

Playing the Hand You're Dealt

Nancy Todd Tyner

It's 3:15 in the morning, September 25, and I'm spending yet another night sitting up in a plastic chair, in a hospital, watching over a sick son. With nothing but time on my hands, watching monitors change and flicker, I calculate how much of the last three years I've spent in ICU: a year, an entire year, an incredible 365 days. I remember being pregnant with my first child, Hayden, and my and other's excitement about my impending membership in the motherhood club. No one ever mentioned a darker aspect of that membership, the agony of a sick child, the fear of hospital admissions, the probability of losing a child. Everyone talked of healthy children; no one mentioned those babies who struggle for the smallest achievement, sometimes, even for life itself.

I'm a political consultant, a spin doctor, a hired gun, not as acerbic as James Carville or as capricious as Dick Morris, but still one whose chosen career has garnered many a name over the years and not all of them pleasant. In a traditionally male-dominated field, I am a woman who has lasted in this profession and now hold wide the door for other women to enter what once was an ABC ... All Boys' Club. I understand the uphill climb.

On college campuses across our nation, I've often spoken to young people about the political process and the need to be involved. I've talked to them about believing in themselves when no one else does, about overcoming tremendous obstacles and using naysayers for motivation. As a motivator and commentator on life, I've identified my rules for enduring: for example, I "always have a parachute" and "always figure out why the other guy is in the game." My standard closure is the admonition to "be prepared to hit life's curve balls," since politics is an ever-changing challenge, with problems, surprises, and unexpected shifts from unexpected directions. Politics is an extreme rollercoaster of life at its essence in an intense, tumultuous sprint for some finish line with a term limit.

Life, on the other hand, stretches before us like unending, rolling hills; the rises and falls of the rollercoaster are there, but, thankfully, disguised by the routine of daily living. The game is on, nevertheless, and the curve balls fly toward you, no matter your profession. I had my first child at 36 years of age, a pleasant but surprising reality in the early 90's. In 2002, I gave birth to full term twins at 47, a decidedly surprising curve ball but doubly delightful.

Lincoln, one of the twins, was born with Tetralogy of Fallot, a heart condition, one of those curves I knew nothing about until I had a child born with it, and then I learned it's fairly common in children born to mothers over forty. Lincoln is now five, a veteran of six surgeries by the time he was three. Dr. Vaughan Starnes, a world class pediatric heart surgeon at Children's Hospital in Los Angeles, cut through Lincoln's sternum and replaced his faulty heart valve in the first surgery when he was only eight weeks of age.

A tiny doll-sized patient on the gurney, Lincoln breezed through the surgery, but the hospital, in an effort to increase his caloric intake prior to release, gave him a product, a powdered infant formula, recalled by the FDA eight months prior. All powdered infant formulas had been labeled as suspect in April of 2002; (www.fda.org April 11, 2002) hospitals were never to give it to three classes of children: (1) low birth weight babies, (Lincoln was 3.8 pounds at birth); (2) premature babies, (Lincoln was on the cusp at 38 weeks); and (3) babies with suppressed immune systems (Lincoln's severe heart condition definitely put him in this category). Powdered infant formula is not a sterile product, a fact the makers of this potentially deadly product do not want you to know. Healthy children can shake off the formula's load of bacteria, but the littlest of our species don't have a mature enough system to slough off; instead, it eats through the intestines and releases e-coli through the body with usually fatal results.

I watched, alone, in the wee hours of a Sunday morning in 2002 as Lincoln's heart rate climbed to 210 beats a minute, with 220 defined as cardiac arrest. In the middle of this Code Blue and doctors and wires and drill, I crossed to Lincoln, secured a spot close to his head and leaned in. "Lincoln," I said, "I know you're thinking about going back and I don't blame you. You don't deserve all of this pain; you've done nothing wrong. But please stay, Lincoln, please. If you do, I promise you a spectacular life and a wonderful adventure." Slowly, his heart rate slowed. He spent eleven weeks in ICU, but as I knew he would, he made it. He beat the odds, just as he had when he was born.

The enterobacter (the result of the e-coli) erased his heart surgery benefits, and he had to have his valve replaced, again. This time we traveled to Stanford University where another world renowned surgeon, Frank Hanley, practices. The surgery succeeded, and, expecting the normal "7 – 10 years" from the valve, we traveled home. Unfortunately, Lincoln's valve didn't perform to standard, and one year later, when he turned three, we faced the knife again.

During this time in 2005, my 14-year-old son, Hayden, was diagnosed with leukemia, and another nightmare flared to life. We began aggressive treatment in Las Vegas with the only pediatric oncologist in the area. We learned that progress in the treatment of children's cancer has stood still since 1964, with no changes and no alterations. When asked why the always progressive United States had seen no breakthroughs, the doctors admitted research in this area did not yield significant profit for the medical and pharmaceutical fields. The cancer market is significantly older.

