

## **Tom Buttweiler's Experience with Polio**

I was living in St. Cloud, MN, a town of about 30,000, late summer of 1953. I was 7 years old. My Dad and I went to a local baseball game on the evening of August 31<sup>st</sup>. Dad later reported he suspected a problem as I did not chase around the park as usual. The next morning our family physician came to our house, and almost immediately we headed off to the hospital. I remember being on a gurney in the hallway for quite a while with (I think) an open spinal tap. All of a sudden, I was rushed away. No good-bye, just whooshed away. I landed in a ward with 15 other kids.

The ward was bedlam. No visitors, and all providers were gowned and masked. An alien world. We shared one phone and were allowed one five-minute call each evening. Twice a day, a wringer washing machine was rolled into the ward. It had scalding hot water into which they placed army blankets, wrang out most of the water, and then wrapped us head-to-toe in them for a half hour. I was nearest the door so first wrapped and first unwrapped. Since I was also the only one who could see the clock out in the hall, I pretty much announced the passage of every minute. It was very uncomfortable and kids kept yelling asking the time. While in that ward I was lowered by a net into a bath a couple times. Kind of scary procedure, but not nearly as frightening as seeing the kids across the hall in iron lungs.

I was transferred out of isolation on September 7th——my 8th birthday——best birthday ever.

My first night on a regular ward was one of the most terrifying of my entire life. After the constant bedlam in isolation I was in a room all alone. I imagined total abandonment. I imagined all kinds of stuff.

The next day, I got a roommate, saw my folks for the first time, and started adjusting to my new reality. There was no pain, no fever. I was there for 4 or 5 weeks——a basically healthy 8 year-old. My right leg was not working, otherwise feeling good. On two occasions I got out of bed, slid across the hall on a visitors chair into the room where they kept wheel chairs. I got into one and pushed another back to the room for my roomy, and we escaped. Both times we got off the ward, and one time onto an elevator before they caught us. Ah freedom! We got in even more trouble when we filled some balloons with grape juice and threw them at a nurse. The nurses still wore white uniforms! Balloons we're all confiscated, and we were warned any more of that and the afternoon juice cart would be skipping us. I think there was no reason to keep us so long other than to be available for the two or three sessions per week of very painful physical therapy.

On the ward visiting hours were strictly enforced. Mom and or Dad, pretty much made at least one visit every day. Each bed had a coin operated radio with a speaker for under your pillow——5 or 10 cents an hour——I got an hour's worth of radio time every day——The Lone Ranger and the Green Hornet nightly.

Another regular visitor was my third-grade teacher, Sister Giles. If there are saints, she is one. She brought all my lessons, kept me up to date, taught me all the Latin prayers I would need to

know to be an altar boy. There were other visitors, who I think I drove crazy with cribbage. Dad brought me a cribbage board and taught me the game. I became a fanatic, and insisted all visitors play cribbage. (A skill that over the years has been profitable.)

The vaccine arrived in St. Cloud while I was in the hospital.

I was discharged from the hospital with a right foot that had no lift, a weakened right leg, and I later learned the whole right side of my body was somewhat compromised. I wore a standard metal and leather brace with a spring at the joint to lift my foot. Not very mobile!!!! I spent third grade in the brace, with very limited mobility. My Dad spent many evenings putting me through very painful physical therapy on our living room floor——almost all stretching exercises for my back and right leg. (My younger sister recently recounted how she would hide during those sessions because she did not like seeing both Dad and me crying.)

During 4th grade I somehow or another got hooked up with an orthopedic doctor (Burnham) who had a solo practice in Minneapolis. (Strangely, I was never connected with Sister Kenny.). He attempted to help me acquire some lift by both trying to strengthen the lifting muscles and weaken my Achilles' tendon in my right ankle and leg. Weakening the tendon was excruciating. Every third Friday we would go to his office and he would lay me on a table, put my foot in his chest, and then press my foot back as far as he could——stretching the tendon. Two assistants would hold my foot while he applied a plaster cast. They would send me home with some of the best drugs ever created——I can still call up some of the images from those weekends. However the drugs soon ran out, and there were a few days of serious pain. Eventually the tendon acclimated and life went on. The casts all had a rubber bumper on the bottom so I was mobile. By the end of the third week some of those casts were practically shredded. Then I would get a new one. My 4th grade teacher, Sister Pierre, quite the opposite of the saintly Sister Giles, tried to have me expelled for too many absences. Mom put up a terrific fight all the way to the school board and the parish pastor——then came home and made damn sure I was not going to do anything but excel academically. (I can still visualize multiplication flash cards.)

