

Title: Amazing Grace – Amazing Race: My Journey as a GBS Survivor

Category: Adult

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The phrase, “Life is a journey” has a different meaning for each and every individual. There are moments of extreme clarity and others of great confusion. Hopefully, there are more of the latter than the former. However, there is one moment in my own life’s journey that I consider my paradigm shift – when all of my assumptions of where I had been and where I was going changed dramatically and challenged both my faith in God and my ability to know what kind of future God had in store for me.

For most of the 2010s, I had been serving a dual role – in my career as a librarian and in my role as a caregiver for my mom, who was once a vibrant, talented teacher and wife who succumbed to Parkinson’s Disease and dementia. This dichotomy of the successes/challenges of managing library materials and information with the successes/challenges of caring for someone you love and watching them slowly die a natural death were both exhilarating at times and equally exhausting.

Beginnings in New Philadelphia

Throughout this time, I continued to run – the daily activity that had been a natural part of my life for almost four decades since age 11 when I ran junior high track for Welty Middle School in my hometown of New Philadelphia, Ohio – wearing canvas tennis shoes and running on a cinder track. Running was that time when I could focus on the experience of my activity and my surroundings – the “controlled freedom” oxymoron that allowed me to run for miles, yet continue to encounter the beauty of my surroundings.

It was also a way to embrace the changes that becoming a teenager along with changes at home brought to the forefront. My family had lived on Oak Street near New Philadelphia’s Tuscora Park since

1966. One could say that my mom and dad had achieved post-WWII success – my dad was a talented engineer who worked for Joy Manufacturing (maker of industrial fans for mines and other applications) and my mom was a former teacher who started her teaching career in Akron in the late 1950s and took time off to raise my two older sisters and me in a small-town atmosphere.

Tuscora Park was my playground; spending time playing games with neighborhood friends – Jim and Joe Viers (their dad was superintendent of schools during the 1970s), Rob Smitley (his parents ran a successful real estate firm located on 2nd Street Northwest across from the Goshen Dairy), and Jay Sullivan (his mom worked with my dad at Joy in the office) are still vivid memories. My earliest running sequences (along with riding my bike all over New Philadelphia and Dover to visit car dealers / collect car brochures – my hobby) prepared me for living in the safety and familiarity of a community. That spatial grounding along with my education at Sacred Heart Catholic School (where I also served as an altar boy – circa 1973) allowed me to explore, yet feel safe and reassured knowing people were looking out for me.

Our Oak Street neighborhood was also somewhat idyllic – the Renners, Wallicks, Lingos, Krebs, Golders, Ersicks, McKees, Kings, Tuffords, Gowans, Himes, Rankins, Trucinskis, and others lived on our street. The age range of those individuals was quite dramatic (I remember sitting talking with Mr. Hime on his porch at age 5). Yet, the interaction that those people had with each other represents the good of New Philadelphia and the entire Tuscarawas Valley – that sense of people interacting with each other on a daily basis -- living life with a seamless focus that probably wasn't easy but was doable because of the people who were there and their commitment to the microcosm of our street and the macrocosm of our town, county, state, country, etc.

In late 1977, my dad made the decision to move our family to Tampa Bay, Florida (specifically Seminole/Largo) in order to continue to build his engineering business – The Electrical Associates (he left

Joy in 1973 after I, as the youngest, was firmly ensconced in school, and my mom had returned to teaching – her first assignment was teaching half-time Kindergarten at Tuscarawas Avenue Elementary in New Philadelphia). Part of that move involved leaving Oak Street and moving temporarily into an apartment on New Philadelphia’s Southside while our new home was being built in Florida.

I recall the days when I left track practice (held at what is today Woody Hayes Quaker Stadium – part of the Tuscora Park complex) and ran down Broadway to the southside in those canvas tennis shoes (certainly not appropriate running shoes – but I didn’t know any better). My dad was rarely home – traveling to his Florida accounts – so, my sisters and I basically worked as members of my mom’s team running our household – something not very common in 1970s America (or at least not in my Oak Street neighborhood or in New Philadelphia). It was definitely a time of change, but it also define both the physical and mental “running” that has defined all of my life’s chapters.

My dad was a very smart man; he claimed to have a photographic memory. He could display both an amiable public persona one moment and a tough, demanding persona the next. My mom had her own special persona – a kind strength that could deal with my dad’s temperament and work with the thousands of students and parents with whom she interacted with over her career (both in Akron and New Philadelphia).

