

Photo on screen of infant me, screaming.

You may recognise this screaming infant on the screen. Health problems and the efforts to shut me up, began the day I was born.

I was screaming because I was in pain and I was hungry. My mother couldn't nurse me. My father, a physician, tried to pressure her to nurse me anyway. I caused her pain and my constant screaming and projectile vomiting as they tried to find a formula I wasn't allergic to, ruptured the family. I learned early that making a fuss, even a legitimate fuss, was annoying to others.

I learned to read at three, reading everything I could get my hands on, including my father's medical journals. I often sat on his lap, age three, sounding out the words under the pictures in his medical journals while he explained to me, never dumbing down to my level, but always bringing my level up toward his. He never answered my questions with an answer, but always with another question. He said he was teaching me the Socratic method. I just wanted the answers, but absorbed the lesson.

Photo of me in cowgirl outfit.

Later, age 6, we'd sit on the front porch in George playing Sheriff and Deputy. "Deputy," he'd say, "round up the bad guys." He'd point to the left and I'd run around the house and run around the house and run around the house again. And then I'd go up to him and say, "Can't find 'em, Sheriff." And he'd point to the right and say, "Deputy, they went THAT way." And I'd begin running around the house the other way.

To me, we were playing together and I loved it. For him, he was sitting on the porch, smoking his pipe, finally getting some peace and quiet. Who could predict the intellectual and geographic influence on my life of playing cowboys with my dad.

Later, we had painful differences that were never overcome. His generation wasn't much for talking things through. His last words to me before he died were, "Will you remember me in twenty years?" What do you think?

The most moving part of the eucharist, long before my father's last words to me, has always been the very human Jesus, asking his friends to remember him.

Every American kid's hero in 1953 was Davy Crockett.

Disney's movie influenced a post-war generation. Crockett, frontiersman in buckskin, stood up for justice and was true to himself. In 1825, he was elected to Congress and sent to Washington.

His motto was, "Be sure you're right, then go ahead." A generation of kids..."Be sure you're right, then go ahead."

Crockett defended the Cherokee Nation's right to remain in their homeland, the Great Smoky Mountains. President Jackson wanted them removed to the flat dry lands of Oklahoma, a thousand miles to the west. Their presence in their homes was not convenient to the powers that be.

When Crockett realized, in the movie, he'd been sent on a fool's errand to get him away for the crucial vote on the Indian Removal Act, he spun his horse around and galloped back to Washington.

The doors to the Senate Chamber closed in his face. A generation of kids watched their hero break down the doors of Congress to speak for justice. The Act passed anyway. Thousands of Cherokee died on the Trail of Tears, a shameful act in our history.

We had observed Crockett's effort to stop it, and we learned, "Be sure you're right, then go ahead."

As Reform Jewish kids, and I am a Jewish woman, we learned the ancient teachings Jesus would have learned as well, "If I am not for myself, who am I? But if I am only for myself, who am I? – If not now, when? And if not me, who?"

Long after the movie, in 1969, Father James Groppi, an activist priest in Milwaukee, learned the state legislature was voting to cut benefits on Mother with Dependent Children.

He led a mother's march 90 miles from Milwaukee to Madison, the state capital and home of the university. They were joined the last mile by a thousand students, me among them.

When the mothers reached the capital, the big oak doors swung shut in their faces. A thousand students broke them down.

We occupied the Senate and one by one, the mothers told their stories. It was a defining moment of my life. The mother I remember most, had cerebral palsy. The legislature planned to cut her benefits.

When the storm troopers entered with truncheons and tear gas, I fled and have never forgiven my cowardice. That was also a defining moment. Who was I really, when push came to shove?

The mothers won by the way. Their benefits were not cut.

But I was left with the question, "If not me, who?"

Decades later, doing research on the American West and riding my horse in the mountains, I came home one night in 1987 and found a small tick had burrowed into my skin. I had just moved West and been assured there was no Lyme Disease at that altitude. I thought I was safe just pulling out the tick and flushing it.

I'm reminded since of the scene in the Pink Panther movie when Inspector Clouseau asks a man if his dog bites and the man says, "No." Clouseau bends to pet the dog who bites him. "I thought you said your dog did not bite," he says. And the man replies, "But monsieur, that is not my dog."

There are tick-borne diseases in those mountains which can cause an inflammation of the brain, an encephalitis. The incubation period for Colorado Tick Fever, which I'd never heard of, is about four days.

Four days after the tick bite, I had a temperature of 40.2 and a blinding headache. I'd never heard of Colorado Tick Fever. Unfortunately, neither had the physician whose wrong diagnosis and inappropriate treatment took years from my life, left me with a brain injury and probably the brain tumour, and eventually a stroke.