Proceeding with the protocols available, after seven weeks, Hayden entered remission, and we breathed a sigh of relief, ultimately, for the remission but also for the cessation of the daily horror and wrenching pain of the seven weeks of treatment. Our relief was short lived, however; the doctor insisted on three years of the protocol. I was watching Hayden's face as the doctor spoke. I saw the light leave his eyes, the dark stain of fear and dread erasing their bright twinkle. I immediately inquired about more humane options; the doctor, Dr B., told me that I "had no choice."

I'm an intelligent person and a caring mother, and I don't believe in no choice. I had read and learned all that was humanly possible about leukemia, my questions were on point, but the doctors had no answers, just the same protocol, no matter what effect or circumstances. Nor did he look my child in his eyes as he talked over him to a woman, one, who his tone indicated, would realize her place and follow his direction. He was incensed that I would question his judgment.

To enforce his point, the doctor immediately sued me, enlisting the assistance of Child Protective Services and the District Attorney. He painted me an unfit, irresponsible mother, his proof, that I had questioned his judgment. To make matters worse, Hayden's biological father, a Louisiana attorney who saw him twice a year in 12 years of forced visitation, joined with the doctors in a sudden show of concern. He filed a "Friends of the Court" memo fighting his son and his son's mother in treatment options and not allowing us to leave Las Vegas to find a more humane doctor and a more caring treatment. Learning his own father would act this way toward him, arbitrarily with no inquiry, no discussion, not even a visit, devastated Hayden.

Hayden and I trooped to court four times between May, 2005, and July, 2005, on this senseless charge. By the time the case was dismissed in July, 2005, Hayden had relapsed from the stress and hassle, and the cancer had returned. The doctor couldn't wait to release us at this juncture and told me in the hospital corridor to "take Hayden home to die."

Hayden and I left immediately for Europe, bound for a clinic in Switzerland. We found humane treatment and a kind doctor who genuinely cared about Hayden and his treatment. We had discovered a home that treated my son as a patient and not as a protocol. We eventually moved to Germany where the doctors were doing some innovative procedures with viruses. We found a virus that ate the leukemic cells and saw an immediate turnaround in his cancer; the virus literally flipped the bad and good cells. We learned that the chemo we had to use to bring the bad cells down enough to administer the virus used only 10% of the standard U.S. treatment for the same result, a relief to Hayden and a sobering validation of our opinion of the U.S. protocol administered by Bernstein.

Our viral treatments reduced the cancer, and we were within striking distance of eradicating all of the bad cells. For the four months while Hayden completed this rigorous treatment, Hayden's father, the only person who hadn't agreed to drop the charges against us, finally found a sympathetic judge in Las Vegas to mandate I return Hayden to the United States by October 25, 2005, or he would take custody of him. The issue of physical custody of Hayden didn't frighten me but the medical custody by a man who would condemn my son to three years of an unwanted, torturous protocol overwhelmed Hayden and me, especially when we were experiencing such unqualified success in Germany. The judge also threatened to take my twins, now three years old and safe with my husband, unless Hayden and I returned immediately. We packed.

Hayden and I returned to Las Vegas on October 21 to address this case the following week and return to Germany to finish our treatments. I was a genetic match for Hayden. My natural cancer fighting cells substituted for those destroyed in Hayden by the cancer and the chemo. The doctors in Germany took 10 billion of my natural killer cells (NKcells) and increased them to 50 billion 10 days later. They put them in Hayden with incredible results. We were to finish the last of the treatment and to do it once more to return Hayden to a cancer free life. Our court appearance took ten minutes to effect a complete dismissal of his father's weak and lingering case. Unfortunately, on the trip, Hayden caught a fungal infection in his port line (inserted in the chest to administer treatment), was admitted to the hospital, and died from the infection on November 21, 2005.

While Hayden experienced such success in Europe, my second son, Lincoln, faced another heart surgery at the end of 2005. The surgery, scheduled for December 1, occurred five days after we buried his older brother. Although I could have delayed his surgery, Lincoln needed the heart valve replacement, and delaying it would not improve a dark and tragic year. For the third time in as many years, the doctors cracked Lincoln's chest and repaired his heart with a new valve, again with a proclaimed durability of seven to ten years. The curve balls just kept coming.

I began 2006 with a determination to make some sense of all these curve balls. There had to be a message somewhere, and there had to be a way to make good come from bad, a way to help others. I fought through the pain. I struggled to live abundantly, giving my heart to my twins, my family, my friends and my work. It was a challenge.