The year of casts and drugs accomplished little. I had no lift in my right ankle. I had lateral movement so I ended up walking on the side of my foot——not a viable long term solution. Dr. Burnham suggested what I have been led to believe was a somewhat radical surgery. My folks agreed and in March of 5th grade I went under the knife. As I understand it he cut all around my ankle (the scar still there) fused all the little bones so I would have no lateral movement, then he cut about a foot above the first cut and pulled out the muscle that provided the lateral movement and re-threaded it, ultimately literally tying it to a tongue depressor on the bottom of my foot. It hurt like the devil when he cut that depressor off. The surgery per my Mom, lasted 12 hours. When the Doc saw my folks he said he was optimistic, but was unable to save full circulation so I was left with a perpetually cold foot and ankle.

The surgery was transformative. It happened in March of 5th grade. Our school began grade school football in 6th grade. My folks reported the biggest disagreement of their lives was the go,

or no go, on football. Eventually the decision was left to Dr. Burnham whose response was “We did the surgery so he could have as normal a life as possible.” I played football. I eventually started two years at center on a very successful high school team, even earning honors on some post season teams.

I’ve gone through most of my life with a right ankle that has no lateral movement, a right foot that has just enough lift to allow me to walk and a weakened left leg. The whole right side of my body overworks and perspires more. I noticed the perspiration on my right arm years ago when biking hard but could never explain it, until I met Dr. Sizer. My right foot and ankle are cold as hell all the time—they over work, sweat and get wet. I have a little limp that seems to be worsening. (I have known people for years who will suddenly ask if I injured myself as they see I am limping.)

Polio did provide two benefits. First, I was awarded a grant from a Minnesota Rehabilitation program that covered part of my college tuition. Secondly, I was exempt from the draft.

There have been some later in life repercussions. In junior high I broke a bone in my right hand during a disagreement on the playground. Treating physician was the same family Doc and he said were it not for the polio I would not have broken the hand. I had my left knee (non polio side) replaced about twelve years ago, probably a result of over use. I had my right shoulder replaced about five years ago—I did dislocate it once many years before that while cross county skiing so who knows. I have very poor circulation below my knee and that is somewhat concerning—also results in a very cold foot and ankle.

Beyond that I have had a very normal life. In my late 30’s I started doing triathlons and have completed 30 or thereabouts. (Not full Ironman lengths. The ones I did were usually 1/2 mile swim, 25 mile bike, and 5 mile or 10 k run.). I could swim OK, I was a powerful biker, having logged thousands of miles on bikes, and I just held on through the runs, usually being passed like a parade was going by. But I was never the last to finish and very proud and happy that I did. I have quit biking. When I walked out of re-hab for my shoulder they told me the one thing I needed to avoid is falling on it.

In my mid forties I learned about post-polio when I became self employed and found out I could not buy health insurance that would cover polio residuals. I did manage to work around that but it took some doing. My treating physician at that time had never heard of post polio. To his credit he looked it up and referred me to Sister Kenny where I went for an evaluation. I met a wonderful physician, Dr. Seizer, who in a very good bedside manner told me I was wasting her time—go do another triathlon, come back when you need to. She was great, and I have been back.

About five years ago I foolishly way overdid some physical work—helping my son move. I ended up damaging my upper leg muscles. I returned to Doctor Seizer. She recommended very slow rehab, message, discontinuation of statin blood thinners, and a carbon fiber brace. After a

few months of hobbling around with a walker, I got into the brace, discarded the walker. I now go to an old people's exercise group for some weight lifting and stretching 2 or 3 times a week and do the same at home on days I do not go to the group. I walk 2 to 4 miles a day. Life is very good.

I have had a great life, I caused some of my own problems——alcoholism, divorce, near bankruptcy, but I think the determination and resiliency I learned dealing with polio assisted me in overcoming those difficulties. In the end, I have three great kids with whom I have a great relationship, I am financially secure, in a solid marriage. I have traveled the country——all 50 states, and the world——over 31 foreign countries. I have had a great life.

I am now 74, living in St. Cloud, Minnesota (now about 100,000 population) getting along fine. I wear my brace when I leave home, but am able to walk around the house without it. I do fear losing mobility, but I am not overwhelmed by that fear. At the moment I am way more concerned with covid-19 than I am with polio. I hope I get a vaccine before the virus gets me.