It was my dad who said, “Make the best of where you are.” It was probably a rallying cry for my sisters and me to look at our move to Florida in a positive light

As we left our Oak Street neighborhood behind for the new beginnings that were ahead of us in Florida, there was definitely a sense of uncertainty and trepidation. What would our neighborhood be like? Would our new community be as supportive and encouraging as our New Philadelphia / Tuscarawas Valley had been over the years.

The Florida Years

For the most part, my dad's predictions of making the best of our new home in Florida became a reality. While our neighborhood of mostly new homes – built in the midst of former orange groves – was significantly larger than Oak Street, the ability to form relationships with our neighbors continued. Most of our neighbors came from all over the Midwest and Northeast – Michigan, Wisconsin, New Jersey, etc. The main difference between our new Florida neighborhood and Oak Street was that these individuals also brought their home cultures with them -- some were “urban, big city approaches”; others were more akin with our Ohio, Midwest sensibilities.

An example of the “new community's diversity” could be found next door. Our neighbors, the Tuminellos, were a young, attractive Italian couple from New Jersey with two young children. The husband, Charlie, was an electrician sent by union bosses in the Northeast to try to organize electricians in Florida (Florida was one of three of the original right-to-work states – the others being Arkansas and Arizona who held the designations via statute since the 1940s). They were sophisticated and “big-city savvy”. I babysat for their kids – Jen and Greg (the latter had “banjo eyes”, according to my dad). When Charlie's efforts to organize the electrical workers failed, they were “called back” to New Jersey; some in the neighborhood said the union experiment was mafia-funded.

Down the street, the Vinutos were another Italian family from Detroit, Michigan. Americo “Rico” Vinuto was the family patriarch – a barber who some said was involved in more than cutting hair for automotive executives. Rico's wife and children were friendly (son Tony was popular with local girls). The Vinutos also had what many Floridians wanted but didn't have during its hot, humid summers – a pool.

One time, I was invited to swim at the Vinutos. Like when I talked with Mr. Hime on his porch back on Oak Street in New Philadelphia, I talked with Rico about life and current events. Somehow, on this day, Rico told me, “If you don’t do anything else in your life, get a good education and do good work in your chosen career. Since I was fourteen at the time, the advice was sound and wise. Little did either of us know that Rico would suffer a massive heart attack and die a week later.

There were many people on our Florida street that worked hard to “make it to Florida retirement” to later meet an early earthly demise. Another neighbor, in his mid-50s (the same age I am now) recently relocated from Wisconsin and bought a beautiful powder blue 1975 Pontiac Grandville to celebrate the accomplishment. He entered God’s pearly gates a mere week after he arrived.

It was during this time that my running took me on the sandy, unpaved roads that surrounded our neighborhood, through orange groves that dotted our neighborhood (the last remaining groves in Pinellas County), over bridges where fisherman used nets to catch fresh mullet to smoke, and along the shores of the Gulf of Mexico. Like in Ohio and, particularly, in New Philadelphia, I carved out my running “neighborhoods” and explored. My dad was still working but home more, and my mom chose not to return to teaching. The move had been challenging for her and for my parents’ marriage (my grandmother passed away in 1979, shortly before we moved – another contributing factor). While I didn’t know all of the details of that story at the time, I knew that our move to Florida had both professional and personal implications for my parents and our family.

High school was a stream of consciousness experience in my view – schoolwork and running. It was probably a way to deal positively with life in general and with my dad’s challenges. We also had to work during this time – my first paying job was at age thirteen as a weekend porter and assistance at a local funeral home. Ron Bennett’s family operated funeral homes in Western Kentucky, and he operated his Largo, Florida funeral home on a tight margin. I rode my bike to work, and, in addition to

cleaning Ron's apartment, I was given a lunch of barbecue sandwiches from a local restaurant – Roger's BBQ -- with Little Debbie Swiss Cake Rolls for dessert. Ron's parents – Mamaw and Daddy Ray – often visited from Kentucky. Due to the fact that most of Ron's business was low-cost "body ship-outs" (preparing the body for transport back home to their native locations for full funerals), he later sold the funeral home to one of the large conglomerate companies that grew up around the area.

I had a surprisingly-successful high school career running cross country and track; I never really planned it, as it happened somewhat organically. I received several offers from small colleges to run (including Ohio's Denison University and Geneva College in Pennsylvania). My dad wasn't in favor of collegiate running; I had too many responsibilities at home in spite of his being around more.

Fast forward to 1986; my dad decided he wanted to move back to Ohio to address the changing market for the electric motors he designed (used in aircraft and military applications). He felt it would be better for him and for my mom. It was his decision, but my mom was always an amicable partner – her silent strength able to deal with the many details that were always part of my dad's plans. As the youngest, I was also part of the plan to "help". My sisters were graduating from college and starting grad school, so they weren't in the picture.