By the end of 2006, Lincoln's heart valve failed, again. His flow on the valve climbed above 50% and then escalated. The local cardiologists moved his check ups from every six months to three months, always a sign, and not a good one. I prayed. My husband talked of returning to Stanford. I cringed at the thought of putting Lincoln through this horrific risk and pain, again, and facing it possibly a dozen more times before he was grown. It was clear, though, that we couldn't continue without action. With each doctor visit, the failure was more evident and more threatening.

In June of 2007 I had a dream, a dream where I cried about Lincoln and the pain he would endure again. Hayden came to me in that dream and told me to look in England. I woke up the next morning a little dazed and more than curious about what was being done outside of the U.S.

My search revealed that Hayden was right. I was amazed to find that Dr. Philipp Bonhoeffer had created and patented a process where the heart valve could be replaced without surgery by entering through the femoral vein. I couldn't wait to see if we could replace Lincoln's valve that way. I reached out to political colleagues in Europe who promptly piqued the doctor's interest. I sent Lincoln's records, and three days later the doctor called with the magical words, "I believe I can help your son."

My husband, anxious about this procedure, felt it was too much outside the box. He wanted to wait until it was offered in the U.S. He worried that Lincoln's weight of 37 pounds was too far below the previous successful surgical low of 45 pounds. Not until we talked with Lincoln's cardiologists here did my husband consent. The U.S. doctors were ecstatic and supported the new procedure wholly. They had never understood why Lincoln's valves wore out so quickly and knew he faced another twelve or so of these surgeries before adulthood. Every surgical procedure carries great risk with it, and they knew this, too.

I told Dr. Bonhoeffer Lincoln and I would be there the second he could see us. He graciously cleared his schedule for the following week. We took off. The MRI and other tests showed Lincoln's heart valve was working minimally, and we did not think Lincoln could last until his weight rose to their minimum weight of 45 pounds. The doctor and I talked for several hours. We both needed to be comfortable and secure taking this big step together. We agreed that he would proceed, and if the vein proved too small or he felt the surgery too risky, he would stop. It was so nice to trust someone so much and to feel we were both working to help my son.

The procedure took place the following week, September 25, 2007, and it transpired without a hitch. Lincoln now has a new heart valve, one that works normally for the first time in his entire five years. I spent the night at the hospital with him, of course. At 3:00 a.m. he began to rub his heart. I asked him if it hurt, and he said, "No, mom, but it sure feels different." I told him it worked; finally, it worked. Grateful for the darkness, I hid the tears in my eyes.

We flew back to the United States the next day, new heart valve in place and instructions to take a baby aspirin every day for six months to avoid clotting. Lincoln left England without having his chest opened, with no pain, having experienced far less risk and danger, and with a simple appointment for a yearly checkup. I left England with my son's heart restored to normal function and with my own full of gratitude and thanks.

Yes, I'm lucky to be able to travel anywhere in the world to seek treatment for my sons' challenging medical conditions and diseases. I'm blessed to be able to afford these treatments. I know that. Long before I had any money, I was a citizen of this country, and I have always known it to be the greatest country in the world. In all my travels, I've been to many other countries, and nothing has shaken my faith and pride in living in the best of all countries. So, why can't we offer up-to-date medical care? Why do Americans have to slip off to Mexico to receive cancer treatments that work? Why do Americans have to fly to Switzerland to obtain chemotherapy that is 10%, a mere 10% of what we are prescribed here? Why do Americans give doctors and the FDA and the drug companies this power over our lives? Why are scare tactics the most predominant theme of cancer treatment in the greatest country in the world?

I made a difference in the lives of my two sons. Hayden experienced a transcendent hope and the climb to good health without the harsh protocol or awful side effects of the selected U.S. treatment of his disease. Without the stubborn willfulness of his biological

father, he would have realized a medical cure. Lincoln's good health greets me every morning. I had the resources, and I acted for the best treatment for my sons.

And they have made a significant difference in my life. What worries me now is how to make a difference for other mothers who sense or know that more humane and effective treatments are available. What worries me are the number of doctors in our country who do not want to be questioned and who demonstrate no desire to be on the cutting edge. What worries me are the people in our country who look upon doctors as godlike authorities whose verdicts are to be accepted as the ultimate truth.

We can make a difference, and we can do it the old fashioned American way of sharing knowledge and letting that knowledge become our power. We cannot let our medical care be only as good as our doctors, any more than we can let our country be only as good as our politicians. We must arm ourselves as citizens and protect our rights by demanding responsible care. The more we know, the stronger we become. The stronger we become, the fewer of our sons will fall to complacent, self-satisfied health providers.

I tell this story to encourage you and to empower you. I ask that you believe in yourself, listen to your instincts, follow them, and ask questions. None of the treatments I discovered for my sons is allowed in the U. S. Between the drug companies and the FDA, they probably never will be. We have precious few young men and women to lose to an uninspired health system and government agencies that exist to serve us as citizens. It is time to stand up for our children so that they may secure a better future for us all.

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