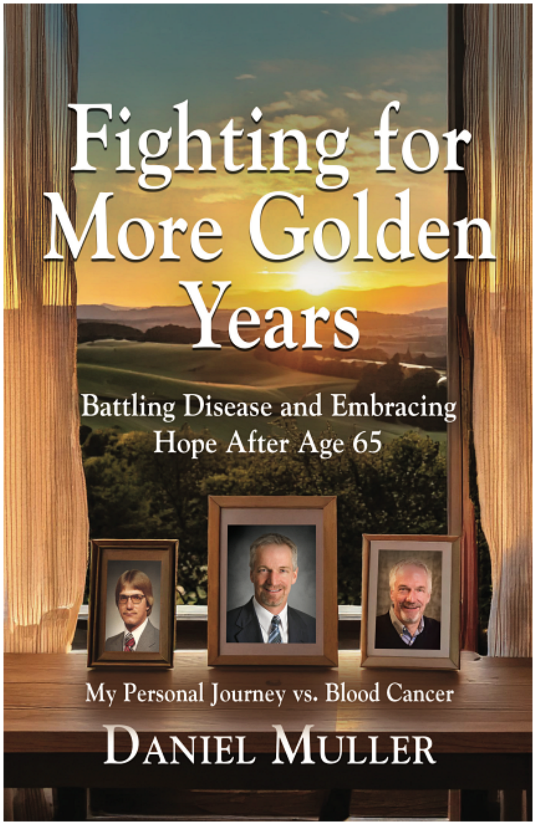


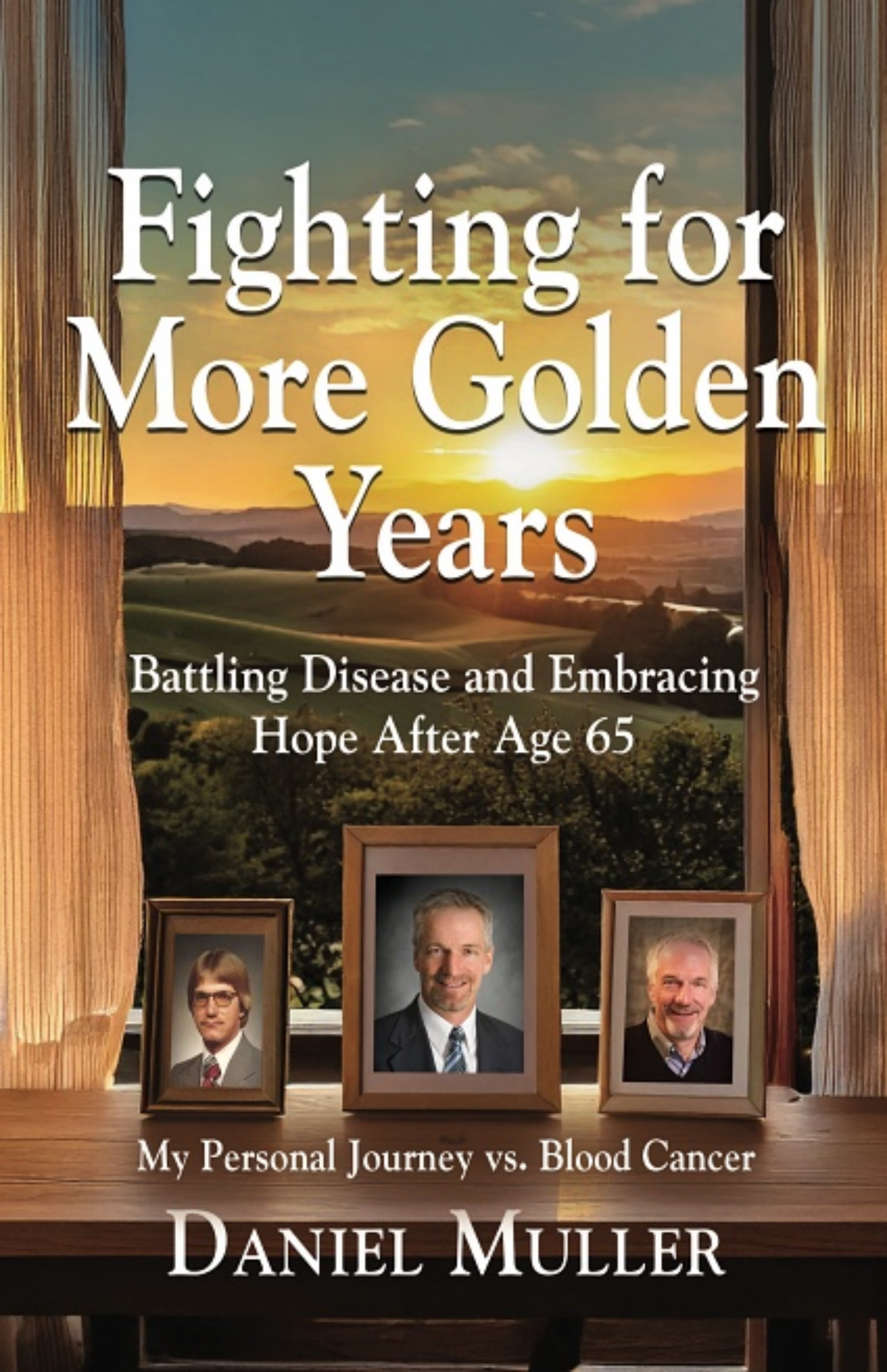
Told in journal format, this is the author's true personal story about being diagnosed with, and fighting, leukemia. The author relates all the treatments and side effects from his battle, while trying to find hope throughout the process.

Fighting for More Golden Years:

Battling Disease and Embracing Hope After Age 65

By Daniel Muller

Order the book from the publisher Booklocker.com
https://booklocker.com/books/13837.html?s=pdf
or from your favorite neighborhood
or online bookstore.



Fighting for More Golden Years

Battling Disease and Embracing Hope After Age 65

My Personal Journey vs. Blood Cancer

DANIEL MULLER

Print ISBN: 978-1-959622-34-5
Ebook ISBN: 979-8-88531-943-0

Published by BookLocker.com, Inc., Trenton, Georgia.

BookLocker.com, Inc.
2025

First Edition

DISCLAIMER

This book details the author's personal experiences with life after age 65, and fighting to survive a blood cancer. The author is not a doctor or healthcare professional.

The author and publisher are providing this book and its contents on an 'as is' basis and make no representations or warranties of any kind with respect to this book and its contents. The author and publisher disclaim all such representations and warranties, including representations about medications, treatments, processes, and medical advice. In addition, the author and publisher do not represent or warrant that the information accessible via this book is accurate, complete or current.

The statements made about products, processes, habits and services have not been evaluated by the U.S. government, nor any government. Please consult with your own advisors, medical professionals, or other licensed professionals regarding suggestions and recommendations made in the book.

Except as specifically stated in this book, neither the author or publisher, nor any authors, contributors, or other representatives will be liable for damages arising out of, or in connection with, the use of this book. This is a comprehensive limitation of liability that applies to all damages of any kind, including (without limitation) compensatory; direct, indirect, or consequential damages; loss of data, income or profit; loss of or damage to property and claims of third parties.

You understand that this book is not intended as a substitute for consultation with a licensed medical, legal, or accounting professional. Before you begin any change of your lifestyle or health situation in any way, you will consult a licensed professional to ensure that you are doing what’s best for your situation.

This book provides content related to aging, illnesses and diseases. As such, use of this book implies your personal acceptance of this disclaimer.

TABLE OF CONTENTS

INTRODUCTION

An estimated 1.6 million Americans are living with, and/or in remission from, blood cancers including leukemia, lymphoma, myeloma, myelodysplastic syndrome (MDS), myeloproliferative neoplasms (MPN) and others.

About 54,000 are under age 20, including children. The American Cancer Society estimates that 187,000 new cases are diagnosed each year. These blood cancers represent about 10% of all new cancer diagnoses each year in the United States.

Over 57,000 will die from these blood disorders in 2024, almost 10% of all cancer deaths.

There are over 100 different types and sub-types, but what most have in common is that the cancer develops in the white blood cells, vs red cells or platelets. There is no clear indication of cause. Most researchers point to heredity/genetics, exposure to radiation, or exposure to chemicals as primary cause ‘suspects’. For each individual case, there is no irrefutable proof or clear source of the disease, unless someone lived a portion of their life with exposure to chemicals, had high levels of radiation from a prior disease, or had a high percentage of relatives with blood cancer.

There are about 60 million Americans who have reached the age of 65 or older. Approximately 1-2% of these elderly Americans have been diagnosed with a blood cancer. The good news is that 98%+ do NOT have a blood cancer today, but clearly, aging increases the risk for them, as over a lifetime, the immune system’s ability to kill cancer cells slows down and becomes less effective.

The tolls taken on patients with blood cancer, and their families, are immense. Besides the treatments with their nearly infinite number of temporary or permanent side effects and secondary toxicities, there are likely, for each patient, hundreds of needles in arms each year to check blood status or administer chemotherapy, dozens if not hundreds of doctor appointments and travel, physical exhaustion, mental anxiety, and high-cost bills from doctors, testing, medications, and hospitals. The treatment cost can be a huge toll for the patient and their families, but even if they have solid insurance, the societal toll is large as well, as these treatments are expensive, whether Medicare, Medicaid, or a private health insurance company foots most of the costs.

For most of these blood cancers, but not all, there are no cures, only the hope of getting to remission, and the hope of having an extended one before the next recurrence begins. Sometimes, the same treatment might not be used twice due to the toxicity of the chemo drugs, leaving the patient who has a recurrence to find alternative treatments or to sign up for a clinical trial where doctors attempt new or revised treatments, which they call ‘protocols’.

For those blood cancers that can be cured, there are a multitude of treatments depending upon the specific type of cancer. Bone marrow or stem cell transplants, immunotherapy, surgery, radiation, and chemotherapy are just some of the treatments that can lead to cures of some blood cancers.

There is significant research and a number of clinical trials going on to find better treatments and to extend lives and improve the quality of lives.

There are always doubts in the minds of patients, contributing to their anxiety, if they chose the best doctor and medical center for them. There is also the torment of considering the tradeoffs between large, distant medical centers that are leading the way with new treatments and more experience with their specific cancer, and the local care that is available, albeit perhaps without the leading experience, technologies and research.

Regarding chemo drugs, as a doctor said, in one of our sessions – "Nobody ever says that their chemo treatment went very well with no side effects, and that they feel as good as before the blood cancer.''

Everybody who goes through chemo treatments has side effects, with the hope that the benefits (staying alive!) outweigh the negatives after treatment is complete.

