

Death reunites sisters who shared life

Younger of two girls afflicted with rare disease to be laid to rest next to sibling today

NISKAYUNA -- Even late at night, fighting sleep in the back seat of her mom's minivan, Alyssa Barbiero, 8, would always remember her sister as they drove by the cemetery where she was buried, a mile from home.

"Good night, 'Bri," Alyssa would say. It took a lot of effort. Those were all the words the little girl could manage to say in honor of her big sister, Sabrina.

A neurological disorder had slowly robbed Alyssa's speech and stolen her muscle control. She spoke mostly by pushing buttons on a computer keyboard. Alyssa would fall into painful spasms that caused her tiny body to pulsate and writhe painfully, uncontrollably. No drugs helped.

Alyssa had once drawn strength and comfort from Sabrina, who had suffered the same way.

Now, she was the only one.

Neurodegeneration with Brain Iron Accumulation, NBIA, is an exceedingly rare disease of the nervous system. It occurs due to a recessive gene in both parents, who are carriers and have no symptoms. Often confused with cerebral palsy, there is no known cause or cure.

There is a one-in-a-million chance for a child to be diagnosed with NBIA.

Among parents with one child who suffers from NBIA, the likelihood that their other children will have NBIA is from 25 percent to 50 percent.

The odds caught up with Gennaro and Anabela Barbiero.

Both girls died in the past eight months.

Today, they will bury Alyssa beside her sister in Most Holy Redeemer Cemetery off Route 7 in Niskayuna.

Sabrina died on March 21 at age 9. Alyssa died Monday. She was 8.

"I'm numb. It hasn't sunk in yet that they're both gone," their mother said Wednesday.

"I was preparing how to get through Christmas without one," she said. "Now, how will we get through it without two?" she asked.

While other parents were feeling stressed out about toy shopping and decorating for the holidays, the Barbiero's were struggling to come to terms with their loss even while they celebrated their daughters' brief, joy-filled lives.

Alyssa loved her black Labrador retriever, Emmy, more than anything. Except maybe the beach.

When she could no longer walk, Alyssa would sit in a baby stroller and let the dog pull her around the neighborhood.

Even when her body was breaking down, Alyssa loved to float on her back in a lake or a pool. Her dad's arms cradled her as she floated and she gazed up into a wide, blue sky. Into heaven. To 'Bri.

The girls would say a prayer in bed each night, "Now I lay me down to sleep ..."

They had put their beds side-by-side in the same bedroom.

Alyssa ended her prayer with, "Love you, 'Bri."

"Love you, 'Ly 'Ly," her sister Sabrina would respond.

Alyssa usually fell asleep with a SpongeBob SquarePants book on her chest instead of a teddy bear.

Both girls were third-graders at Birchwood Elementary School in Niskayuna when they died and had previously attended Rosendale School.

Their classmates have twice made sympathy cards.

"I'm very sorry that Alyssa died," Felicia wrote. "I almost always think of the good things like she's up in heaven with her sister getting anything she wants."

On her card, Felicia depicted the sisters as two angels, smiling, floating above the clouds.

Classmates at Rosendale planted a red maple in Sabrina's memory. They tied purple ribbons on the branches. Purple was Sabrina's favorite color. The kids replace the ribbons when they begin to fade.

Her classmates will plant a tree for Alyssa, too.

"In class she brought joy," Megan wrote. "I loved her beautiful smile. Alyssa will be happy in heaven."

With Sabrina's death, the decline came slowly and inexorably, over the course of a year. The parents had time to prepare.

With Alyssa, it was abrupt and shocking. Three weeks ago, she appeared stable.

None of the doctors who treat this disorder or the other

families who have children who suffer from it have seen such a rapid death.

The only explanation doctors have offered is that Alyssa never recovered from the emotional trauma of her sister's death.

The little girl may have died of a broken heart.

"She missed her sister so bad," their mother said of Alyssa.

"They didn't like to be apart. Whenever one was gone, the other one looked for her sister."

The couple -- he's 38 and she's 39 -- have no other children and plan not to have any more.

Their relatives are now being tested for the disorder. So far, it has not been found in anyone else in their family.

The couple moved from Montreal six years ago. They relocated partly for the husband's job, but also because the Canadian school system does not mainstream children with special needs.

"We wanted them to have a full and regular life as long as they could," the father said.

Their daughters attended mostly mainstream classes in the Niskayuna school district.

Their father, a research chemist at Schenectady International, is a board member of NBIA Disorders Association. Their mother quit her job to devote herself to her daughters' care. The couple raised \$23,000 in honor of Sabrina last year. His company's foundation contributed \$50,000.

The license plate on their mom's van reads SABALY, the first three letters of her daughters' two names joined together.

The girls were inseparable, even when Sabrina was pulling Alyssa's hair. Or when Alyssa fought back with a bite to Sabrina's arm and ended up on the living room stairs, in timeout.

SABALY. It was the sisters' secret word, the middle name they gave the dog, Emmy, who Alyssa got as a puppy as her Make-A-Wish Foundation gift.

Emmy nuzzled alongside Sabrina, comforting the girl as her body shook with terrifying spasms. The dog still sleeps in the bedroom that the sisters shared, near the spot where Sabrina died.

On Wednesday, Emmy was out of sorts, barking and jumping on visitors in unusual behavior.

Even a dog could sense there was something terribly wrong.

There are two girls buried alongside each other in a cemetery today.

There are no answers.

Only a secret word. SABALY. Forever.



www.sabaly.org