

Family Values

Contributed by Tom Gallagher

A severely handicapped granddaughter defines a family

By Tom Gallagher, 11/14/06

I never knew my own grandfather. He died in 1945, just a year after I was born. My father was thirty at the time. He had just come home from the Pacific fleet to see his new son for the first time.

What little I do know about my dad's father comes from dog-eared photos in family albums - pictures of the farm in rural Michigan where he was born, of the ice-house he built in the 1870's to store the ice he cut from the lake, the rowboat he built with my father when he was a boy.

I know Grandpa Jim was good with his hands; he could build almost anything from wood. I know that he felt strongly about education. He found a way to make sure that my father and his two sisters each could finish college. And I know he believed in God and wanted to pass his faith to his children, because that is exactly what he did. (The strength of my own father's faith is the most vivid memory that I have of him even now, twenty years after his death.)

Those few facts are almost all that I know about my grandfather. I know very little about the life he lived, about the lessons he learned in that life, about the goals he had for his children. And most of all, I know nothing about the hopes he had for me as his first grandson or for my seven brothers and sisters who he never knew because they were born after he died.

In that sense, I have been given something that my grandfather was not. I have lived long enough to know six grandchildren. Last Monday our first grandson, Ethan, was born. He joins our five granddaughters in giving joy to every day. But my story as a grandfather is a very different one — a story of the challenges faced by one of those granddaughters and the things we have learned about our family and ourselves as we have faced those challenges with her.

Brooke was born August 30, 2004, midway into my campaign for Congress. She was a beautiful blue-eyed blonde who looked exactly like her then two year old sister Katherine. She was born two days before her anticipated uneventful delivery date. But Brooke's birth was not uneventful. Somehow, in a way that is still unexplained, Brooke's supply of oxygen was constricted just before her birth and she suffered severe damage to her brain.

Extraordinary efforts by a remarkable team of doctors and nurses saved her life, but could not repair the damage she had suffered. She was not expected to survive more than a few days. After seven weeks in the hospital, most of them in the neonatal intensive care unit, she was sent home to my daughter Erin and her husband Brian and big sister Katherine, with a referral for hospice care. She would have no possibility for any cognitive ability and sooner or later her organs

would fail, unable to support her life as she grows larger.

In August 2006 Brooke had a birthday party, her second. No, this is not a miracle story. Nothing has changed her prognosis. At some point in all likelihood her kidneys or some other vital organ will fail and we will lose her. But this is not a story of tragedy and sadness. Rather the story is in the joy she gives us each day and the things she has helped us learn about ourselves.

Every day, the news is full of tragic stories. Innocent children are murdered by deranged people. Brave soldiers are killed or maimed in battle. First responders lose their lives, sometimes in ways that are unspeakably tragic. And sooner or later everyone affected by such events asks the inevitable question – why does this happen? Often, for people of faith, it becomes a test of that faith – how could God let this happen?

Until Brooke, we had never faced that question directly as a family. The tragic stories were always about other people. So as the day of Ethan’s birth grew near, and our fears of a recurrence of Brooke’s still unexplained injury peaked, we could not avoid reflecting about what Brooke meant to us and what we would do if the pattern repeated.

Thankfully, Ethan’s birth (although three weeks early) went as we all had prayed. He is healthy in all respects and even has the same blue eyes as his sisters (though with his father’s dark hair). But in ways that perhaps are not unexpected, the thoughts we had in the days leading up to his birth are if anything even more vivid. How does Brooke’s life, however long it lasts, give meaning to her and to us?

I cannot speak for Erin and Brian as Brooke’s parents. Only they can know the full measure of the heartbreak and the joy Brooke has given to their lives. The answer is a very personal one for each of us. I can speak to what I have learned from them and the depth of the admiration that I have for what they have endured and how they have dealt with it.

Until Brooke, I never understood how families with severely handicapped children could endure the daily challenges they face. I knew that somehow they do it, one day at a time, but it was always third hand assumptions. What Brooke has taught me is that the joy comes from the smallest details.

The doctors cannot tell us what if anything Brooke can see or hear, much less understand. We know that her hearing is acute because the smallest, most insignificant sound, if unexpected, startles her. We don’t know if or how she processes sounds. We know she can distinguish light and darkness, but seems unable to focus on anything for more than an instant. We don’t know what makes her cry so frequently; she cannot tell us because she will never have the ability to speak. We don’t know why she can’t sleep for more than an hour or two at night or why she has such difficulty breathing. She cannot be fed with a bottle or spoon, so for as long as she lives, she will be fed through a tube in her stomach. All of these issues are in some way related to the damage to her brain in the hours before her birth.

What has become important each day is finding ways to make Brooke smile, even though we have no idea why she smiles or what if anything is going through her mind as she does so. A smile from Brooke is often the highpoint of a day.

I have also learned that the ability of families to deal with children such as Brooke has become in large measure a function of the formal and informal networks of families that form around children with similar problems. In many ways, the Internet has become the critical vehicle of support and communication. For all of the fears that arise about the abuses and scams facilitated by the Internet, there are also the hopes and the comforts that come from sharing information and stories among families with children like Brooke.

Even the seemingly mundane details shared among parents can become critical to obtaining proper treatment. Swapping of assistive equipment, outgrown by one family, desperately needed by another, takes place every day through the Internet. Brooke is now almost 25 pounds, the size of a typical toddler, but cannot sit up, hold an object in her hand or otherwise function like a toddler in any way. Through Internet support groups, Erin has found a wheelchair/stroller, outgrown by another child, which will allow Brooke to come with her family almost anywhere. When she outgrows it, it will be passed on to another child through the same Internet support group.

We have also experienced all too often the highs and lows involved with institutional assistance for children like Brooke. Although in almost every case well-intentioned, the bureaucratic procedures dictated by governmental agencies all too often test the endurance of families most in need.

As a practical matter in the weeks before Ethan's birth, and for months after, Mary and I have spent, and will continue to spend much of each week staying with Erin and Brian to help them with Brooke so that they can focus on week-old Ethan. The fact that availability of night nurses is virtually non-existent given the general shortage of nurses in our healthcare system has meant that each of us takes turns staying up all night to care for Brooke.

Why am I writing all of this? There are probably many reasons. First, in some measure it is because it helps to talk about Brooke, it helps us in some small way give meaning to her life, however short it may be. Second, it is to give voice to the many families who each day struggle silently to find their own meaning in similar challenges and to hold on to their hopes and their faith. Third, it is to contribute to the broader dialogue now underway on how our system of health care compounds the challenges these families face and how we can do better. The fact is that for almost eighteen months of her life, some governmental agencies declined to recognize Brooke as "handicapped" within their regulations.

Children like Brooke are born every day in hospitals throughout our country. They are not just statistics, they embody the fondest hopes of parents and grandparents. For Mary and me, Brooke has become the definition of our family. She has given our lives meaning in ways we could never have understood without her.

A version of this essay by NevedaTODAY founder Tom Gallagher originally appeared in the Las Vegas Review-Journal.