I learned early on that two words associated with blood cancers have very different meanings. 'Acute' means that the disease is aggressive and must be treated right away. Acute diseases can sometimes be cured, however, with modern treatments. 'Chronic' means that the disease is slow-growing and sometimes 'indolent', and there is usually time to get second opinions, monitor disease progress before beginning treatment (watch and wait is the term), and is more common. Chronic blood cancers, with some exceptions, usually cannot be cured, the goal is remission, with extended remissions (years) the best possible outcome. I liken these two categories to the turtle and the hare.

There seems to be sort of a stigma associated with blood cancers, in that most reactions from friends or family to news about someone having any kind of blood cancer, is sort of a 'Oh, I am so sorry'. I contrast that to my prostate cancer, or even some skin cancers, when most others react with 'Well, that is a good kind to have, it is very curable'.

My family had no history at all of blood cancer, and I was, like most, not at all aware of chemotherapy, side effects, the process, cures / remissions, or what to ask. All I knew was that this unknown disease was scary just because of how little I knew about it!

As I write this, I have no idea how long I might survive, but we are trying to find hope for more years. I have asked my wife, Sally, to get this story published if something unexpected happens to me, as I want to share my story with other patients and family members in an attempt to help them.

I have decided that if I can get to remission, confirmed by a variety of lab tests, I will end my journal and publish my story in order to help others, versus continuing to write about my life after remission begins.

Why would anyone want to read about the journey of someone going through this battle?

All I know is that when I began this trek, the anxiety was overwhelming, and writing about it gave me an outlet, helping me mentally, I believe. I wanted to create a record of my story. I also know that getting information from others with my affliction helped me greatly, to better understand what I was going through, and to get basic questions answered. I hope that my story will help others beginning or in the midst of a blood cancer battle, and help them prepare and understand some of the challenges to come, as well as the importance of hope.

My story is *not* one of bravery, miracles, or of overcoming terrible odds and circumstance. It is also *not* just about capturing lessons that others should follow during their journeys and 'fights', although I do list some lessons learned at the end, for what they are worth. Rather, it is just my story, and I am sure that as a human being, I did well with some challenges, and not so well with others. I admitted to a friend that as much as I was trying to be strong and brave, deep down inside I knew I was just a chicken!

I have thought extensively about the word that best describes the past two years. The best word I can come up with is 'battle', although there are other words that come to mind also starting with the letter 'b'! The experience was, in all senses, a *very* difficult physical and mental battle against an enemy that I could not see or confront directly. Since the enemy was, and is, totally within my own body, I am sure I sometimes took my frustrations out on others, or was not as patient or courteous as I could have been.

I believe that I am, in some ways at least, a better person now than when I was cruising along without much concern over my health. I *think* I am more patient, thoughtful, and delayed in how I respond to others. On the flip side, at least right now, I believe I am more forgetful, physically weaker, and less energetic, maybe from the treatments that are designed to do good things, but like most medicines, have unwelcome side effects.

Like all battles, I believe we all emerge from health battles mentally stronger in some ways, but also with some scars and bad memories that change you to the core, perhaps a form of PTSD. I believe that these sorts of challenges are all part of the life experience that shapes us and makes us who we are, for better or worse.

It is important to note that I have not used the real names of my healthcare professionals to ensure their privacy. I sometimes use names such ‘Dr. Y’ or ‘Dr. F’ or ‘Nate’, but these initials and names have nothing to do with, and do not match, the actual doctor or nurse name. Also, in my daily journals, I sometimes expressed frustration, impatience or dismay with one or more of my caregivers and/or circumstances, but that was just me recording how I felt on that particular day. I hope others battling blood cancer will understand that it is OK to feel frustration or impatience during their journeys, it is human nature. In no way are any of my comments meant to convey anything negative about my caregivers, as they all did an excellent job helping me. I am so thankful for their talents, training, professionalism and patience.

CHAPTER 1:
My Life Prior to the Golden Years

Let me begin my story by sharing a very short synopsis of my life prior to age 65, a life that I enjoyed greatly. I share this because my background might explain a bit of how I coped with the struggles during my golden years.

I was born in 1957 into a family of five, in the small town of Brewster, located in northeast Ohio, with a population of around 2,000. I was the youngest of three, having a brother Ron, eight years older, and a sister, Kathy, four years older. My father worked on the local railroad as a locomotive fireman, and then as a locomotive engineer. We were the classic 1960's Midwest family, with the father working and the mother staying at home to take care of the kids and home. My father was of German heritage, my mother of Polish descent. Other than the five of us, we hosted my grandmother Estella (on my mother's side) for months at a time, as she had a terminal disease and could not live alone. Then she would go stay with my uncle, or the other uncle, until she came back when it was our turn to care for her. I suppose financially the family could not afford for her to be in assisted living, and she probably would not have wanted that either.

My father, probably due to his upbringing with his grandparents who taught him how to work and solve problems at a young age, was a do-it-yourselfer. Because of that, I was often recruited to be his 'helper' on home fix-it projects, when I mainly served to hold a flashlight, hand him tools, or to go get him a different tool that he needed. Little did I know, he indirectly taught me a lot about how to do things around the house, or around the car, such that I always tried, during adulthood, to fix things myself before paying someone to do it for me.

I grew up with many good friends in town, and some of those friendships continue today.

I was a fairly good athlete, playing football, basketball, and baseball as I grew up, but I really took to golf at a young age. At 16, I decided I would be better served focusing exclusively on golf versus getting banged up in contact sports. As a skinny, slow athlete, with good hand-eye coordination, this just made sense to me.

I credit my dad for supporting that interest, first with buying me a set of used golf clubs, then driving me to get lessons from a local golf pro, then shuttling me to junior tournaments later as I developed my skills. I did well in high school both in golf and academically. I loved my high school experience.

I almost chose to not attend college, as nobody else in my family knew much about college or why you should attend, but thanks to a high school teacher and coach who encouraged me, I decided to matriculate to Kent State University in Ohio. Even though I was recruited for the golf team, there was no scholarship offered, and I felt as though I was a walk-on tryout for their Division I golf team. I chose Business Administration as a major, because I had to write down a major to sign up for my first classes, and this sounded impressive to me. I was more interested in using college to become a pro on the golf tour, than I was in earning a degree! Deep down, due to self-doubts, I thought that perhaps neither was in the cards for me.

I made the golf team in my freshman year, barely, on the reserve team. But in my sophomore year, I played well and broke onto the varsity team and began the ‘fun’ and rigors of weekly golf trips and tournaments, and learned how to do the near-impossible; practicing golf 40-50 hours per week, plus attending classes and getting good grades through learning how to manage my time wisely. I was a double major in computer science and operations research, so I had full class loads with challenging material.

These golf tournaments and trips varied from playing 18 holes out of town on Friday and Saturday, with a practice round Thursday, to playing two tournaments per weekend, where we would play Friday and Saturday, travel Sunday to a new tournament, then play 36 holes on Monday. This was an accelerated course in how to manage my time, a skill that I found to be extremely useful in the business world much later. The only days that I could always attend classes during the spring and fall golf season were Tuesdays and Wednesdays. You might imagine how difficult it was to stay current on classes and materials when I usually missed class on Mondays, Thursdays and Fridays.

There was zero ‘goofing off’ during my four years, I was totally consumed with studying and golf. Our sophomore year, we won the Mid-American Conference golf championship, which qualified us to play in the NCAA division I golf championship in upstate New York, where we played against future PGA stars. I missed all my finals and had to beg / cajole / convince my professors that they should help me to take the finals at a different time. One wonderful professor even invited me to her home to take the calculus III final! I also was medalist at the Canadian-American Invitational shooting 67-71. Somehow, even with the time demands of golf in the fall and spring quarters, I graduated on time in four years.

After taking a job and beginning my career after graduation, I went through a broken engagement. After this happened, I was left feeling as though there was nobody out there for me, even though there were probably about 5 million single women in the country around my age! I was certain that I would never have a serious relationship again. It’s funny how when a relationship ends, it can change the perception you have of yourself, robbing you of whatever self-confidence you may have earned to that point.

I dated a bit, and fortunately for me, I found my future wife, Sally, about six months later at the company where I worked, and the timing was right. I had met her at college, but we only knew each other casually through mutual friends. She also was coming off a broken engagement, and we found so much in common, more in common than any other person I have ever met, not so much in our hobbies and interests, but in terms of our background and family values. We both grew up in similar families from blue-collar backgrounds. It seemed as though our views of most things were closely aligned. We fell in love, with me being happier than I have ever been. That happiness has continued for over 43 years now!

Let me say this about my life partner, a term I like better is 'life witness'. Nobody I know is as nice, loving, and caring for her family, and for me. She has little tolerance for things she sees as being wrong, and she always talks about her strict upbringing and learning right from wrong at an early age. When we were dating, I realized that Sally was not one of the kinds of young women who would see a young child and pick them up, kiss them, hug them, etc., because she had no nieces or nephews at that time and had little exposure to children. However, I always just knew she would be a wonderful mother, and a mother that would ensure that our children, however many we had, would be safe and secure.

Let me share a visual to demonstrate this. At our local pool, when other mothers with young kids would belly up to the bar, and just let the lifeguards keep an eye on their kids, Sally would always be right there with the kids, making sure they were safe. This gave me great comfort throughout my life knowing that I didn't need to worry about the children's safety.

Throughout our lives, we always enjoyed spending a lot of time together, and lately our 'happy hour' each evening before dinner, even if we are not having any wine, is one of our favorite things to do, to catch up a bit on things we did or heard about that day, or to reflect on earlier times in our lives.

We married in 1981, had Sara in 1985, Cory in 1989, and began living our lives. She ended her career as a systems analyst to be a fulltime

Mom when we had Sara, and I somehow managed to earn enough, barely, to support the family in those early years. I decided to pursue my MBA in 1988, with the support of Sally and my employer, who picked up the tuition costs. When Cory was born the next year, I was never so busy as working fulltime, attending evening classes, and trying my best to be a good father and husband. We built our first home in 1990, and I graduated with my MBA in 1991. Those were some of the best years I can remember in my life. We were both working very hard to make a home and a future for our family, and having children made all our work so worthwhile.

Over the years, as our children grew, and new career assignments and promotions occurred, physical home moves were required on four occasions. Our children were active in school activities and sports. We always enjoyed watching them in whatever they were doing at that time in their lives.

About the time both children were leaving the nest, we decided to build a new home closer to my father, who had become a widower when Mom passed away in 2009, and was increasingly needing some assistance. We still live in that home, although we both feel it is becoming too much to maintain!

CHAPTER 2:
My Career Before the Golden Years

I won't go into the details of my career, but I want to share the highlights, as my career set the stage for retirement and life after age 65.

