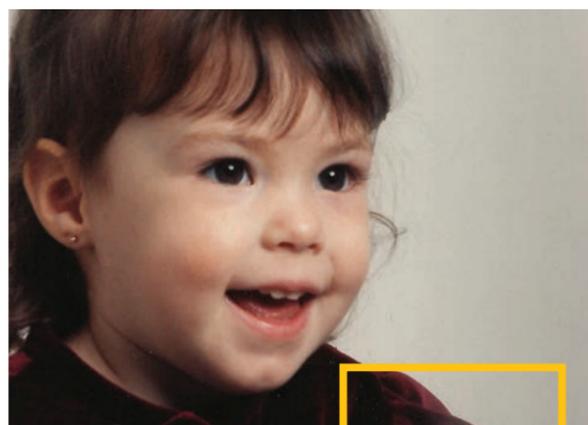


MARIANNE'S MISSION

Guy Brodeur and Ginette Larose, a solid, caring couple, were already the proud parents of Guillaume, Élisabeth, and Xavier when little Marianne was born on October 21, 1994. A beautiful pink baby who was already smiling just an hour after being born, she nonetheless proved highly vulnerable to infection, gained little weight, and gradually displayed poor balance.

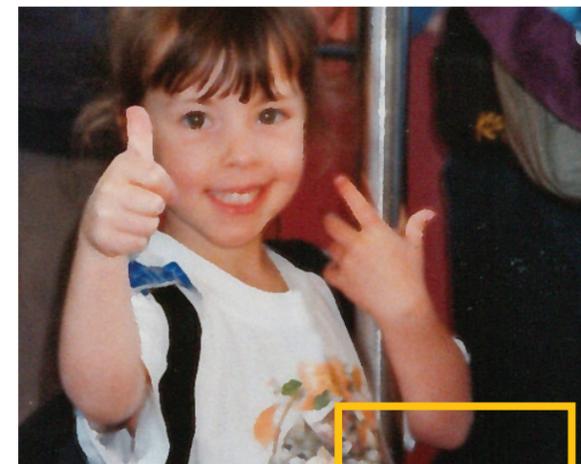


Marianne, age 2

Marianne's development was atypical, to be sure, but doctors weren't overly concerned and reminded her worried parents that some kids just take longer to get going. But Ginette's maternal instincts told her otherwise—she felt as though a dark cloud was hovering over their frail princess. But the doctors assured her it was merely delayed development and a few motor skill problems. Still, her condition was deemed serious enough to warrant a referral to the preschool and kindergarten program at Marie-Enfant Hospital. With close supervision and constant stimulation, Marianne developed by leaps and bounds and, when it was time to start grade 1, she was deemed ready to move to the neighborhood elementary school. An endearing student who got good grades and loved going to school, Marianne made an impression on teachers and classmates, despite feeling that everything was moving too fast—a secret she confided only to her Mom.

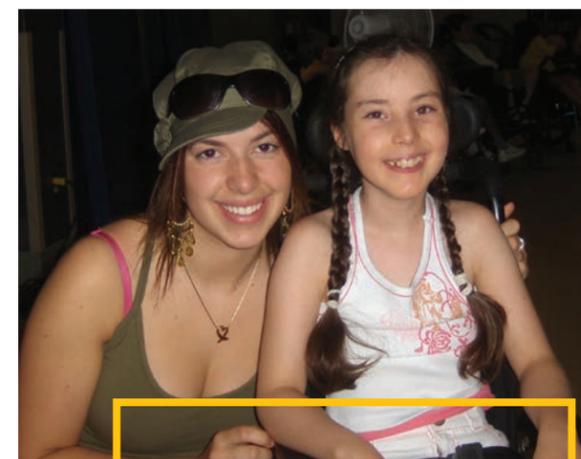
Marianne was later struck by a series of pneumonias that left her weak and prompted a full battery of hospital tests. The verdict came in November 2001: at seven years old, this sweet child with angelic features and a candid smile was diagnosed with ataxia-telangiectasia, a degenerative disease so rare that her neurologist had only seen one other case in 30 years of practice. Very little was known about the condition, including its development, prognosis, and possible treatments. Guy and Ginette learned that each case is unique and that each patient has a different experience. But the multiple effects on Marianne's immune system were clear, and explained her repeated infections.

