

The Broeniman Family

**A Story Of Family Love, Loss,
& Surviving Childhood Cancer
by Billy Soden**



**When it rains, look for rainbows.
When it's dark, look for stars.**

Jim and Amie Broeniman of Appleton, Wisconsin were enjoying the playful interaction and development of their 15-month-old daughter, Emma, just as most parents do. Every milestone was celebrated in that short journey from baby to toddlerhood. The private moments they shared as they each bonded with each other through play and love was beyond precious, and beyond words. That kind of love was the overwhelming gift that can only be experienced, not described. Little did the Broeniman's know that this love for each other, given to them in abundance, would soon be sabotaged with a diagnosis that would rock their world and change their lives forever.

Beautiful little Emma was just learning how to stand and walk. She couldn't contain her excitement as she amazed herself with the wonderment of her newfound mobility! As Emma's mom sat at the computer, Emma balanced herself with one hand on the wall as she bent her knees, bouncing happily. Her legs suddenly gave way and she fell to the floor landing squarely on her diaper-padded butt. For most, this would be considered nothing more than a sweet little toddler falling on her tush, one of many to come in the days and weeks to follow. Emma's fall, however, was followed by a snapping sound and Emma began to cry. She had broken one of her legs by merely bouncing with excitement.

Jim and Amie took Emma to the doctor's office where they performed some x-rays. Emma was diagnosed with congenital pseudoarthrosis of the tibia (CPT). Pseudoarthrosis refers to a "false joint," and the tibia is, of course, the larger of the two bones that make up the part of the leg just below the knee. It is normally the stronger of the two leg bones and the one that typically bears the most weight. Emma's tibia was hour-glass shaped and at its thinnest points were more like cartilage rather than bone. When broken in these places the tibia does not want to heal, hence the name "pseudo" or "false" joint.

Amie had suspected that Emma may have neurofibromatosis (NF), a genetic disorder that causes tumors to form on nerve tissue. Jim wasn't convinced. The chances of Emma having NF were, he was told, pretty small. But that reality was confirmed, and Emma was diagnosed with NF. The orthopedic surgeon explained that in order to save Emma's leg, they could expect to go through years and years of surgeries hoping for a cure. Hope was all they had because there was no cure for NF. Unless a cure was found, it was inevitable that Emma's leg would eventually need to be amputated. "This was my baby girl," Jim described, "and that leg became everything to me."

The Broeniman's were referred to American Family Children's Hospital of Madison, Wisconsin where they met with another orthopedic surgeon. Both Jim and Amie wanted to do everything they could to save her leg. Numerous surgeries were performed to address the particulars of what exactly was occurring in Emma's tibia. She was also given an electromagnetic device intended to promote bone growth that her parents wrapped around her leg every night. In another type of treatment, Emma also became the first child in the nation, if not the world, to have INFUSE (a morphogenic protein generally used on adults with spinal cord injuries) used on her tibia. That first surgery attempt to get Emma's bones to heal back together was scheduled to last six hours. It took twelve – and more surgeries followed.

Just before her 5th birthday, Emma started getting headaches and became very lethargic. The doctor diagnosed it as a virus and suggested to let her "just work through it." The vomiting that accompanied her headaches did lessen, but never completely went away. Simple trips to the city park to listen to bands and enjoy other similar outings would trigger Emma's headaches.

It was around that same time that Jim and Amie learned that recent research had suggested that kids with NF could get brain tumors around their optic pathway. "Just another thing to worry about" resulted in several years of visits to a pediatric ophthalmologist. As their insurance changed, so did the doctors. On their first visit to a new ophthalmologist, they discovered pale nerves on the optic nerves of Emma's eyes. It was just before the fourth of July that year when an revealed a tumor on Emma's optical pathway that had also spread back to her brain.

They also discovered a lime-sized tumor in her left temporal lobe which was disrupting the flow of Emma's cerebral spinal fluids. Hydrocephalus, as it is called, puts pressure on the optic nerve and was the cause of optic nerve damage as well the headaches and vomiting. Still, in her 5th year of life, Emma's parents referred her to a neurosurgeon at UW-Madison. Upon reviewing the MRI scans, more brain tumors were found. Neurosurgery was scheduled to insert a shunt (a valve connected to a tube) which would reroute the brain fluid to relieve the Hydrocephalus. "When something goes into your kids' brain, it's nerve-racking and painfully scary," explained Jim. "I was so scared and so worried, and we didn't trust the doctor, only because we didn't know him."



The hours of surgery were grueling as Amie and Jim waited to learn how things would turn out. Jim went into an introverted state, frozen into painful numbness as he just stared at the floor. When the surgery was finally over, they were told the shunt was inserted successfully. "Emma came out as chipper as could be! She wanted to color and play and it just kind of blew me away!" described Jim.