

Family Fight to Save Grace

June 18, 2008

By April Drew

LITTLE Grace O’Gorman has the ability to turn a bad day into a fantastic one with her soulful brown eyes and her ear to ear smile.

Grace, or Gracie to her parents, shows off her red lollipop that her mommy had given her minutes earlier in a cozy breakfast diner on the corner of 79th Street and First Avenue in New York.

“Lolly” she smiles, as she silently studies it and then sticks it in her mouth.

Grace is always smiling. She smiles when she hears her six-year old sister Alice’s voice, she smiles when her name is spoken and she smiles the most when you admire her smoothie concoction — made of water, scrambled egg, butter and her lolly.



“Drink,” she asks.

It’s that smile that Kevin and Millicent Gorman — Grace’s parents — never want to see disappear from their daughter’s face.

Grace, 2, has cancer, neuroblastoma — stage four — the last stage. Her little delicate body has been undergoing rigorous treatment since October, yet through it all Grace never complains, not when needles are inserted into her tiny body on a daily basis, not when she has to spend endless hours in the hospital for tests, and not even when doctors surgically removed a tumor the size of her dad’s fist from her belly.

Neuroblastoma is a cancer that forms in the nerve tissue. The cancer often begins in early childhood. Sometimes it begins before a child is born.

It is unknown when Grace first developed it. By the time doctors find the cancer, it has usually spread to other parts of the body. There are approximately 10-15 cases a year in Ireland, 80-100 in the U.K. and 600-700 per year in the U.S.

Grace and her sister Alice are the daughters of Dr. Millicent Stone from Co. Wexford and civil engineer Kevin O’Gorman from Cork. The family lives in Bath, England but have been in New York since January. They put their lives on hold in order to seek the best medical treatment in the world for their ailing daughter.

“We were told from the very outset that antibody treatment (the antibody is derived from a mouse) in the U.S. is the new way to go and the possible solution to our problems,” said Millicent.

Research showed that Grace's best chance of survival — 80% — was at Memorial Sloan Kettering Hospital in New York. In the Bristol Royal Hospital for Children in England, the O'Gormans were told Grace had a 20-25% chance of outliving her cancer.

Up until October of last year, the O'Gormans had everything they ever wanted — two beautiful daughters, two wonderful jobs, great friends and family and a lovely house. Within a matter of minutes their happiness came crashing down around them.

Grace developed a slight swelling on the right side of her face. Naturally worried, the O'Gormans brought her to the doctor. Not to worry they were told, it's probably only Mumps.

Mumps would have been a blessing. As the swelling got bigger and harder during the days ahead, Kevin (Millicent was in Texas at a conference) took his daughter to the accident and emergency.

"She was so happy the morning I took her in I was nearly not going to bother," said Kevin.

Never in his wildest dreams did he think doctors were going to tell him his baby girl had cancer.

Further testing revealed that the swelling on Grace's face was a secondary tumor. The first was the size of an adult's fist growing in her stomach. He made the heartbreaking call to Millicent in Texas.

"Our child has a tumor," he said.

She was on the next flight home to be with her family. She was distraught. Further tests were carried out on little Grace.

"Every long bone in her body lit up with cancer," says Kevin. "The tumor in her face was secondary, the one in her stomach was the primary tumor and there was another four or five throughout her body. Neuroblastoma travels at a very rapid rate through the nervous system."

Within weeks, Grace was undergoing chemotherapy and taking several antibiotics for various side effects the chemo was causing and yet she never complained — she just smiled.

Millicent explains, while swiftly removing a jug of milk from the table before Grace added it to her "smoothie," that their youngest daughter never once displayed signs of being sick before the swelling in her face appeared.

"It was a total shock to us," she said.

Grace began several bouts of chemotherapy in England. "The tumor began to reduce but Grace was very, very sick," Millicent remembers.

"And," Kevin added, "Bristol hospital only gave Grace a 20-25% survival chance."

Against the "better judgment" of some doctors who turned their nose up at the idea of the O'Gormans traveling half way across the world to treat their daughters — "America is a strange place," they said — Kevin and Millicent knew if they wanted to save her life they needed to do get on a plane and come to New York.