As Marianne's need for physiotherapy, occupational therapy, and respiratory therapy grew, it became clear the little neighborhood school she loved so well was no longer suitable for her needs. With great dignity and surprising wisdom, Marianne explained to her whole class that she would be leaving the school because her body needed special care. She was transferred to Victor-Doré, a school for children with disabilities, and soon declared that she felt "right at home." Guy and Ginette, on the other hand, were just starting to come to terms with their daughter's diagnosis. Their emotions veered between overwhelming anger at the injustice of the situation and a profound desire to stand by Marianne and support her in her difference.



Marianne, age 6

Between 2002 and 2007, life took on a certain normality for the Brodeur family. Marianne received monthly antibody injections and showed great strength in processing and grieving her successive losses. As the insidious disease progressed, Marianne gradually transitioned from a walker to a wheelchair—painful steps for Guy and Ginette, who also had to deal with the reactions of their three elder children and help them process the emotions that came with their little sister's illness. But the family stayed united. Guillaume, Élisabeth, and Xavier each pitched in, in their own way, to see to Marianne's well-being. With kindness and generosity, they helped with minding, homework, meals, bedtimes, and medication. Utterly devoted to their family, Guy and Ginette managed to provide a life as normal as possible for their children, with sports, trips, and social activities. As they put it, "Life goes on."



Marianne, accompanied by her sister Élisabeth, on her last day at Victor-Doré School

At the beginning of 2007, Marianne's lungs grew significantly worse. After several tests that provided little insight, her doctor decided to try an open lung biopsy—a risky surgery for someone in Marianne's condition. She spent the next 11 days in intensive care with a breathing tube. With extraordinary patience and courage, she stayed positive as she fought for her life. The medical staff were touched by her sweetness and the unspoken gratitude that she managed to convey every time she looked at them. Unfortunately, the diagnosis was devastating and definitive: Marianne had pulmonary fibrosis, a disease associated with ataxia-telangiectasia that affects only 25 % of sufferers. The prognosis was bad. And to make matters worse, the cortisone injections—her only hope for treatment—failed to have any effect.

It was a major blow for Ginette and Guy, who then knew that their daughter's days were numbered. With her lungs in critical condition, Marianne spent the following months at the hospital. Life at home took a sharp turn as Ginette began a permanent watch by her daughter's bedside. With speech growing increasingly tiring and difficult, Marianne had a hard time communicating with hospital staff. For both parents, leaving her alone was not an option. So Guy, a general contractor, had to run his business as well as his household of three teenagers—with all their schoolwork and extracurricular activities—between hospital visits. Looking back on those tumultuous months of strain, worry, and sleepless nights, today Guy has only these soft, tender words for his wife: "We were a really good team."

Despite Marianne's unstable condition, the doctors gave the Brodeur clan the green light to head to Walt Disney World, a trip made possible by the Children's Wish Foundation. With an arsenal of medication, oxygen tanks, and a private nurse in tow, the whole family took off for the magic kingdom. When they got back, Marianne asked to be able to sleep at home before returning to the hospital. She was in for a big surprise. Her room had been completely transformed and was now decked out in one of her favorite themes: butterflies. As she marveled at the walls, furniture, and accessories, Marianne felt as though she was wrapped in a warm, soft cocoon. But the special moment was cut short by her illness, which forced her back to the hospital.

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Marianne, back from Walt Disney World

Exhausted, Guy and Ginette decided to hire a private nurse a few nights a week to help them catch their breath. Reflecting on those days, Ginette can now say that "In life there are no coincidences, only meaningful encounters." And so Heather came into their lives and told them that she also worked at Maison André-Gratton for The Lighthouse, Children and Families. The organization's end-of-life care program was still in its infancy, but in Heather's mind there was no doubt it would be the perfect place for Marianne and her family. They began administering morphine to the girl at home and, despite her fragile condition, The Lighthouse agreed to take her in for a weekend. In the middle of the night on Saturday, Marianne suffered an acute respiratory attack that required immediate medical intervention. "Thank goodness Marianne was at The Lighthouse at the time," Ginette later recalled. "If it weren't for the medical staff on hand, it could have been the end for Marianne, and the experience would have been so much more traumatizing for her and for us. From that moment on, we knew for sure that we were in the right place—that The Lighthouse was shining into our lives for a reason."