The decision was made to move back to New Philadelphia; he found an apartment owned by his college friend Chet Stocker on Third Street Northeast (across from Tuscarawas Central Catholic High School). Since I had started college in Florida (first at St. Petersburg College, then at the University of South Florida), I had mixed feelings; however, like in the past, I ran and kept moving forward – knowing that not supporting my dad was not a good option.

The fact that we returned to New Philadelphia and our Northwest neighborhood was a blessing – the same infrastructure we left just a few years prior was still there. The plan was to either purchase

an existing home or build a new one. The latter became the option of choice, as my dad located nearly 5 acres of property on the edge of New Philadelphia near the Boulevard found by friend Mabel Avon (her husband, Bob, was a good friend and co-worker of my dad's from his Joy Manufacturing days). I spent the summer of 1987 helping build our new home – culling brick for the bricklayers and painting waterproofing tar on the foundation, among other duties.

I also commuted to the University of Akron (where I received a teaching degree) and, later, to Kent State University to obtain my Masters in Library Science – all the while running all over the Tuscarawas Valley and working multiple jobs (including six years as a production assistant at Midwest Offset/Times Reporter). Again, these years – as well as my early years as a librarian – were spent running, both literally and figuratively.

Fast forward again to January 17, 2017. My mom, who I had cared for over a 6-year period (I lifted her daily like a bride to put her to bed along with bathing, feeding, and diaper changes) was dying, and I had a weird feeling in my arms following one of my daily runs. I chalked it off as fatigue. However, by the beginning of January 18, 2017, I could barely stand or turn a door knob with one hand. In my attempt to open the door (to have my dad take me to Union Hospital's Emergency Room), I fell and didn't walk again for nearly 7 months.

I lost all use of my arms and legs as a result of Guillian-Barre Syndrome (a condition where one's immune system turns on itself, compromising the myelin coating on the nerves). The disease moves from the extremities inward; if left untreated, it could affect the heart, lungs and digestive system.

I spent forty-five days in hospital rehab and the next 3 years regaining balance, mobility, and basic functions (especially opening jars/caps and turning knobs). My other main objective was returning to work as soon as possible; I never received disability payments and declined efforts to apply.

Through the whole process, I knew God had the plan for this chapter of my life (as he had for all of the previous chapters I have written about). As far as my running was concerned, while I couldn't do it for a while, I was "running" in my mind – the basis for all of my runs of the past; another God-directed activity.

When I reached the point that I could run again (which was very awkward since I lost over 35 years of muscle in six days when I first contracted GBS), I was amazed that the mental part of the activity was retained. In that sense, I never really "stopped" running.

Things were going along pretty smoothly until October 26, 2020 when my dad suffered a stroke (thankfully I was home that day from my job in Michigan as library faculty for a community college). Once again, God needed me to be a caregiver; navigating the uncharted waters associated with caring for a stroke patient who has lost memory and mobility.

As I write this story, I'm still caring for my dad at home and working remotely – both through my Visiting Librarian Service (which I have operated either F/T or P/T since 1993) and for a library systems company based outside of Washington, D.C. It is often challenging to juggle caring for a loved one, a house, household/personal finances, and other tasks along with taking care of my personal and mental health – including running.

It is that part of my current chapter of the story that takes me back to the Oak Street story I started telling at the beginning of this narrative. I still run in that neighborhood – which, ironically, looks very much like it did nearly fifty years ago. I reflect on the good people that live/lived there and the New Philadelphia of the past. I also circle around to Tuscora Park, remembering the past and celebrating the present of being able to run again. When I was recovering, the New Philadelphia Football program recognized my humble efforts to rehabilitate during my daily treks to the stadium. It

gave me hope for the future that even though some things have changed in the old neighborhood, others haven't.

The main thing that hasn't changed is God's guiding hand and the grace that He shares with me and all of us daily. He planned (and continues to plan) every part of my life's journey, as I strive to seek salvation following the end of my earthly life. I'm not perfect; I join others in sin and repentance. I know that God's grace and the kindness of His followers (both those in New Philadelphia and those where I lived in Florida and elsewhere) will lead us to eternal life if we are chosen by God to receive it. I also know that God enabled me to use my arms and legs again as well as not lose my mind.

Unfortunately, my dad has lost a great deal of his memory. Yet, God gives him the grace to live and do his best every day. I often pray Sirach 3:12-14 and know he will enter the Kingdom when God is ready:

My child, help your father in his old age,

and do not grieve him as long as he lives;

even if his mind fails, be patient with him;

because you have all your faculties do not despise him.

For kindness to a father will not be forgotten,

and will be credited to you against your sins;