"I don't think you could live with yourself if you didn't do everything in your power to save your

daughter's life," said Kevin, with tears in his eyes.

"Sloan is giving us what no one else in the world can give us," said Millicent.

While her parents, visibly upset by their daughter's sickness, continue to tell her story, Grace proudly shows off the areas in her body where she has received numerous injections.

"Mr. Tubby" she points, then looks again. "All gone," she smiles.

She turns her attention back to her smoothie. "I made milk," she said with a twinkle in her eye and not a care in the world.

"See," said Kevin, his heart breaking, "Just look at her, she is gas. She is just so happy."

After borrowing \$350,000 from Millicent's brother — the deposit needed to get Grace on the antibody treatment — a flight was booked and the O'Gormans made the necessary arrangements to set up some kind of temporary life in New York. They rented an apartment on 79th Street and Second Avenue in Manhattan, close to Sloan Kettering, and they enrolled Alice in the Rudolf Steiner School around the corner.

After weeks of tests and treatments, doctors at Sloan removed the tumor Grace had growing in her little stomach on January 21. "They did the surgery on a Monday and it was a huge success," said Millie gratefully.

Four days later, Grace started chemo. "The chemo was four times the concentration that she had at home so she was incredibly sick for three weeks. After three days her bone marrow completely crashed. But they told us that was normal. She had no white cells for 21 days," her mom added.

They worried and worried, but Grace became strong again. Her little body was ready to begin the treatment her parents brought her to the U.S. for.

Ironically enough — maybe for good luck — the treatment began on March 17, St. Patrick's Day. Millicent describes the procedure:

"Over half an hour, the antibody is given to Grace. It attaches to all of her nerve endings, causing her extreme pain."

Kevin adds, "You should see her, her whole body crunches up and she screeches."

The treatment wipes Grace out. She spends the remainder of the afternoon in bed. Her sister Alice gets upset too. She can't understand why her sister is so sick.

Grace's treatment doesn't come cheap. The O'Gormans, who are in the U.S. on a visitor visa and cannot seek employment while in the country, have to pay approximately \$100,000 a month for Sloan. In addition to the money paid to the hospital to date, they have spent an additional \$10,000 approximately on drugs for Grace.

"Only American insurance covers American hospitals so we can't use our U.K. insurance," explained Kevin.

Friends and family of the O’Gormans have been doing everything in their power to help their friends, including hosting and organizing several fundraisers in Ireland and England. As a result thousands upon thousands of dollars has been raised but it still isn’t enough.

This Saturday, the County Cork Association in New York will also host a major fundraiser to help alleviate some of the cost associated with Grace’s treatment.

At the time of interview, Kevin said they were in approximately \$150,000 debt. Kevin and Millie are funding their stay and cost of living in New York themselves. Every penny raised by the fundraisers goes directly towards helping to save Grace’s life.

Grace, as evident by her constant chat and glimmering smile, is responding wonderful to the treatment. “She is doing very well,” said Millicent with a smile. “We are pleased because she doesn’t need to have a bone marrow transplant. A lot of kids die during those operation due to infections so we are very glad.”

If Grace’s body continues to respond well to the antibody, the doses will become less frequent and in time, if successful, it will rid her of all the cancer. If her body develops its own resistance to the antibody — which commonly happens — the treatment (along with the costs) will have to be started all over again.

For now, Kevin and Millicent take it one day at a time. “I don’t even think about tomorrow,” said Kevin, adding, “All we do is think as far as dinner time.”

For now, the O’Gorman’s wait patiently and think positively about their daughter’s recovery.

“We repeated the bone marrow test four times and it has been clear to date,” Kevin said. “We don’t see her as critically as we did last October which allows us to think more positively.”

A fundraiser, including music by Donie Carroll of Cork City and light refreshments and food, will be held on Saturday, June 21 between 8 p.m.-midnight, in the Cork Club and Bantry Bay Public House, 33-01 Greenpoint Avenue, Long Island City. The suggested donation at the door for this event will be \$20 and all are welcome.

For more information about Grace, go to www.graceogorman.com. All donations are gratefully received. Make checks payable to the Co.

Cork Association, Grace O’Gorman Fund.