

Our "Ride" With Heather: Perspectives from Caregivers

J. Thomas Megerian, M.D., Ph.D.

Kristen Megerian, LICSW

We will never forget our first encounter with Heather Siebert in 2000. Tom had just completed his Fellowship in Neurology at Boston Children's Hospital and was a "newly-minted" Attending in Child Neurology. Kristen had recently graduated with a Master's Degree in Social Work and had landed her dream job of working in the Neuroscience inpatient unit at Children's. For both of us, the pace was daunting, the hours were long, and the patients' needs were at times overwhelming. We loved every moment.

When Heather was first admitted to the unit, she was striking in both her appearance and symptoms. She was a little wisp of a teenage girl with a halo of tight curls that surrounded her apple-shaped face. Her lips were rosy-red and her eyes were bright blue. Heather was a cheerleader, a Straight A student, and by all accounts, an "All American" girl. Her beauty and spirit were only matched by the dreadfulness of her disease.

During those first few weeks, Heather would frenetically pace around the unit, seeming to take some solace in constant movement. She experienced frightening hallucinations, was very confused, and mumbled indecipherable phrases. Through this haze, however, we could see glimpses of the "true" Heather and knew that she was fighting her way back.

No one knew at the time that Heather would fight her way back to health countless times over the next few years, through repeated hospital admissions and infinite appointments. Heather's overarching diagnosis was never clear and certainly proved enigmatic to the medical teams who treated her. Informally, we referred to her constellation of symptoms as "Heather's Syndrome". It ravaged nearly every system in her body: neurological, endocrine, gastro-intestinal, respiratory, etc. In its most insidious form, "Heather's Syndrome" tried most arduously to ravage her spirit as well. While it might have had some hold on her body, it was no match for her character.

Heather grew up during those formative high school and college years under the cloud of acute and chronic illness. She couldn't get her driver's license on time. She missed so much school and all of the accompanying social opportunities and drama. She couldn't be carefree like her friends. She was forced to mature a lifetime in the blink of an eye. While at times, Heather gave in to her pain, fatigue, and despair, these moments were short-lived. Heather coped by the strength of her spirit, resilience, and amazing character. She had a great sense of humor and endeared herself to everyone fortunate enough to care for her. No one knew what Heather's prognosis and future was, but we were certain that Heather's convictions to get better would help. Against all odds, Heather pulled through all of her major and minor setbacks. We all rejoiced with each milestone, knowing how much stamina it required and effort she made. Heather had to learn how to walk again, how to talk again, how to dress and feed herself again. Eventually, she made it to the prom, to her High School graduation, to college, and to her own apartment.

Heather's resilience was due to the fortitude of her own character, and also because of the unwavering help of her family. Barb, more than a Mom, was her constant companion, friend, and coach. As with all pediatric chronic illnesses, "Heather's Syndrome" not only affected Heather, but the lives of her family members as well. Their sacrifices, commitment, and dedication to her were ever-present. They gave her unconditional support and love.

They also did not allow her to give up or use her declining health as an excuse to refrain from pursuing her dreams. Barb, especially, demanded that the vast team of providers at Children's work together and communicate in order to coordinate her complex care.

The former cheerleader had created her own cheerleading squad of sorts at Children's Hospital that comprised physicians, nurses, aides, and countless others. When Heather was feeling well, she relished in playing practical jokes and pulling pranks on the staff. We all loved to see that glimmer in her eye and those dimples in her cheeks. Heather's usual greeting to Tom was to say "Hi, Short, Bald Man". Her emails to Tom were addressed the same way. It became a term of endearment, one which Tom treasures to this day.

During these many years in which Heather frequented the hospital, we (Tom and Kristen) fell in love with one another. We like to think that our many hours working together on Heather's behalf brought us closer on many levels. Before we were engaged, we tried to separate our personal from professional lives. Heather unfortunately saw through our act and took great delight in knowing our "secret" even though we continued our denial. We now have 2 beautiful children together. Our children are a legacy of our time together at Children's Hospital and of the lessons our patients and families taught us. Our love and admiration for Heather, above all, reigns as exemplar of the experiences which bonded us together.

For Tom as a young attending, he expected to be taught by other, more senior physicians who had years of experience. In most cases, that certainly was the case. But not when it came to Heather. She was also an instructor all of those who came in contact with her. She defied the wisdom and experience of the most seasoned physicians. She broke novel territory with her disease and her treating physicians needed to use the methods of trial and error at times to successfully manage her symptoms. Humility and creativity were often necessary.

Heather was on the verge of death a few times. It was inconceivable that her body, so ravaged and fatigued, could recover. However, it was Heather's spirit and love for life that triumphed over her illness. Heather simply had more to do, more to accomplish, more people to love, and more lessons to teach. Heather's body ultimately lost this battle with her disease. But, as always, her spirit prevailed. That is no more exemplified by the tribute we pay to her today, and every day we remember the lessons she taught us. We will never forget our "ride" with Heather.

Read by Tom Siebert (Heather's Dad) at the 5th Annual Heather Lynne Siebert Memorial Ride in Meredith, NH on July 19, 2014 at Laconia Harley Davidson.