

She Survived a Brain Tumor at Age 4. It Was Just the Start of Her Fight.

The Neediest Cases Fund

By JOHN OTIS

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From right, Rosa Fraticelli and her daughters, Allia and Ariel Villa, on their way to visit Ms. Fraticelli's mother in the Hell's Kitchen neighborhood of Manhattan. Credit Laylah Amatullah Barrayn for The New York Times

By the time Allia Villa underwent emergency surgery, an aggressive brain tumor had paralyzed the right side of her body. She was 4 years old.

Hours after the procedure, she awoke, turned to her mother and waved hello, with her right hand.

"It was our first glimpse of hope," recalled her mother, Rosa Fraticelli, 43. "We were very relieved."

The surgery and the frightening circumstances that preceded it occurred in 2004. Allia, now 17, developed a lazy eye just as her older sister, Ariel Villa, had when she was a toddler. But it was Allia's dramatic personality shift that truly alarmed Ms. Fraticelli.

"She became very withdrawn. She was depressed, crying all the time," Ms. Fraticelli said. "That's not how she was. She was always a happy-go-lucky child, very sassy, very hyper."

Because the change in Allia's behavior coincided with her starting prekindergarten, pediatricians believed separation anxiety had brought it on. But Ms. Fraticelli, a physical therapist assistant who was working with patients who had traumatic brain injuries, had an inkling that something worse was happening.

After visits to multiple doctors, an optometrist discovered that Allia had swollen optic nerves. She was rushed to a hospital in Manhattan. Paralysis set in on the way there.

Doctors said Allia had an atypical teratoid rhabdoid tumor, a rare, fast-growing cancer of the brain and the spinal cord.

Surgery a few days later alleviated the swelling in her brain. Allia's restored mobility reassured Ms. Fraticelli, as did other improvements.

"She said: 'These people are starving me. When am I going to eat?'" Ms. Fraticelli said. "That sassy attitude was back."



Allia beside a childhood photo at her grandmother's home. After her brain tumor was discovered, Allia was given less than a 50 percent chance of survival. Credit Laylah Amatullah Barrayn for The New York Times

The consolation was fleeting. Allia's tumor was malignant. She was given less than a 50 percent overall chance of survival.

The St. Jude Children's Research Hospital in Memphis forecast a better chance of survival. So Ms. Fraticelli made the difficult decision to move south in November 2004, leaving Ms. Villa, then 10, in the care of relatives in New York.

The absence of her mother was difficult. "Even from a young age until now, my mom is my best friend," said Ms. Villa, now 23. "It was hard not having them around."

Ms. Fraticelli and Allia lived in Memphis for nearly a year. Allia had a second surgery within the first month. She received four rounds of chemotherapy, a bone-marrow transplant and radiation treatment, which successfully purged the cancer from her body.

When Ms. Fraticelli and Allia returned to New York in August 2005, the transition period was more difficult than Ms. Fraticelli had expected.



Allia and her family at her grandmother's apartment. Much of Ms. Fraticelli's time is now spent caring for her mother, who has dementia. Credit Laylah Amatullah Barrayn for The New York Times

"You're kind of in a bubble over there where everyone is sick," she said. "You see all the kids are the same as yours. They're all bald and they're all going through the same thing. You come back to real life and it's like, 'Where do we fit in now?'"

For the next two years, Allia and her mother returned to Memphis every three months for checkups, and then every six months over the next three years. They now make the trip once a year.

Chaos and stress were ever-present at home, Ms. Fraticelli said, and in addition to trying to care for her younger daughter, she wanted to ease the anxiety and loneliness of her older daughter.

Ms. Fraticelli enrolled Ms. Villa in Catholic Big Sisters and Big Brothers, an affiliate of Catholic Charities Archdiocese of New York, one of the eight organizations supported by The New York Times Neediest Cases Fund. Ms. Villa and her mother said the help did wonders for Ms. Villa, who was being bullied at school and keeping it from her mother.

"I knew there was so much on her plate," Ms. Villa said. "I just felt like I didn't want to add onto that."



After Allia's tumor was diagnosed, she and Ms. Fraticelli lived in Memphis for nearly a year so that Allia could be treated at St. Jude Children's Research Hospital. Credit Laylah Amatullah Barrayn for The New York Times

Today, Allia's cancer remains in remission. She has permanent hair loss on the left side of her head, which she conceals with a baseball cap, and cataracts and thyroid problems. Last summer, she began having seizures, though they have subsided with medication.

Additionally, Allia has learning disabilities. She attends Cooke Center Academy, a special needs high school in Lower Manhattan. After graduation, she will attend Cooke Skills, where she will learn job skills and how to live more independently.

Allia has a taciturn nature and difficulty socializing. In May, she got a Big Sister of her own: Sarah Hill, director of development at St. Stephen of Hungary School. The pair have begun exploring parts of the city and attended a New York Rangers game on Sunday.

"It's a highlight to my life," Ms. Hill said. "I don't know if she knows she's giving back to me as well."

Much of Ms. Fraticelli's time is now spent caring for her mother, who has dementia and lives just three blocks from the family's two-bedroom Section 8 apartment in Hell's Kitchen.



The family at a doughnut shop in Hell's Kitchen. In addition to caring for Allia after returning from Memphis, Ms. Fraticelli, left, had to ease the anxiety and loneliness of her older daughter. Credit Laylah Amatullah Barrayn for The New York Times

Money is tight. Ms. Fraticelli is a registered nurse, but her current family responsibilities allow her to work only part time as a receptionist at a radiology office. Ms. Villa also works part time, at a waxing center. The family receives child support from the girls' father, who is active in their lives, and Allia receives \$550 each month in Supplemental Security Income disability benefits.

In October, Catholic Charities used \$377 in Neediest Cases funds so Allia could replace her 10-year-old computer. An avid illustrator, she uses the new one regularly to produce art, and she sketches almost every day.

One image depicts the stooped figure of a girl adorned with a halo, devil horns and bat wings; her face is concealed by long hair. Allia said it represented the confused emotional state of a child facing both the trauma of cancer and the invasive, rigorous processes used to destroy it.

Ms. Fraticelli, who hopes to return to nursing next year, explained that her family meets adversity head-on. She has high expectations for both of her daughters.

Ms. Villa recently earned her photography degree from Fashion Institute of Technology and has taken a few freelance jobs. Her goal is to balance a photography business with a career in teaching.

Ms. Fraticelli is confident that Allia will embark on an equally fulfilling path.

"I always told her with all the difficulties that she's had, she will be a productive member of society," Ms. Fraticelli said. "There's no reason for her not to be."