MY WORLD TURNED UPSIDE DOWN
BY JIM CARR

During all the years I have had polio, I never heard the term Upside Down Polio. In 2018 I attended my first polio retreat at Easterseals Camp in Empire, Colorado. I noticed that out of the approximate 40 polios, I was one of the few that had polio primarily in the upper body. That is where I learned the term used for this was “upside down polio”.

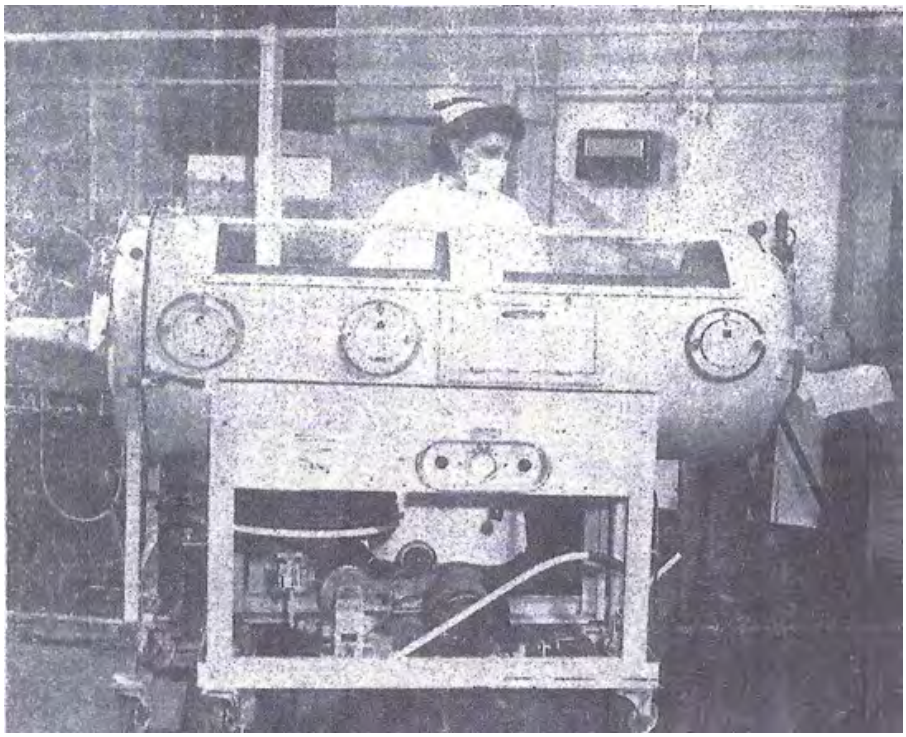
The lasting visible effects of my polio include a paralyzed right arm, a partially paralyzed left arm, and a very weak neck and shoulders. In my case I also have no quadriceps in my left leg making me now prone to falling. Because of my significant upper body weakness, I am unable to use a cane, crutches, walker, unable to break a fall with my hands/arms and it is very difficult to get back up from the floor or ground. When I was encouraged to write my story, one person suggested I call it “Face First”.

In 1952, we moved from Arizona to Michigan where there were more opportunities to work. The auto industry was booming in Flint. That summer I got real sick with flu like conditions that continued to get worse. My dad took me to the doctor and the doctor prescribed medicine for the flu. The next morning at breakfast we had oatmeal and I couldn’t lift my right arm to eat. My parents knew something was not right and took me back to the doctor. He examined me again, checked my spine and sent me to the hospital. My spine was fine, but it was then he was considering polio.

My world turned upside down at the age of three in 1952. I believe that was the time when the polio epidemic in the Flint area started escalating. Mostly it was kids who were admitted to the hospital, but some adults were as well. This was also the year more cases of polio were reported in the US than during any of the 29 years of the polio epidemic. There was no cure, no way to stop polio and nowhere to run from it. In 1952, the US reported 57,600 cases, 3,150 deaths and 21,270 left with paralysis. People lived in fear.

Most of this story, my story, is what I have learned from my dear mother. She is 92 years old and remembers this time very well. My parents’ experience with polio was, by far, much worse than mine. I was three years old and don’t remember much about the initial stages. While my mom was with me most of the time at the hospital, she was also pregnant with my brother. During my hospital stay, my younger brother was born in the same hospital and I was the first family member to see him.

