all the songs all night."

RANDEE DADDONA