During my senior year in college, I accepted an offer at a global manufacturer as a computer programmer. I did well over my first several years, and was promoted into management. I decided to pursue my MBA after about 9 years of work, and my career began to flourish after completing that degree, armed with a new set of skills. I was transferred to another division in 1995, and we relocated to Canfield, Ohio while I worked in Youngstown, Ohio. Six years later, we returned to company headquarters in our home area, where I was promoted into a series of executive roles, with each new role requiring significant time commitments, which at times took its toll on the amount of time I could spend with my family.

Later, during an eight-year period, beginning in 2001, I had global responsibility as a vice-president and then president of a large operating division which grew in sales to over $1B, and I spent a great deal of time travelling overseas. I loved this job and the team I was on, despite the personal sacrifices of my family time. Others talked about the 'glamor job' I had of flying around the world, seeing the sights, and learning new cultures. If only others knew how difficult life can be when travelling so much, and how your sleep patterns get destroyed as you travel halfway around the world through multiple time zones, and then return home. At that time, getting to spend just one week with Sally and the kids seemed like a wonderful treat. I was gone about 50% of the time travelling, and definitely missed my time with the family.

I then was promoted to a staff role at headquarters in 2009, as a Senior Vice-President with global responsibility for information technology and corporate strategy.

Throughout my career with many hours invested in various roles, Sally did a wonderful job with our children, and both Sara and Cory grew to be outstanding people. They were both married the same summer, in 2012, marrying Dan and Katelyn respectively, two wonderful people on their own!

Two years later, I retired after 35 years of service at the same company. It was nice to experience the going-away lunch and dinner, and well-wishes, but I was ready to move forward. Due to the demands of the job, in my last 20 years of my career, I was typically working 60 hours per week or more, plus some weekends. I was very ready to retire and get *out* of that habit, and pursue those hobbies and interests where I wanted to invest more time.

CHAPTER 3:
Retirement Before the Golden Years

I have debated, since retiring, if my dedication and immense hours at my job were worth it, in the grand scheme of things. I am sure that this dedication had a lot to do with my success, but did I go overboard? The older I get, the answer of ‘yes’ is coming more into focus, but we never know for sure, do we?

My retirement began much earlier than most retirements, at age 57, just because financially, I thought I could. Other leaders at my company were shocked that I would consider retiring at such a young age, when in their words, I had so much more to offer and more to accomplish in my career. My response – “I am leaving because there are literally hundreds of things I want to do in life outside of working here, plus, financially I can do it!” I always appreciated my company, the opportunities, and the career I had there, but it was time to move on.

I started a small consulting company just to ‘fill-in’ any spare time I might have in retirement, began to finish the book I had begun writing while still employed, and began playing a lot more golf. We began spending winters, or parts of winters, in Florida. We quickly found out that retirement, during some of the cold winter months, was very much a treat if you could live in a sunny warm climate!

These years truly felt like our best ones, as Sara and Dan had a son, then a daughter, and Cory and Katelyn had a daughter and then two sons. With five grandchildren and happily-married children, life was wonderful. Sara eventually became a high school business teacher and head of her department, and Cory began teaching, but then became a principal at a local school system. We are so proud that they continued their educations and both earned master’s degrees. Both Sara and Cory’s spouses have careers as well, and are doing very well. Dan is in construction management, and Katelyn is a labor and delivery nurse. (our entire family below)

Holidays were wonderful, as we would usually host the entire family for a cookout or lunch, and the grandkids got to know their cousins that way, since Cory and Sara lived about 60 miles apart. We were so fortunate that our children and their families lived in the same state as us, Ohio, and that we could go visit whenever we wanted.

In my son's words, we were living the dream! We had built such a fine life for ourselves, between family, friends, hobbies, and being able to do whatever we wanted to do.

HEALTH BECOMES AN ISSUE

Our lives were interrupted, unfortunately, by a few health issues. In 2017, after some outpatient surgery, Sally developed extreme pain at home, so we went to the ER, where they did a CAT scan. It turned out that the pain was due to cramping, but they discovered a spot on her left kidney. That spot was later determined to be cancer, so she had a partial nephrectomy (a partial removal) of her left kidney, using robotic surgery, leaving about 80% of that kidney intact. The doctor said that all went well, and she would have less than a 1% chance of the cancer returning, as it was caught early and was small. As we left the medical center, I said to Sally – “Thank goodness we won’t be coming back here anymore!” In hindsight, I wish I had not said that.

A few months later, I was diagnosed with prostate cancer, which was not a surprise, as it ran in my family. But here we were, back at the same medical center just a few months after Sally’s visit! I was referred to a well-regarded urology surgeon there. I then had surgery to remove the prostate robotically, using the same robotic surgery technology that Sally’s surgeon utilized.

We both recovered, although with my prostate removed, it took months for me to get back to 100%. We tried to get back to living our lives normally, albeit with the mandatory follow-up scans and tests to check for cancer returning. There is no getting away from them, we will have them for the rest of our lives. One thing we learned about cancer as we aged, was that there is not really a status where a doctor will say you are ‘cured’ from cancer, there is always a chance it will return.

Sally was 61 when her cancer was found, I was also 61 when my cancer was discovered. We had a lot of anxiety and stress from those times, but once the cancers were discovered, it seemed as though the steps to get to treatment and recovery were fairly rapid, and the whole process seemed to be over quickly.

We had 3 or 4 more good years, but in 2020, Covid hit, and we both had two vaccines as most Americans did at that time. Sally got a little sick from hers, but my vaccines were different. I had zero reaction from the first, but when the second was given a month later, I went deaf in my right ear just a few hours after the vaccine, which was given in my right arm. A week later, I went deaf in my left ear! Luckily, my hearing returned within a day or so, but I developed tinnitus in both ears that has bothered me 24x7 ever since. What I hear constantly is a 9000 MHz high-pitched buzz. If you download a noise app, you can recreate exactly what I hear! I will return to these vaccines later.

CHAPTER 4:
The Golden Years - Health Issues Begin

I crossed that magical line of hitting age 65! A lot was happening at that time, and I call these ‘event milestones’, since I believe they happen with many people as they turn 65. But certainly, life was becoming much different. I began keeping an informal journal to record our lives, because concerns and problems began creeping into our days like never before. I thought in some way, this journal would be therapeutic for me, trying to make sense of the physical and mental changes at this age.

These must be ‘The Golden Years’ that others talk about, and in the main, they really are. We can sleep as late as we want, and we have few day-to-day responsibilities. We can make last-minute plans and do things that come to mind, financially we are doing fine, and we have wonderful families, children and grandchildren that we adore, and life-long and new friends.

However, health-wise, relative to earlier years, these years are not so golden.

I am writing my story in journal format, day-to-day, because I wanted to remember the sequences and dates of my journey, and because the timeline may be helpful for the reader. Already, it has been useful for me to go back to find dates and times when certain medications were begun, or when I talked to a specific doctor, etc.

The time gaps between entries in my journal vary widely, but it seems as though the more serious the health issues, the more frequently I seemed to write in my journal.

Maybe I should call these ‘the brass years’, as on many days, they do not seem too golden.

April 22, 2022

This month, I had three significant life milestones pass me by.

First, I turned 65, an age that I was not sure I would reach when I was younger.

Second, I went on Medicare, and one year earlier, on Social Security.

Third, ever since I retired eight years earlier, Sally and I dreamed of the day when we would have our son or daughter and grandkids visit us in Florida in the winter. Well, this spring everything worked out for my daughter, and she was able to bring her two children, Colton and Hayden, ages 8 and 5, to visit us for four days.

Now that they have returned to their homes up north, I am finding myself a little depressed, which is unusual for me, as I always consider myself to be an optimist if not a realist. What was going on here? Was this some sort of "Age 65 Depression Thing" going on? If only I knew what was ahead!

Regarding Medicare and Social Security, to say that signing up for each was stressful, might be overstating it. But it was definitely NOT a fun time, and very frustrating. First, for some reason, many of the government employees were still working exclusively from home due to Covid, even though most other businesses and organizations were back to work at the office, if not five days per week, at least a few days per week. Therefore, they had all sorts of reasons why they could not handle the needed requests or issues with us on the phone. Second, whether it was intentional or not, we would wait on hold on the phone for 30-60 minutes, waiting to talk to the next available person. When we finally were able to talk to someone, as soon as they heard our name and heard what we were trying to do, we got cut off from the call! This happened at least four times, and *they would never call us back to re-establish the call*. So, we would call again, wait in queue, get someone different, and have to start all over to describe our problem.

You would think that getting my wife onto Medicare at age 65 (she is a year older than me) would not be a problem, but wrong again! We had to send them a certified copy of our marriage license, but we found out that the license we had was not the 'type' they were looking for! After a maddening search, we found a different one, and then had to call again, wait in queue, talk to someone, then get cut off again! That Medicare journey was extremely frustrating.

Then I decided to start drawing social security at age 64, even though my full retirement age was 66.5. I paid the max into social security during 35+ years of working, and thought that the worst decision anyone could make was to defer taking social security until age 70, in order to get about 8% more per year later, but to die before you start collecting!

But as I applied, you would think I was a criminal or non-citizen wanting to get social security! Too many times, someone in Social Security would say something such as "I could normally get this done right now, but I am going on vacation for two weeks, and don't have the time now, but when I get back in two weeks, I will process this and you should see some sort of mailing confirming that you will be receiving monthly Social Security checks."

Of course, after 3-4 weeks of waiting, I received nothing. Then I had to start all over. Later, once I finally was on Social Security, we wanted to enroll Sally on Social Security, as she had reached full retirement age, and was to receive 50% of my benefit. Since we had already enrolled her in Medicare, we assumed this would be an easy process.

This became another confusing mess with poor service and responses. All of our efforts and documentation about Sally already being on Medicare made no difference. Later, I tried to get on Medicare at age 65, and this was another unpleasant adventure.

I concluded then that for whatever reason, both Social Security and Medicare are failing in terms of providing good, or even average, service to deserving citizens. We should all be ashamed that we have tolerated this lack of customer service for too long, and nobody seems to have authority or a willingness to rectify this. There seems to be no incentive for them to improve their service, or to become more efficient. Maybe it is like this because some people applying are dishonest and trying to scam the system, so they treat everyone like they are cheaters and make the process very difficult, to weed out the scammers.

I will say that once you struggle through the bureaucracy and get on these programs, they do a good job of sending checks on time and processing health claims. It seems that the onboarding process is the one that is broken.

My theory about any organization, and how well they service customers, is to count how many surveys they send you after you have an interaction with them. Surveys do not always indicate good customer service, but if an organization NEVER sends you a survey, you can bet nobody in management cares about customer service. Neither Social Security nor Medicare ever sent me a survey that I recall.

January 5, 2023

I finally have time to write again, as the past 6 months have been very busy and difficult.