Marianne stayed at The Lighthouse from February 16 to March 5, 2008. In a way she knew she was something of a pioneer, helping to forge what would become The Lighthouse's palliative care department. Life at The Lighthouse was a warm bubble of humanity for Marianne and her family. They felt at home there and quickly realized it was a place where each of them could get the care, attention, and support they needed. From the medical personnel to regular staff and volunteers, everyone kept a watchful eye, ever mindful of the needs of each member of the Brodeur family. They all did everything they could to give the family lasting memories together—special moments to add to their memory chest.



Marianne surrounded by her family

The holidays came and went and Marianne kept holding on. In a particularly touching moment—one that Ginette will never forget—Marianne turned to her mother as she was brushing the girl's long brown hair. Puzzled, she asked, "Why am I not dead yet?" After a moment of thought, Ginette replied that Marianne had been born for a reason, that she had something important to do during her time on Earth and that it was up to her to discover that special mission.

Although Marianne still clung to life, her condition remained no less critical, and in the weeks following the holidays the family slipped into a permanent state of extreme anxiety. Medical equipment was able to keep Marianne alive, but her respiratory attacks grew more frequent and unpredictable. The family was perpetually on red alert and kept a constant watch over Marianne, ready to intervene at any moment. You could cut the air with a knife. Faced with the fragility of Marianne's life, her family felt overwhelmed and utterly helpless.

Forced by her illness to leave school suddenly, Marianne had missed the chance to say goodbye to her much-loved friends at teachers at Victor-Doré. So the family piled into a van with a nurse and an oxygen tank and headed off to school! Marianne knew she didn't have much time left and made the most of her farewell visit, taking a solemn tour of the school, saying hello to friends and staff, and touching everyone with this gesture full of meaning for both Marianne and the people at the school.

A few days later, the little group headed to the Botanical Garden for the Butterflies Go Free Exhibition. As her parents later recalled, "She was so beautiful, her face full of wonder—a mix of contemplation and serenity. She watched the little cocoons, hoping that one of them would open and a baby butterfly would fly out. Magic, unforgettable moments that The Lighthouse made possible."

The Brodeur family's daily routine, which was anything but routine, was punctuated by picnics, hospital clown visits, crafts—including a workshop where they took clay molds of Marianne's little hands—and hours spent watching the fish in the huge aquarium in The Lighthouse dining room. It was a time of vivid emotions, but the family felt supported, cared for, and loved. There was humanity, respect, and dignity in the words and gestures of everyone who shared this intensely significant time with the Brodeur family.

Guy, Ginette, and the children slept steps away from Marianne's bed. One by one, they lay beside her, stroking her hair, singing her lullabies, and whispering their love. The days and nights passed, but time seemed to stand still. On March 5, 2008, at 2:22 p.m., the sky grey with clouds and a winter storm blanketing the city in snow, Marianne floated away in a soft fluttering of wings to join her butterfly friends, in peace and without pain, surrounded by her loved ones. At that same moment, a strong beam of sunlight cut through the clouds and fell on The Lighthouse; a sign, no doubt, that Marianne had accomplished her mission. The first little girl to die at The Lighthouse, Marianne paved the way for those who would follow. She embodied the vivid passion for life and the intense beauty of the present moment that children and their families experience as the end approaches.

The Brodeur family hasn't left The Lighthouse—not really. Two weeks after Marianne's death, they were there for our big annual evening fundraiser. And every year since, they've lent a helping hand for various Lighthouse fundraising activities. The children, now grown, continue to contribute and recruit their friends to the cause. In 2011 Élisabeth told Marianne's story in a remarkable speech delivered during a Lighthouse benefit evening. The Lighthouse, she explained, was Marianne's version of "heaven for sick children." Far from paralyzing the family in suffering and grief, getting actively involved is a way for them to continue Marianne's mission—to keep the candle she lit shining brightly in their hearts.

Through her warm presence and infectious love of life, Marianne moved, touched, and transformed all those who crossed her path. Her dad says she taught them how important it is to live in the present, to appreciate the little things, to always give more, to let go, and to persevere. Her mom says that Marianne gave her parents, brothers, and sister the chance to become better human beings, to be open, to understand people's differences, and to seek out honest, sincere human relationships. But Marianne's light shines well beyond the borders of her little family. She's in the very walls and foundations of Maison André-Gratton, where she gave meaning to The Lighthouse's pediatric palliative care project, and put a face to the noble mission of treasuring—and enjoying—life until the very end.

