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Anne Marie's Christmas

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"I'll be home for Christmas, if only in my dreams" (Kim Gannon).

"You are going home for Christmas, Anne Marie" the intensivist told the frail little girl while she lay in the pediatric ICU bed on a ventilator. Anne Marie's eyes lit up with excitement, a smile appeared on her face. This was the best news she had heard in almost a month of painful procedures, altered sleep cycles, and breathing at the command of a machine with regular suctioning of the tube. Now the end of this ordeal was within sight and she would be going home for Christmas.

Anne Marie was diagnosed as having acute lymphoblastic leukemia (ALL) at 8 years of age. She was undergoing methotrexate and cytarabine consolidation chemotherapy protocol for B-precursor cell ALL. After

finishing the first 1½ years of a 3-year chemotherapy regimen the family took her on a trip to Disney World on Thanksgiving. But the vacation was cut short on the first day at the park as Anne Marie developed fever and respiratory difficulty. The family rushed back to Detroit. There was rapid worsening in her condition, requiring mechanical ventilation with escalating support. Chest X-rays showed diffuse alveolar interstitial opacification with air bronchograms. Treatment was initiated for presumed *Pneumocystis carinii* pneumonia. The prognosis appeared grim, with frequent ups and downs. Anne Marie's mom kept vigil at the bedside. Christmas of 1985 was approaching quickly as she made some halfhearted preparations; she had two younger children and it was difficult for them to understand all that was going on with Anne Marie. But things changed, slowly at first. After a couple of weeks in ICU, Anne Marie's oxygen requirements started to decrease and the ventilator support was gradually weaned. Christmas was still 2 weeks away, and Anne Marie was getting better. Since she was expected to be extubated in a day or two the intensivist felt confident in making the declaration that she would be going home for Christmas.

Finally, the much anticipated day arrived and Anne Marie was extubated. She had a big smile that could only be matched by that of her mother's. Her voice was hoarse but that was to be expected. Everything else seemed fine for half an hour, but then Anne Marie developed increasing respiratory distress and loud-pitched inspiratory stridor. It was clear that she would not be able to sustain her breathing with airway obstruction of this severity.

"These types of things do happen sometimes after prolonged intubation," the intensivist said, trying to reassure the mother. "We will put a smaller tube in, put her on steroids, and extubate in a couple of days. Her lungs are fine. We still have enough time for her to recover and go home for Christmas."

Alas, the next two attempts at extubation met with similar results; a short period of apparent success followed by inspiratory stridor and severe retractions unresponsive to nebulized racemic epinephrine. Anne Marie could walk around the ICU hallway with an endotracheal tube in place without any oxygen requirement, and her lungs were fine. Endoscopy showed severe subglottic stenosis. It was clear that she was going to require tracheostomy for some time until her subglottic stenosis could be corrected. There were still 5 days left before Christmas. If tracheostomy could be done promptly, there was still time for sufficient healing to occur, a track to form, and she could still be home on Christmas Day. There was only one problem: the pediatric ENT surgeon was not available. The next couple of days were rough emotionally for Anne Marie and her mom. The intensivist was also very disappointed. The only thing that was keeping Anne Marie from celebrating Christmas at home with her family was the wretched endotracheal tube.

It was a simple idea. If Anne Marie could walk around in the ICU with the endotracheal tube, why couldn't she go home with it? The more the intensivist thought about it, the more the idea seemed attractive to him. He discussed it with the ICU staff.

"But we have never done this before," the nurse manager said. "Taking a patient home with an endotracheal tube! We should first clear this with risk management".

"Please don't," the intensivist said, "that will be the end of that idea. Better to apologize later than asking for permission and getting it denied".

An experienced nurse, an ICU fellow and a respiratory therapist eagerly volunteered to be accomplices in this "we have never done this before" idea. A strategy was formulated to handle possible adverse events and individual roles were designated. The idea along with its risks and safety precautions were discussed with Anne Marie's mom on Christmas Eve. She thought her van would be just perfect for such an endeavor, providing ample space for medical personnel, oxygen cylinder and intubation equipment. The intensivist told his sons that they could either open their Christmas presents in the morning without him or wait until he came back. They chose the latter option.

Anne Marie's face was beaming. It was Christmas morning and she was going home to celebrate. The trip to her home went without a hitch. The door opened and Anne Marie entered. The first thing she saw was her brother, sister and cousins sitting on the couch waiting for her. They were somewhat anxious about "the thing" sticking out of her nose that helped Anne Marie breathe. The anxiety lasted only briefly, and the children started doing what children do on Christmas mornings. The room was filled with joy and laughter. Presents were opened much to everyone's delight. Anne Marie was happy and excited. The intensivist, the ICU fellow, the nurse, and the respiratory therapist blended with the walls, unnoticed but content, experiencing this improbable scene.

After a couple of hours the intensivist said, "It's time to go back, Anne Marie".

Anne Marie nodded her head and mouthed "Yes, I know" without a twinge of regret. The siblings and cousins said their goodbyes and Anne Marie waved back at them with a smile.

It was one of the best Christmases ever for all involved. It was the greatest gift Anne Marie's mother and her family could ever have wished for. Rules were broken. Risks were taken. But a promise was kept, a dream came true, and a little girl was able to celebrate Christmas with her family.

Epilogue: Thirty years later, as Rosemary reflects on her experience, she is filled with a deep sense of gratitude. Being a nurse herself, she realizes the overwhelming odds her daughter had to overcome to survive the cancer and its complications, especially in the 1980s when the prognosis was considered poor and the doctors did not try as hard. During those 6 weeks in the ICU she saw firsthand the tireless efforts of the doctors, the nurses, and the respiratory therapists. To Rosemary, the ICU team gave Anne Marie not only the gift of their knowledge and skills but also the gift of their love and compassion.

Anne Marie is a nurse and works as a transplant coordinator of the Blood and Marrow Stem Cell Transplant Program at Barbara Ann Karmanos Cancer Center, Detroit, Michigan.

Compliance with ethical standards

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