On November 14, my father passed away at age 94, in a nursing home. The year before that was challenging, trying to share tasks with my siblings taking care of Dad in his home. Dad was still our great Dad, he was pretty sharp mentally, but his outlook began to turn more negative. We eventually figured out that Dad had developed dementia, and had become difficult at times, mainly due to his frustration at not being able to do the basic things in life that he was used to doing easily.

Dad was placed on hospice months before he passed, because he told his doctor that he could no longer travel to the office for bloodwork and appointments, that it was too difficult physically. The hospice caretakers that came into his home were doing their best, but Dad did not like the intrusion, even though they were getting him his medications and checking his vitals and blood without him having to leave home.

Dad's immobility and inability to go purchase things he needed, required that we do those things for him, and most of that burden fell on my sister Kathy, who lived a block away. But Ron and I talked to Kathy and we split some of the chores, specifically getting lunch for him every day and being there to prepare it and clean up the kitchen afterwards. During that time, Dad would occasionally thank one of us, but usually did not, and usually had some complaint about the food or something else related to his lunch. He would say things such as 'I need my coffee warmed up, it is too damned cold', or 'Who the hell made this sandwich?' or 'Why in the hell do they put 20 napkins in the bag with the food?' It made us feel badly that we couldn't really make him happy or content, even though we were doing the best we could. But we all knew this was not the dad that we knew our entire lives, this was his dementia and his frustration talking.

There were two times in particular where I finally realized how far he had gone downhill mentally. The first time was when we had to take him to the hospital due to his leg weakness and falling, as we realized something was not right. We called an ambulance to come get him, and we decided I would follow the ambulance and help get him admitted. When I arrived, I met him in the ER, and he was in an examining room. A doctor came in, and the doctor asked him how long he had been using a walker to get around. Dad was hard of hearing, and I could tell he did not understand the question. I answered that he had been using a walker for 3-4 years now to get around. He looked at me as if I was insane, and yelled to me and the doctor that I was lying, that he *never* used a walker to get around, that he was walking fine with a cane. The doctor looked at me and said ‘Maybe he tells YOU that he is using a walker, but he isn’t really.’ Of course, that was not the case, but I did not want to argue with Dad in front of the doctor. After a week in the hospital, they remedied some imbalances in his blood, and he returned home a lot stronger and more able to walk again with a walker.

The second time was also when he was still living at home, and it was the middle of the night. He called my sister Kathy and said he was out driving and got lost, and now he was in a room in the city somewhere, being held against his will. He begged her to come find him and bring him home.

He rarely drove anymore, as he had great difficulty getting down the steps to the garage, or getting into and out of his car. He told my sister he had no idea where he was. My sister was terrified, and just out of the blue, decided to go to his house to see if maybe he was there. Wouldn’t you know, he was lying on the floor at home. She could not get him up to a chair by herself, and she called my brother and me to come help her. When we got there, he was on the floor, and pleading for us to get him up to a chair.

I asked him why he thought he was lost in the city, and he looked at me and was incredulous that I was there. “How did you find me?” Then he looked at his couch, and said “That couch looks a lot like the couch I have at home!” I told him that the reason it looked so similar was because he WAS at home! He just looked at me, and shook his head; you could tell he was very confused.

He was still a big man, and we could not figure out a way to get him into a chair on our own, because he was in a lot of pain each time we tried to move him. So, we called the rescue squad to come lift him. Once they got him in his chair, he seemed to calm down, and told us all he was OK, that we could go home now. That is when I realized what his real mental state was.

We were fortunate enough to be able to hire a few retired nurses to come stay with him at night and other times we could not be there, as the risk of a fall for him was significant in getting out of bed and going to the bathroom. Because of the nurses there, I had to discretely remove his rifles and loaded pistol that he kept by his bed, since we were worried that he might hear a noise and forget that one of the nurses was there at night and shoot them, or us!

Eventually, as his mental state diminished further and his frustration grew, he accused us of stealing from him, as he said things in his house were missing. Perhaps what he was talking about was that he noticed his guns were gone. But one day, he looked at me as if I was the worst human being in the world and said – “Boy, someone really got me. One of you ripped me off good. Well, don’t worry, I am going to find out who did this and when I do, you are going to be sorry!” We knew he kept cash hidden at home, despite us warning him not to do that, since there were now a lot of strangers coming into his house. Maybe he thought some cash was missing and he was not talking about the guns?

“Dad, I can honestly tell you, the last time I stole something from you was when I was 7, and I stole a pack of cigarettes from you, because the neighbor kids wanted me to get them cigarettes. After that, I have never, and will never, steal anything from you.” I had tears in my eyes telling him that, feeling so unfairly accused. I thought he might apologize, but no, he said “Well, Ron is out of the woods, because he was not here the day that I got ripped off, so it is down to you and Kathy.” Wow. What could I say? I told him that Kathy would never ever consider taking anything from him, nor would Ron.

Finally, he lost the ability to get up himself to get to the bathroom or the kitchen. He was just stuck, and wanted us to sleep there in his house to help him get into a wheelchair and wheel him to the bathroom, where it took all three of us (all with bad backs) to lift him and get him from the wheelchair to the toilet, and then reverse that whole process. What made it worse was that his bathroom was tiny, and there was just no room for four of us to be in there lifting him up, then down, then up again, etc. But we did the best we could, all of us.

At that point, we had to get him into a nursing home, and once he was there, he went downhill quickly, and passed two weeks later. It was extremely sad to watch what his quality of life was in a nursing home. Other than when one of us was there, he was ignored, other than someone delivering a small breakfast or lunch or dinner, or someone bringing him his pills. He seemed to never eat anything they brought him. He would lay in bed all day with the TV on, with nobody to talk to, and nothing to do. Since he had never gotten the Covid vaccine, the nursing home had a policy that he could not leave his room for 14 days, so he could not even be taken to the lunchroom in a wheelchair to have a meal with others. He never left his room, since there was a bathroom there. They were supposed to take him to a different place for a shower every few days, and they assured us that they had done this, but Dad never remembered it if they did.

A few days before he passed, he was in a wheelchair, and asked me to take him to look out into the hall. It was against the rules, but I pushed his wheelchair out into the hall, and he looked up and down the hall, and just said ‘That is a long hall!’ Nothing else. A few days later, I came to visit in the morning as I always did, and he was still in bed sleeping. I tried to wake him, but he would not move or open his eyes. I went out to talk to the nurse, who said he was given his pain medication recently, and that he probably was in a deep sleep. I did not agree.

Since Dad was on the hospice program, I called them, and told them that I could not rouse Dad. They sent someone over, and after examining him, they told me that he was close to passing. Oh my, how did this happen so fast? He had just gotten used to his new room and place, or so I had hoped. I called my siblings, and soon we were all there with him, along with the hospice person. She said he could pass away in an hour, or it might be three more days, but that he was definitely on his way. Little did we know that he would never regain consciousness. I went home to take a nap, then got a call shortly after, that I needed to get back to the nursing home. He had already passed, but at least my brother and sister were there with him when he went.

When I arrived, it was tears all around for quite a while, and I felt so guilty that I was not there when he died. We just sat there with him for hours, talking to him, and about him, and our lives together over the years. Unlike when Mom died, we had time to be with him in his room, without any time pressure. Finally, we decided it was time for us to leave, so we coordinated with the hospice person, who was just wonderful throughout the day, to have his body taken to the funeral home.

All of those memories are bad ones, there were few if any positive last discussions or words with him, and I think I try to block it all out the best that I can. We can only take comfort in our involvement in his life during the past year or so, and our time we were able to spend with him. We thought a lot about parents who are in a similar situation with no family or children around to look after them, and we cannot imagine how they can possibly get by in their final years.

The funeral preparations were OK, we got through it all, Dad was cremated, and we had a very nice service honoring both he and my mother, since Mom didn’t want any sort of service when she passed 14 years earlier.

That 12-month period of caring for Dad drew me closer to my brother Ron and sister Kathy, which was very nice. We have stayed closer ever since, although it is mainly via text and not normal get-togethers. But the one phrase that kept repeating in my head as we planned his funeral was ‘Now, you are on deck!’ I guess that phrase kept entering my head because now my siblings and I were the oldest generation in my family.

CHAPTER 5:
Finding Relevance

I had seriously thought a lot about life cycles and death, especially after I retired. At the time, I had decided that if I was fortunate to live anywhere close to as long as my mother and father, I had completed about 2/3 of my life, and that I had about 1/3 of my life remaining. I even began writing a song called 'The Last Third' with lyrics mostly complete, waiting for the tune and notes to pop into my head (which they never did), but the chorus seemed catchy enough:

"Staring down at the start of the last third,

Two in hand, one in the bush, that elusive bird

Praying it will last to be that final third,

Just hoping to get my share and final word."

At that time, a brief nine years ago, I had, in my mind, defined each of these thirds as follows:

The First Third – Learning all the necessary brain, physical, and societal skills to be setup for success in the second third. I included the years of trying to find a partner within this stage, but that was just my way of making it out to be around 25 years. This third included learning to walk, talk, be potty trained, read, do math, become socially adept, develop physically, etc. To me, this stage was all about you CONSUMING resources and not CONTRIBUTING much if anything at all to the society good. During this stage, you consumed food and clothing, became educated at others' expense, enjoyed housing, warmth, entertainment, travel, etc.

The Second Third – This is where you CONTRIBUTED to society, by providing your skills and work to others in exchange for pay. In addition, some have children and pay for those children as they grow up, educating them, feeding them, etc. In my simple way of thinking, The First Third was all about preparing for the Second Third.

The Final Third – This stage of life was most perplexing to me. For many, there *is* no final third. Some may work most of their lives *contributing* to society without ever retiring. Some die before they can get to The Final Third. But many will 'retire' in some way, and then try to find relevance.

My new way of describing The Final Third is exactly that – *finding relevance*. Once I retired, I thought of myself proudly as the guy who had a lot of business expertise, had strong leadership skills, could organize a lot of things, and had a lot of business acquaintances. Once I retired, that guy was gone! Who was this person now? Early on, I decided I was going to leverage my past experience and do some consulting, and work part-time to write my first book. I also decided I would dedicate myself to becoming the best golfer I could, given the time I now had to practice and take lessons. That was my way to find relevance in society, to try to contribute in some way, but also to enjoy myself more than ever before now that I had the time and financial security to do so.

However, I realized quickly that I did not relish consulting, as the pay was poor given the time invested. I also found that writing my book was very difficult and time-consuming. Last, I realized that I did not have the energy or drive to practice golf 4-5 hours per day as I thought I might. That was not fun, but playing golf with my buddies *was* fun.

So, here I am, still trying to find relevance as my original goals have not panned out as I thought they would, and I am stuck a bit. I am trying to figure out the next step.