There was no internet in 1987, no way to research a diagnosis. I was seriously ill, bedbound, in constant pain and deep fatigue for fifteen years. I got a computer in 2000, but was too ill to do much with it.

I had trusted the doctor. I knew his credentials, knew his family, knew his dog. What wasn't to trust?

In 2002, he developed a brain tumour and quit his practice. The next doctor, who failed to mention he was leaving town in a week, said, when asked to renew my primary prescription, "You don't have to be on that drug," and stopped the drug cold turkey. The drug company had lied to the US Government about its dangerous properties. That drug

should never be given to anyone with a history of migraine or a tick-borne encephalitis. We also didn't know it was addictive.

Remember, I was taking that drug for a drug I didn't have, while the encephalitis went untreated.

The first four days off that drug, all my symptoms disappeared. No pain. No vertigo. No headaches. No blurred vision. I could go downstairs in my own house again. I could walk my dogs. I could do my laundry. Mixed with joy was the equal horror of what had been done to me. My brain went into neurologic shock on the fourth day.

The United States still believed the drug company's statements it was a harmless drug. I couldn't find help in America. Having lived in London years before, I went online and found that, in the UK, the dangers of that drug were being exposed. I researched to find a neurologist in London to help me and, with letters from him, applied for a visa to return for private medical treatment.

The neurologist's private secretary told me he had an outpatient programme especially for people who had suffered brain injuries from that drug. "Come on over," she said. "We know all about that drug."

Based on what the hospital in London and the neurologist's secretary told me, I said farewell to my beloved dogs and home and came to London on my own in 2004, with a serious frontal lobe brain injury, to work with that physician, as a private patient, in his outpatient programme.

When we met, he looked at the scan I'd brought from the States, acknowledged I'd suffered a brain injury, and said, "I'm sorry. My secretary gave you the wrong information. My programme is for people who've been hit in the head by a lorry. I can't help you." He knew what I had sacrificed and all the hope to come here to work with him – knew I was alone in London and, without an ounce of empathy, never referred me to anyone.

Only time, the stimulus of London and my own determination began to rebuild neural pathways to recovery. We're talking years. I'm no quitter.

The brain tumour I developed was likely a result of that prescription drug. The private London neurosurgeon who removed the tumour in October 2009, never answered my questions, never wrote a surgical report, never warned me about the 41% chance of epilepsy after the surgery or referred me for followup care. I had to be my own consultant once again – after major brain surgery – in charge of every aspect of my own recovery.

Getting on with life, still stubborn and self-determined, in February 2015, my vision suddenly changed. I thought it was a migraine. At the same time, I lost sensation in half my body. It was a major stroke.

The A&E nurse where my friend and I were taken by ambulance, said I was having a stroke. After taking my history and vitals, she walked us to the quiet waiting room and left us there. After two hours, I went to the desk. That's when I learned she'd forgotten to check me in. The hospital had no record I was there.

An hour later, a doctor walked up to me, having seen her notes, and without examination, scan, or empathy said, "It appears you've had a left occipital stroke, but since it's now past the four hour window we could give you a drug that might reverse your symptoms, there's nothing we can do - so you're at the bottom of our priority list. It will be at least four and a half hours before you can be seen." Just ...like....that.

We left. NHS 111 sent another ambulance and took us to a second hospital which did a scan confirming I'd had a major stroke, but the registrar didn't speak much English and I was never admitted to the stroke unit. Where do they find these people?

Now on the NHS, and half-blind, but receiving no care, I read an article in the BMJ, the British Medical Journal, on posterior strokes in the brain, and requested referral to the neurologist who'd written it. Sometimes my dad is right at my shoulder.

Four months after the stroke, I met with that neurologist. He ran tests that should have been done immediately. I'd had a stroke in two parts of my brain. I've lost my vision on one side, much of my hearing on that side, my balance has been affected and more.

I have no traditional risk factors for stroke. As I write this, I am wearing a 7-day heart monitor because the neurologist believes I may have a congenital heart defect which caused it.

Remember that screaming baby? Maybe she knew something.

I learned early to question. Davy Crockett taught me to utilize what I knew, “Be sure you’re right, then go ahead.”

Our medical system is in fragile shape. I want to be part of the solution.

People get annoyed. They’ve been annoyed at me since birth. But in the words Jesus himself would have heard, “If I am not for myself, who am I? and if I am only for myself, who am I? If not now, when, and if not me, who?”

Thank you. (1993wds)