My polio started out with paralysis in my right arm and upper part of my left arm with weakness in my upper body. I don't think at the time they knew my left leg was affected. After two months it turned into bulbar polio affecting my ability to breathe and I was put in an iron lung. The iron lung breathed for me 24 hours a day for six months. The port holes on the side of the iron lung is where the nurses would provide hygiene care. The neck collar was tight to prevent air leakage while the machine breathed for me moving the padded tray, I laid on, back and forth. I had a bald spot on the back of my head from the movement.



This picture from the Flint Journal in September 1952 shows the first two-person iron lung at that hospital. I am the kid on the right side. Those in the iron lung were the sickest and represented most of those who were dying.

Nobody could visit the kids in the iron lung section except for, on occasion, parents with mask and gown. Parents were made to sit in a semi-circle in an area by the iron lung room anxiously waiting for the door to open and a doctor to come out. When a doctor finally came out, it usually meant someone's child had died. Each hoped it wasn't their child and grieved together with the unfortunate parents. My mom told me they were filled with nervous anticipation every time they would come see me, hoping I was still alive. To my surprise, my mom remembered that 127 died from polio at Hurley Hospital that year. After six months in the iron lung, I improved to where I was put back with the other kids. I stayed an additional four months making my total time hospitalized almost one year.

I was four years old when I was finally allowed to go home to be with my family. I started working with a physical therapist that had been in the military who had worked with injured WWII veterans. She took a lot of interest in me and was like a part of our family. I received a birthday card every year until she couldn't because of dementia in her later years. Most of the time she would drive us the one-hour trip, three times a month, to the large and intimidating University Hospital in Ann Arbor, Michigan. Her actions and concern made a significant difference in my quality of life. There would be several doctors lined up with me sitting there, along with my mom and therapist while the doctors discussed my situation. The doctors didn't really know what to do and considered amputating my arm. My PT was adamant that was

not going to happen. I am so thankful to her for being there and preventing that from happening. As all people with disabilities do, you learn to adapt to your physical limitations and the more you have to work with, more things are possible.

After a few visits to Ann Arbor, and my right arm still attached, they tried different braces on my right hand and wrist designed to hold my fingers straight and to prevent them from curling up.

The picture on the left shows a bilateral "airplane" brace to lift both arms. I would run into doors and walls. Seeing it now, I wonder how I could sleep with it. I was supposed to wear it 24/7. They were experimenting and didn't know what would work best so shortly after that they went to surgeries.

My first surgery was done on my right hand when I was six years old. They grafted a bone from my hip placed it between my thumb and index finger to make my hand more functional. The intent was to make it so I could carry light things using my right hand. My second surgery was when I was eight years old on my left hand to prevent my fingers and hand from curling up. Both surgeries were successful and helped improve my quality of life.

After experimenting with braces and two surgeries, at the age of eight I was free from the frequent hospital visits and started living a life like other kids. I never thought to much about having polio growing up and was a happy kid. My parents were old school and never gave me any preferential treatment over my brothers and sister. When it was my turn to mow the yard, I mowed it. As I look back at it now, I am very appreciative of the way I was raised. There was very little I thought I couldn't do, and it gave me confidence to try most anything.

As an active child I never had issues with my left leg. I was always playing different sports with my brothers and neighbors. As an adult, I played tennis, ran 10 K's (6.2 miles), hiked trails, skied, played soccer, golfed and climbed Longs Peak. It was during my 50s I started to occasionally fall while playing tennis. Falling on a tennis court is no fun. Another clue something was not right was when I could no longer push my left leg down into my ski binding. It was then that I first learned about post-polio syndrome. As my muscle weakness continues to get worse, I must be very careful when walking. I tend to drag my left leg, more so when tired. When I don't pick my foot up and my left leg bends at the knee, I start to fall. With no quadriceps in my left leg there is no way to stop the fall.

My world turned upside down at the age of three. The good thing is when you are three years old you don't really understand what is upside down or right side up.