OK, enough about the thirds of life, back to the milestones.

I have thought about these milestones for a few days, asking myself why I am feeling so melancholy and negative.

Maybe it is the ‘age 65’ milestone that we never really think we will reach. Maybe it is now being on Medicare, although I feel satisfied that my out-of-pocket costs will be less than before, and with good coverage. Maybe with Dad passing away, I am feeling a bit lost and realizing that I am a bit closer to the end of life.

Or maybe it is that this dream of being able to spend dedicated time with our family is over, at least for this year. Maybe it is the realization that spending precious, meaningful time with our children, now adults, is all too rare and short-lived.

Maybe this negativity isn’t the occurrence of these milestones at all. Maybe it is a culmination of things that are hitting all at once. My mother-in-law is in declining health at 94. Maybe it is realizing that the health problems (cancer) that Sally and I have had since turning 60 are likely going to be replaced with some other ailment, or the existing problems could re-surface. Maybe it is the time spent worrying about each other’s health that is getting to us, as it seems that every month or so, one of us is visiting a specific doctor for a specific test, and each time, we pray that nothing new is discovered. Maybe it is seeing our siblings begin to struggle with some health problems. Maybe for me, it is the impact of experiencing, in a short three years, prostate cancer and surgery, having cataracts removed in both eyes, development of permanent tinnitus, temporary loss of hearing in both ears, vitreous detachments in both eyes that has created a set of permanent ‘big floaters’ that blocks my clear vision, the finding of 3 pre-cancerous polyps during a screening colonoscopy, development of plantar fasciitis last summer, and helping Sally through first, kidney cancer, then multiple other surgeries and bouts of dizziness and ‘just not feeling right’, and losing Dad.

It could be that I am noticing more and more, looking in the mirror, less hair, more wrinkles, more age spots, etc. Or that I am finally noticing a loss of distance when playing golf, due to aging and loss of muscle mass. Maybe it is realizing that part of our winters spent in Florida will end at some point, likely due to health issues.

I discussed this a bit with a good friend a few days ago who is in a similar situation and a similar age. He admitted that he understood, but said that he had the attitude that he is still alive and kicking, and that he is going to enjoy what time he has to the fullest. I like that response to what is happening! I am just not sure I am there yet mentally. I need to get over this attitude I have. I must be the only old person spending so much time thinking about getting old and even writing about it.

CHAPTER 6:
Is Looking Forward a Solution?

I wonder if we should do ‘something big’ just to have something to look forward to, such as tackling some home renovation, throwing a party, planning a big vacation, etc. But right now, I am not sure I have the energy for that, nor the desire. I saw most of the world when I had a career, and I travelled so much I swore I would never leave the country again. So, the thought of staying in the comfort of either our permanent home or vacationing in Florida is good enough for me as I grow older.

I focused upon writing a second book, hoping it would provide some fulfillment, but I am realizing that although it is finished, and a very good read, I will be dependent again on my own marketing efforts, which takes work and a lot of time. I am still excited about the content and message, but am finding that the writing, editing, and publishing were wearisome and consuming of too much time.

Maybe it is just that we all feel a little let down after we finish something we had thought about and anticipated for so long. What is the next thing to look forward to? My father always told me ‘Just remember, you ALWAYS should have something to look forward to!’ I’m not sure I know what that should be, at my age.

Maybe that’s the real answer for me to contemplate.

June 5, 2023

Well, back to my second book. The subject of the book kept changing as I got further into the project, but I am proud of the result. I enjoyed writing about other people who are about my same age (Boomers), and meeting others, and renewing acquaintances at this stage of life. I hate the work promoting the book, but it is a necessary evil in order to get some readers out there to digest the book and perhaps think about the messages and open questions it raises.

The title is ‘SEX, DRUGS, ROCK and WAR: The Boomer Generation’, with a tagline of ’14 Boomer Life Stories that Bring a New Perspective to the Conflict Between Generations’.

On the day I received a shipment of my books for me to sell personally, I felt that same sense of satisfaction as the first book, but only a few hours later, the bubble burst, and it was a significant ‘burst’!

My doctor discovered, a few days earlier, during a routine annual physical exam, that my blood platelets fell below the normal range. He did not seem overly concerned, but we agreed to do a second blood test just to see if the first test was in error. I received the results of the second blood test a few hours after receiving my books in the mail.

The result was that the platelet count fell even further, and my lymphocyte count went even higher than the prior blood test, which showed the lymphocytes as being high and out of range also. Was this a harbinger of things to come? I began to do internet searches on ‘low platelets, high lymphocytes’, and *began to see words such as leukemia and lymphoma.* Oh, boy. Those words hit hard.

I called my GP office to see what we should do next, and a nurse said that my GP wanted me to get an ultrasound of my liver and spleen, with no explanation why. I had to wait three weeks for the appointment. The test went OK, but the technician seemed to spend forever on one spot. I waited 4 days for the results, the whole time imagining the worst. It turned out that my liver and spleen looked more or less normal. Now what?

I called my GP again, and was told by a nurse that he was referring me to a hematologist / oncologist in town, and that they would call me to setup an appointment. I called them after waiting for three days, and was told that the instructions from my GP were to wait for 4-5 weeks before the hematologist would see me. This seemed strange, why would my GP want me to wait that long for an appointment?

June 28, 2023

I had done some research on the three doctors in that practice, and asked for one in particular. I was told that he only sees cancer patients, but if I wanted to wait two months for the first opening, I could. No, that wouldn't make sense, I needed answers now! So, I took an appointment with someone who was new to the practice, but the appointment was still one month away!

During that month, I kept doing online research, and worried even more. Sleep became a precious commodity. Sally also began worrying, losing sleep as I was. We talked daily about the whole process and how worrisome it was! I read that vitamin B12 could help increase platelets, so for 3-4 weeks, I took vitamin B12 religiously, more than I needed. But I also read that taking too much is OK, since your body just sheds the excess it does not use. I ate a lot of green leafy vegetables, and tried to eat more berries, all potential enablers to increasing the number of platelets. I started drinking a smoothie every morning with juice, kale, berries, and wheat grass powder.

Finally, the appointment day came, and a lady who draws blood came to get me, and took six big vials from my arm. On my way to the examining room, I looked into a large room, where there must have been 20 or more people hooked to IV drips, likely getting chemo or transfusions, or whatever else patients might do at a hematologist. That hit me harder than I expected, as I realized that a lot of the people who have appointments with hematologists / oncologists are very sick and getting regular treatments and chemo.

Then we went into an office to wait for the doctor.

He came in about 45 minutes later with the blood results. My platelets had stayed exactly the same, no boost from the vitamin B12, unfortunately. My other key blood numbers got a little better, my white blood cell count went from 3.6 to 4.3 (still slightly below normal), and my red blood cell count increased from 4.73 to 4.87, up into the normal range.

After reviewing my chart and asking me only one question (Had I had a colonoscopy? Yes, I had, just last year, and they found three polyps which they removed), he stood up and asked if there was anything else he could do for me, and began walking out! We hadn't even talked about the platelets and potential causes of a falling platelet number, or my lymphocytes, or my health history, etc. I asked what the next steps should be. He just said that we should wait for some of the other autoimmune tests to come back in (some of those vials of blood got sent out), and once we had those results, if all looked OK, we would monitor my blood counts going forward every few months.

Sally asked if I could have another appointment to review the autoimmune test results, as I likely would not understand them. He just told us to check out and get an appointment in about two weeks. That was that! No more discussions, no clue as to what was happening with my blood numbers, etc. No discussion of what the hell was going on with my blood. This is an expert?

But at checkout, the scheduling lady seemed upset that the doctor wanted another appointment with me so soon, and told me it would be another month before I could see him again, as he would be on vacation for two weeks. Why did this make her so angry? Really?

July 1, 2023

About four days after that appointment, the autoimmune tests began to show up in my 'patient portal'. I had no idea what many of the test terms were, but began to research them to find out what each test was measuring. There was an 'ANA' test which showed a result of 'Negative 40'. There was a protein test which showed differing amounts of Alpha, Beta, Gamma and Albumin proteins, all within 'normal' ranges. Then there was the Kappa and Lambda free serum tests. I saw these early one morning just 15 minutes before I had to leave to play golf. The Lambda test was within range, but the Kappa test was high, out of range, plus the ratio between Kappa and Lambda was high, out of range.

I did another search on 'high Kappa serum test', and it basically said that I had a plasma disorder, which could be multiple myeloma. I did a search on multiple myeloma, and it said that untreated, the average life span is 13 months! Treated, the life span was anywhere from one year to six years! Well, being 66 years old, with a mother who lived to 80, and a father who lived to 94, I was not prepared to read this!

I was in shock. I felt like someone had punched me in the gut and I could not get my breath. I debated just staying home and telling Sally, but decided that I did not want to give her this bad news just now, so I decided to just go play golf. Of course, I could not concentrate, but for some reason, the ball kept going in the hole, and I shot my lowest score of the year, a 70. Maybe it was because I just didn't care where the ball went; there was no pressure compared to what I had just read.

When the round was over, I despised the thought of having to tell Sally the news, but I could not hide this, she would know something was wrong. I sat down with her and explained what was going on, and we were both emotional as I showed her the test results and what I had found on the internet. It was already Friday afternoon, and I should have called the hematologist's office, but I just did not think that was going to help in any way. She kept telling me to not give up hope.

On the weekend, the hematology office was closed, and I reached out to two friends who were seeing a hematologist. They encouraged me to call the office to ask about this test, and to request that a nurse or doctor call me back. On Monday, I did call, but of course, they don't answer the phone, you can only leave a message. By this time, I was a wreck, could not sleep, and I could not get my mind off of the fact that I was going to die before reaching 70, in all likelihood. We talked about our wills and our trusts, and decided that if this was all confirmed, we would consider downsizing our home so that Sally would not, on her own, have to manage a home with a yard, maintenance, etc.

I was in the garden late Monday morning, when I got a call back from the doctor's office. It was some girl asking what I wanted. I told her the story, she looked on the computer, and said that the Kappa test was not in my file, where did I see this? I told her it came from the a nearby medical center, via email. She asked me to fax it to her, but I told her I did not have a fax. "Can't I just scan it and email it to you?" "Well, I am not aware of any email address here you could send it to. I am going to have to research this and get back to you, hopefully I can find an email address you can use." WHAT? This office is affiliated with this medical center, so if she had just logged onto that website, she could have seen the results.

She hung up, then I realized that I live about two miles from their office, so I printed the test results and drove them to their office. When I arrived, I told the receptionist why I was there, she looked me up on the computer, and said that I was not a patient there! I was about to go nuts, but I stayed calm. Finally, she found my file, and looked at the test results, and she said "Our doctor didn't even order these tests, your GP did!"

"No, trust me, your doctor DID order these tests, the test just lists my GP because he IS my GP, and is on their records at the testing lab."

"Well, who did you talk to here on the phone?"

"I don't remember, I was in the garden, I had no pen and paper."

“Was it Shelly or Michelle?” “I am not sure; sorry I don’t remember.”

“Well, if you can’t remember who called you, how am I supposed to help you? Just go home and call back on the same number as before, leave a message, and someone will call you back.”

“Well, can you at least take these test results and file them?”

“I will scan them in, but that is all I can do.”

She seemed so upset that I was interrupting her discussion with her co-worker about her party over the weekend. Gosh, I guess patients are second-class citizens here.

I went home, totally discouraged, but did call and left a message again. About 4:00 p.m., the same girl as before called me, and told me that a nurse practitioner would call me by the end of the day, as she told the NP that I was very concerned. Since the next day was a holiday, I was glad someone would call me yet today.

I waited until 5:00, but no call. I waited until an hour after they closed, still no call. The next 36 hours were terrible. I was equally pissed off about the test results and the fact that after four full days, nobody with any knowledge from their office would call me back.

July 4th was not a good day; the worry level and anxiety was extreme. I could not believe how difficult life was, when you know that you are going to die from a terminal illness. I thought about all those people out there with terminal illnesses, trying to cope, trying to live their lives. I know I am a worrier when it comes to health issues, but hopefully, all those others were tougher and worried less than me. But this was the first time I truly understood what a terrible time of life it is when dealing with a new disease! There is no ‘normal’ any more.

Later, on the 4th, I decided that I needed to talk to my GP, as I felt abandoned, uninformed, and lacked understanding of all the testing being done and what these test results meant.

July 5, 2023

First thing in the morning, I called my GP office, and told the girl there why I needed an appointment. She was able to get me an appointment the next day with a nurse practitioner who I knew well and really liked. I told the girl on the phone that I may have multiple myeloma and why I thought that. I started checking on other hematologists in the area, as my experiences thus far were less than stellar with both the doctor and the staff. I really expected that the hematology office would not call me on the 5th, and probably forgot about me.

I was partly right. They never called me, but my computer buzzed, telling me I had a new email. There was an email that was very short from the hematology office – ‘Hello Daniel, I spoke with our NP here, and she said that there is no monoclonal protein on your SPEP, therefore no concern for myeloma. Your elevated light chains (kappa) are only mildly elevated, and this can be from several things. No need to move up your next appointment.’

WHAT? Why wouldn’t the test result online have said ‘your test result is out of range, but only mildly so’ so that I would not freak out for six straight days? Or better yet, why didn’t the test result say ‘since no monoclonal protein, no concern for myeloma.’ No, they send these test results to the patient, with no doctor commentary, leaving the patient to do their own research not knowing what they are even looking for. In my case, I saw the test results 4-5 days BEFORE my doctor even saw them! This is just not fair to patients, in my view. This needs to change in healthcare, it is just not right.

I printed the email and shared with Sally. The relief for both of us was huge, but neither of us could settle down that day, we were still in worry mode. I guess you just cannot turn off anxiety even when the source of the anxiety goes away. But we still had no idea what was causing my blood problems.

What was still lingering was the question – 'OK, maybe I don't have multiple myeloma, but what DO I have given my low platelet count and high kappa?'

That would not even be discussed for another three weeks, when I had the next hematologist appointment. But I did have the Nurse Practitioner (NP) appointment the next day at my GP office! Maybe she could help.

The next day came, and I met with the NP. She told me that she and the doctor had reviewed all the blood tests, and were *optimistic* based upon the test results they had seen! They knew about the SPEP test and no monoclonal proteins, apparently. I asked if they could help me switch hematologists. She said yes, to just call the GP office and ask them to do that. She mentioned MGUS as a possibility as a cause for my platelet count, and she also mentioned that maybe my platelets would just level off at this number. She encouraged me to keep the next hematologist appointment before switching, however, to which I agreed.

I had already researched MGUS (monoclonal gammopathy of undetermined significance). It seems to be a condition that is sometimes non-symptomatic, but that one case in 100 turns into multiple myeloma, but for the 99 others, it is not really anything of concern.

The hematology appointment day finally came, more blood work, and the doctor came in fairly quickly after they drew my blood. The platelets went to 128 from 127, WBC and RBC increased also, a good thing. Lymphocytes were now in the normal range too. He said that he wanted to see me about every four months to monitor the counts, and that if things continued steady, we could reduce the frequency to every six months. He said that MGUS was NOT possible, since with MGUS, there WOULD be a monoclonal protein in my blood test. Just as I was feeling better, as I had dreaded the possibility of a bone marrow biopsy there in the office, my wife asked the doctor, as he was leaving, ‘Well, what might be causing the low platelets?’ He very quickly said ‘you may have myelodysplasia’, and I scrambled to find my pen to write this down, as it was never mentioned before to us. He then said ‘The only problem with myelodysplasia is that we cannot treat that here, and the only treatment is a bone marrow transplant. And the mortality rate of that process is 25%. But if you did have myelodysplasia, given your blood numbers and lack of symptoms, we wouldn’t treat it now if you had it!’

I was in shock trying to absorb what he just said, and suddenly he walked out of the office without saying a word. I thought that maybe he was going to find a brochure about this disease, but no, he never came back into the office. There was no ‘Sorry to give you that news’, or ‘That is a lot to digest, do you have any questions?’ There was no explanation of this, no discussion of what this disease is or what causes it, no encouragement or discouragement such as ‘chances are that you don’t have this’, or ‘you likely do have it and it will progress and you will see your platelets drop more.’ This guy must have no heart or soul or conscience, I thought to myself, as we walked out of the office. What a jerk! How can any doctor with ANY training and experience treat a patient like that?

We stopped to check out to get the next appointment in four months, and the girl gave me the date and time, then said to the girl next to her – ‘Are you working on scheduling his blood transfusion?’ I thought she was talking about someone else, but no, it was me!

“The doctor never said anything about a blood transfusion, you must have me confused with someone else.”

She replied - “No, this is you, I am just scheduling what he wants me to schedule.”

"Sorry, he would have mentioned this to me! I am not agreeing to have a transfusion, especially because I have no idea what it is and why it was ordered."

At that point, in disgust, the scheduling lady told us to go into the waiting room and sit there and wait until they cleared this up. Five minutes later a girl came back and said I was to follow her. When we got to her desk, she said 'I cannot see the doctor, he is with a patient, but your hemoglobin is OK, so he must have just checked the wrong box on your chart." What? Now I was getting really nervous about this doctor. If he could make such a mistake after such a short appointment, what other mistakes might he make? Clearly, this guy was not going to be my doctor any longer!

We walked out into the sunshine, and I found myself very relieved to be out of that office, determined that I would not return. I would find another doctor! But who? Where? How would I make that decision? But mentally, we were still very much struggling as we began reading about MDS, or myelodysplasia, or myelodysplastic syndrome.

I waited a few days to take any action. I found the idea of not visiting another hematologist for four months quite liberating, and I just did not want to drag myself back to that place. Since only one of my blood numbers was out of range, and that one only slightly, maybe I am OK and don't need to see this guy anymore? He did say that another blood count in four months would be fine, maybe he knew better than me?

Then I stumbled upon an organization that was formed to help people with platelet disorders, like me. They had a free newsletter that was very enlightening, which I read very quickly. I joined an online support group and read through many others' situations and questions. I realized that at least currently, I was in a lot better shape than others with this affliction. I felt so sorry for others whose lives were just overturned due to their platelet levels fluctuating often, especially those who were younger and in elementary or high school. Their stories seemed to be a series of different medications, tests, symptoms, and concerns. Through no fault of their own, they were facing severe bleeding, periods of having to stay in the hospital, limits to what they could do, limits on travel, loss of energy, and changing symptoms.

I began to research other hematologists within an hour of our home, and it was just impossible to make a clear decision on which one to go see next.

Over the next few days, I began to realize that there was no emergency right now, that I could try to settle down into my old routine and stop the anxiety a bit. It was early August, and my next hematology appointment was scheduled for early December, with an appointment in early November with my GP. Why not just enjoy August, September and October? Stop thinking about the next doctor to go see! Physically, (although not mentally) I felt great, as good as I ever had. My golf was the best it had been in years, for some unknown reason. I began to sleep a bit better. Could it be that I did not have a terminal illness after all? Or was it lurking in my body somewhere, just waiting to jump on me and make me feel terrible?

I found myself in a dilemma. The more I spent time doing research and finding the right doctor, the more anxiety I felt, which could just accelerate any illness I might have. If I ignored all of this, maybe my anxiety would subside, but would I miss an opportunity to find out what I had sooner, so that I could begin some sort of treatment?

I started to look at U.S. life expectancy, and possible blood diseases and associated life expectancy for each of them. That made me realize that for even healthy men, 76 years old is it, and I am only 10 years away from that! Dad living to 94 made me forget how many years I may really have left. The emotions over those three months were like a roller-coaster, every day was different, but I would guess that at least 20% of every day, I was thinking about my blood disorder.

November 15, 2023

November finally came, to my dismay, to see my GP. I had blood drawn at my GP office, checked the results online and saw that my platelets fell further to 114 (normal is 150 – 450), and my neutrophils fell again for the third time in a row (not good) and I went to the appointment a few days later. The CNP that I saw did seem concerned about the further falling of my platelets. I told her about the last appointment with the hematologist, and how I would never return there. She said she was upset that they were treating her patient that way, and that I was not the first with a bad story about this hematologist. She seemed to agree with me that getting a new hematologist at a larger facility might be a good next step, and I gave her the name of two who I had researched. She said they would refer me there.

A week went by, and no call back. By that time, we had taken a two-week vacation, and I called the GP office, told them I had heard nothing, and they gave me a phone number to call there. I waited on hold for over 45 minutes, and someone answered and said I needed to talk to the nurse ***oncology*** staff, for them to review test results and to select the right doctor. I could not figure out how they had concluded that what I had was cancer! I got transferred there, and waited another 30 minutes. Finally, a person said that they had no record of the referral, but she then checked the 'online' system, and found it there. (wouldn't the online system be the first place you would check?)

She said she saw no test results with the referral, where were they?

"How would I know? My doctor was sending the referral. But I can get you any test result you want; I have access online to them." "No, I need the facilities to send the test results to us. Someone will call you tomorrow, stay close to your phone!" It sounded like some sort of threat, if you don't answer, you wouldn't get an appointment!

We finally did get a call the next day, this person also said they had no test results, so we gave them the numbers of the medical offices that they could call. Finally, they tried to schedule me with one of two doctors, and neither were the ones I had requested. “How about Dr’s X and Y, the ones I requested? Can I get an appointment with them?”

“Well, I can check. Let me see, how about December 20 with Dr X?”

“Sure, that works!”

Luckily, the next day, my son flew down to spend four days with us in Florida, and to play golf. It was great to laugh again and get my mind off of things. When I took him to the airport to leave, I could feel the gloom return, but overall, I did feel better not spending so much time with anxiety. Those three days were such a mental vacation for me, playing golf, eating out, talking about new things in my son’s life that were of interest.

(Left to right, Sally, my son Cory, me – at dinner in Florida)

So, I counted down that I had three weeks to contemplate what might happen at that next appointment, but I suspected I would get no answers, just more blood draws and forms to complete, and future appointments to review blood tests and to schedule a bone marrow biopsy. But at least, I will get to see a hematologist who is respected and one of the best in their field! Or so I hope.

December 3, 2023

We returned home from Florida, and I have 17 days until my hematology appointment. Unfortunately, I developed a large stye in my right eyelid, and it is painful and causing my vision to degrade. My ophthalmologist prescribed an antibiotic and told me to keep applying warm eye compresses, and that he would see me in two weeks. If the stye was still there by then, he would do the ‘flip eyelid inside out, make an incision, scoop out the junk in the stye’ procedure. It was a very painful routine, as I had that done before. A needle in the eyelid to numb you is not fun!

I couldn’t help feeling down. I seem to have so many issues, plus developed a very sore back from the plane ride back home. Sometimes I think it’s not fair how many issues Sally and I are dealing with, as we are the only couple we know that have both had cancer, and the MDS I may have is very rare, 1 in 5000 for people my age. But I also know there are others with WAY worse issues.

December 11, 2023

My eye stye is not any better.

After doing some research last night about MDS, I read some intimidating things about it. I read this just before bed, and could not sleep. I developed an itchy rash that also stopped me from sleeping. I recall reading that skin itches are a symptom of MDS or one of the many blood diseases I had read about. I finally fell asleep at 2 a.m. and awoke at 6 a.m., and the negative thoughts just flooded back into my mind. What the heck! Why me? We have both had cancer, and here we were, both dealing with this issue, plus a variety of other ailments and ongoing testing to see if our other cancers returned.

The only good news was that Sally got a call from her gastroenterologist about some small spots on her pancreas that were seen on an MRI of her kidneys, but it seems that after doing a blood test, it indicated these spots were unlikely to be cancer. I also saw my PSA blood test results; my PSA was non-detectable again for the fifth year in a row after having a prostatectomy due to prostate cancer. Now we could focus upon just my blood issues next. But my itches and styes left me worried if I was falling further down the platelet slope.

THE TIME BETWEEN

All of these tests and doctors' appointments over the past year or so probably consumed about 1-2% of my time. In between appointments, there was time for the usual tasks and events of life. Thank goodness for golf, yard work and meals to consume a fair amount of that spare time. But MOST of the time, I was thinking about what sort of illness I may have, and what life might look like once I got sicker. I realized that dying was a possibility within the next year or two, and that was very tough to handle and think about, especially when Mom lived to 80 and Dad lived to 94. I always thought I would live to at least 80 and maybe into my mid to late 80's. But dying in my 60's was not something I had considered too much as a possibility.

I realized that for so many with serious or terminal illnesses, the dark cloud of death just follows you so much of your waking hours. It was nearly impossible to laugh at the normal things that seemed funny before, and difficult to smile or carryon chit-chat in a normal way. The knot in my stomach just would not go away or dissipate. As much as I tried to do the normal things I had enjoyed, I found myself withdrawn and somehow a different person than before. I found myself resenting, just a bit, others who were going about their lives as if all was well with the world, carrying on as if they were going to live forever.

Over these past 8 months, I thought about my 'bucket list', and realized that there was nothing on that list! I had really done all that I had ever wanted, as I had travelled the world as part of my job, had a strong career, a wonderful marriage, had two wonderful children and now five grandchildren that we loved dearly, and a good group of friends. Clearly, I wanted to continue to spend more time with family and friends, but I assume that is true for many, and not something you might throw onto your bucket list.

What about a golf trip to Scotland? A fishing trip to the far north? A trip to my homeland? Nah, I had golfed all around the world, albeit not in Scotland. I had taken a fly-in fishing trip to Canada with my son and others, and had been to Germany and Poland several times. (my father was German and my mother was Polish) I really did not relish the thought of flying internationally again and losing sleep, living through time zone problems, etc. The good old USA was still a gem as far as I was concerned, and I was living right in the middle of that gem. My life, living most of the time in Ohio, with parts of winters spent in Florida, was just wonderful, thank you.

OK, so the bucket list thing was not important or a priority for me. But what ***should*** I be doing, in the event that I am facing death? Should we downsize the house (i.e., move) for the benefit of Sally? Change our investments or wills and/or estate plans?

Sally and I discussed, briefly, what might happen if I were to pass away. I did some analysis to show her that financially, she should be fine. We discussed further the downsizing of our main home, but neither of us were ready for that just yet. We did delay some other planned expenditures, pending future doctor appointments and tests, until we knew more about my health situation.

We did attend a seminar about estate planning, and made a future appointment with a local lawyer to discuss if there was anything else we should be thinking about in regards to changing our trusts.

I found a book that was about how to reduce stress and anxiety. I have not finished it yet, but one chapter hit home. It said that humans were the only species with enough brain power to ‘think about how we think’. It was clear that pessimism and anxiety create even more health issues, but *how do you stop worrying when you have serious health issues*? The author suggested that you ask yourself some tough questions when you start to feel anxiety. Are you sure you are seriously ill and going to die? Do you know what your life will look like in the future? He said that you can consciously turn off those negative thoughts, from an analytical perspective. Just tell yourself that you don’t need to think negatively, that is your own choice! Optimism and being balanced about the future prospects can help your health, so why not just make that choice when you feel anxiety and pessimism? It’s easier than it sounds for sure, but there was something about ‘thinking about how I think’ that registered with me.

I have always been a believer in finding health issues early before they develop into serious problems. I knew at some point, given my family history, that I was going to get prostate cancer, so I was getting PSA tests every six months. Sure enough, when we did find that I had prostate cancer, it was early, and I had surgery to remove it, and have been doing well since. I know it can always come back, but at least I feel as though I did all I could do to find it early and treat it early.

I have semi-annual checkups with my GP, annual blood tests with my urologist to check for prostate cancer returning, and skin checks annually with my dermatologist. I have eye check-ups regularly, and see my dentist every six months.

It was that semi-annual checkup with my GP that found my low platelets, even though I had no symptoms.

But this time, it was different. I never seriously feared dying from prostate cancer, as I knew if caught early, it is very treatable. My dad had it, had radiation, the cancer came back 5 years later, and he had hormone therapy for close to 20 years. It never killed him.

But this blood disorder, whatever it is, is likely not a 'catch it early and be cured'. From the possibilities of what I might have, at least what I have read, these are eventually terminal and you have limited years of survival. I learned that blood cancers are NOT treated like other cancers. Finding them early is not necessarily a big advantage, with a few exceptions. Basically, once a treatment begins, the chemo / drugs have negative side effects and risks, so doctors do not treat blood cancers as soon as they are discovered. They monitor you a lot, and only begin treatments when the risks to you are more significant, and the likelihood of complications leading to death are real.

Coming to terms with the possibility of dying within a year to three years was not easy, and I am still not completely 'there'. Clearly, two things about death bring fear to anyone. First, that you will be in pain and discomfort, and the pain might worsen as you near the end. Things you enjoy doing will have to end, and quality of life may go out the window. Who wants their final days to be in a hospital with people who don't know you and don't really care about you? After seeing the quality of life my dad experienced in the nursing home, I certainly don't want that to be the way to leave this world, although I know that none of us may have a choice in this regard.

But the second fear of death to me is that I won't be here to enjoy life, I won't be here for my wife, and I won't be here for my children and grandchildren. I actually find myself feeling guilty on this second fear. I feel so badly if I die prematurely, robbing my wife of many golden years together, years we dreamed of during all that time working hard and raising children. Sally is a smart woman, and stronger than she thinks, but there are things that she relies upon me to do. Doing the taxes, house maintenance chores, computers and technology, yard maintenance, car maintenance, and just fixing the variety of things that can go wrong – all are areas she will need help from someone. Just changing a ceiling light bulb that she cannot reach will be problematic.

I know I will do all I can to fight whatever it is that I have, but at some point, we are all going to go. Nonetheless, the guilt is always there about leaving her alone. There is also the guilt about all the worry I may put her through as my illness might develop. The term ‘it is just not fair’ keeps flying through my thoughts, but I know that everyone has issues that are just not fair, why should we be different?

I have always watched my weight, tried to stay active and eat healthy, exercise, etc. My weight has never varied outside of 170-180 pounds over the past 30 years! My investment advisor keeps updating the master plan for our future financial projections, and in the plan, she has chosen an age of 87 for me as the 50-50 point (meaning a 50% change of living longer, a 50% chance of not living to that age), and Sally at 90. (This was from actuarial tables, if you are a non-smoker, have lived into your mid-60’s, etc.) It is hard to believe that I could fall short of ‘average’ by 20 years!

December 14, 2023

This waiting for the new hematologist appointment is killing me, which is December 20. I want that day to come so I can maybe get some answers, but on the other hand, the answers might be worse than what I am assuming now. I try to stay busy, but when it turns cold in Ohio, other than three meals per day and watching TV, and taking a walk, there is not much to do other than worry. I know the anxiety is not good for me, but I just cannot turn it off as much as I try.

December 21, 2023

The big day came. After a long and stressful drive via a new route to get to the hospital, we parked in a huge parking deck and walked through the pedestrian bridge to a big building with 'CANCER CENTER' on the side. It is funny that other buildings on this campus have names that indicate what part of the body or body function they are addressing. Eye Center for eye treatment, Urology Center for urologic parts of the body. But CANCER CENTER sort of hit me the wrong way. Almost like it is saying '*Come here to get cancer*'. Their cardiac building does not say 'Heart Disease Center'!

It struck me that just about everyone we saw walking the halls, other than employees, likely had some sort of cancer, and there were just *hundreds* of patients walking the halls and in waiting areas. There were not many bright cheery faces, including ours. We both commented that this was the last place we wanted to be! Having said that though, we are so thankful that there is a leading-edge cancer center staffed with excellent doctors and nurses and other health practitioners, all less than a few hours drive from our home!

We had a quick lunch on the first floor, then went up to the fourth floor for our appointment. I waited in line to check in, then sat in a waiting area. After what seemed like a long wait, someone came to get us and take us back to a fairly small examining room, just like you would use at your GP office. The nurse asked a few questions, reviewed meds, then told us the Doc would be in soon as we were the first afternoon appointment, at 1:00.

The last thing the nurse said before she left was 'You will love Dr. R; she is a sweetheart!' (I hoped so, I had scouted out all the doctors in hematology for DAYS online, and watcher her video)

At that point, I debated using a Sony recording device I had brought along, to make sure we captured all her comments and suggestions, as most people forget 90% of what they hear at the doctor's office. I had waited for this appointment for close to 5 months, and I didn't want to miss a thing. I had purchased it to record my interviews with over a dozen Baby Boomers as I wrote my second book. It is about 1" by 4", and is an amazing little device. It picks up voices and conversations wonderfully, and only uses an AA battery, and can record HUNDREDS of hours of sound.

I know that some professionals may object to you recording any discussion, out of concerns about lawsuits if they say the wrong thing. But I knew I would NEVER sue anybody, especially a doctor, based upon what they said! Dr. R was fine with us recording the appointment, and boy, was I happy that I did! That recording has served me well several times so far.

When Dr. R came in, after just a few minutes, we knew we chose the right doctor and were confident that it was the correct decision to switch hematologists. She asked a lot of questions, answered our questions well, paid attention to what we said, and knew her stuff!

Basically, after an hour, we had agreed that they would draw blood downstairs, we could go home, then she would call me with the test results in the next week to discuss next steps. A key decision was if I would have a bone marrow biopsy soon before heading to Florida.

I volunteered to go ahead and get the bone marrow biopsy that day since I was there already, but she said she wanted to see the blood results first, as a bone marrow biopsy is a bit of a process and procedure, and she did not want me to go through that unless we had good reason to do so. She called my blood numbers 'fairly stable' over the past year (platelets fell from 157 a year ago to 114 now, which did not seem that stable to me), which made her comfortable in the next blood test going out three months, at least based upon the last bloodwork in early November. However, it all would depend upon the blood test results coming in over the next few days.

We did discuss MDS, as my prior hematologist said I could have this, and she told me that there were other docs there she would refer me to, if it turned out I had MDS, as she was not an expert in the disease. She told me that some cases of MDS are mild, or indolent, and monitoring your numbers was the right course. Others were ‘high risk’ and those were the ones which required a bone marrow transplant in order to survive. We discussed if it was difficult finding a donor who matched your bone marrow, and if I would be a candidate for this, given I was old. Her response - “You are a healthy guy, you would certainly be a candidate, and we have NO age limits on bone marrow transplants!”

We went down to the first floor, checked in at the ‘Lab Tests’ area, and sat down. Within 15 minutes, they called my name, and someone drew about 7 vials of blood in about two minutes. When she put the needle in, I did not feel a thing. She was excellent!

All test results were to be visible on the patient portal, and by the time we got home, a few tests had already showed up online. I debated even viewing them, but I went ahead and saw the first few. The platelets INCREASED from 114 to 126 which was a first over the past two years (HURRAY!) and my neutrophils also increased. But so many other tests were to be sent, this was just the beginning.

Seeing those first test results reminded me of how this whole journey since May has been a roller coaster, and these test results were no different. Each one came with its own numbers and generated more questions for me. I had little comfort in seeing these results!

I found myself just wanting to shut off this whole process. I feel fine and have felt fine all year. I have had so many doctor appointments and so many tests. You realize that you are ‘in the machine’ of health care, and that good doctors have a routine. Each day, they might see or talk to 8-15 patients, but overall, they likely have hundreds and hundreds of patients. All the other health care professionals are there to service them, and they are there to digest what is going on with each patient, and to tell you what is right or wrong and what you should do to address whatever is wrong. They have all the knowledge, nobody else does. And I am sure that most in this profession cannot, and do not, lose sleep when they give someone bad news. They cannot, or the job would just eat them up. But it made me realize that we are just one of the numbers who are sick in some way, and we are all on our own journey. Nobody REALLY loses sleep over your health issues except immediate family and dear friends, and even if doctors or nurses did, hopefully after some time, they learn to block this out.

To me, however, what is lacking is that nobody fills the gap to help you with your emotional issues, the anxiety, the panic attacks you get in the middle of the night when you realize again what you have and what is going on. You are on your own, other than your family. Your spouse gets the worst of it, she cannot get away from it either, and the anxiety is not good for her and other family members. But you realize then, that you are really the one that is 'facing the bear' as my friend Gregg described it. Nobody else will feel the immediate and real threat of death other than you, for your particular ailment.

It's not that it is a bad system, to the contrary, I am pleased that this network of health care workers is there to help those who really need help and treatment. It is just that once you are one of those who needs them, it really sucks. I cannot get away from the anxiety and worry. You dream about a day when you get a phone call saying that some test was in error, or that a new drug could solve my problems, but of course, those things never happen. You just start to realize that your life, for whatever time you have left, is going to be different than what your life was like up to this point. Your disease crosses your mind all the time. Nobody else can 'get it', and really, others should not have to. You don't want them having anxiety either, they should enjoy their health for as long as they can, just as I did when others I knew became sick over the years.

But it would be much better if, once you learn about the possibility or realization that you have a terminal disease, that they say ‘Here is the name and number of a mental health person who is wonderful, I insist you call them, they can help you.’ I wouldn’t care if it was drugs, or discussions, or booklets, or whatever, but anything would be better than being on an island alone, ‘facing the bear’.

I got a text from a friend who said someone told him that three things were important when facing cancer or any serious health issue. (1) Stop doing your own research and internet searches, (2) trust your doctor, and (3) only focus on the next step. This may be good advice, but as is typical of my ‘assume the worst’ makeup, I was already planning my life once I had to go to the hospital and stay there 2-3 months getting a bone marrow transplant, and possibly dying alone there some night when an infection crept in and I had no defenses or immune system in my body. I just wanted to break out of this and breathe for a few days, go back to what my life had been like just a year ago. I suppose that ‘returning to normal’ is unlikely, given where I am in the process, and I realize now how lucky we had been for the first 60+ years of our lives.

How can I stay positive and have a good quality of life as I go through this new journey? That is the million-dollar question!

Well, Christmas is coming, we are celebrating Sally’s birthday tonight with friends, maybe I can relax for just a few hours? I hope so. But I know the friends will have questions about my appointment, and I will be re-living all of this again. Not that I mind others asking, but I am finding that the longer this journey goes, the less relief I am getting by sharing it all with others. Maybe that is how others feel when they get seriously ill and they seem sometimes to ‘fall off the face of the earth’. I am starting to understand that more as this goes along. I always wondered why friends I have lost, never go out on social media or other vehicles of communication and say something such as ‘goodbye dear friends, I love you all, here is what I have and it does not look good'. Nobody does this, and I assume it is only because doing so would make them feel WORSE not better.

December 26*, *2023

I got up a little early because I was hoping my doctor would call me with the test results in the morning, and I didn't want to miss that call! I knew she was vacationing with her family in Florida, but she did say that even on vacation, every morning she has coffee and gets online and reviews blood results. Amazingly, at 9:47 a.m., my phone rang, and it was her. I was impressed! She asked if I had seen the results online, and I admitted that I could not help myself, yes, I did see them.

"Well, overall, I think they look pretty good. Your platelets were up a bit, and your neutrophils even increased. Your kappa ratio was out of range, high, but until it gets to over 3.0, we don't worry too much about it, but we will watch that going forward. I don't see any urgent reason to have a bone marrow biopsy, unless you want to have it done now. Did you think about this over the past week?"

"Yep, I was thinking that if the numbers looked OK, I would just defer the bone marrow test until we come back for the next appointment around April, if that is OK."

"Sure, that is fine, and we will do the blood tests again and have that same discussion about a biopsy after we get the results."

HALLELUJAH! The thought of having three months to not worry about this, and to go to Florida for a while, and enjoy the weather, was just overwhelming. "However, as we discussed, if you get a fever of over 100.4, you should still go to the ER and have them do a 'CBC with differential' to check your neutrophil levels, and if they are low, they will treat you aggressively with antibiotics. And as always, if you get sick, lose a lot of weight, lose energy, etc., you need to contact me."

OK, I can live with that, as I rarely get sick, but the thought of running to the ER with a slight fever was not something I relished.

Once I hung up, Sally and I discussed the interaction and what was said. There was no huge relief mentally for either of us, but as we learned, it takes time for your body to de-stress.

Now, it's time to focus upon our trip to Florida and prepare for family coming over tomorrow!

December 28, 2023

Our family get-together yesterday had to be cancelled as our daughter and her daughter got the flu, and sounded very sick. We are not sure if we can reschedule this now in the next two days or not, it seems there is a big outbreak of flu and Covid right now, and with my shortage of neutrophils, I could not afford to get either right now.

After sleeping better the night of the 26th after hearing from my doctor, yesterday was a bit of a downer. I had been relieved about not having to face the bone marrow test, and relieved that I would not get any news about if I had MDS or some other affliction, at least for three more months. But I somehow was able to have a 'down' day, due to reading some disturbing information about someone with MDS on the support group I was a part of, and others with platelet disorders.

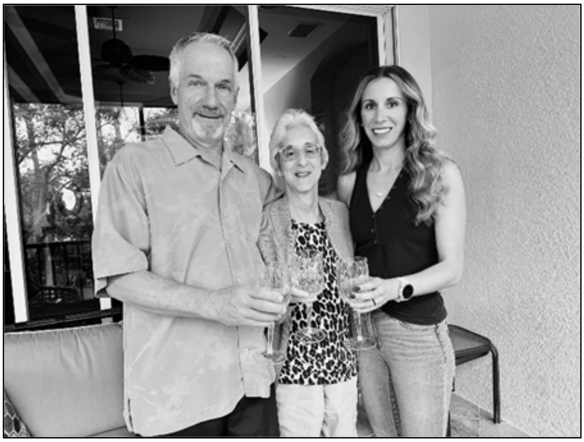
Then as we were watching Jeopardy, one of the questions was about a celebrity and her 10-year anniversary after surviving a stem cell transplant. I searched for her name to see what disease she had, and of course, she had MDS! The article stated that she was fortunate in that she had an identical bone marrow match with her sister, then she talked about the importance of others signing up for the bone marrow donor site. It said that about 4,000 people had already found a bone marrow match in the past 10 years using this donor site. I did some quick math, and found that one person out of 90,000 had a stem cell transplant where they found a match. This was a VERY rare disease! And similar to other information I had heard about MDS, it was typical that most patients with MDS had been through some sort of chemo or intense treatment earlier in life, or they were exposed to vegetation killers due to an outdoor job such as working at a golf course or in landscaping. She actually had chemo for breast cancer just a few years before being diagnosed with MDS. I did not seem to fit the profile, but I am sure there are those who get MDS who do not.

I decided to unplug from the support site at least for a month, and maybe longer, it was not doing me any good currently. I HAD to find a way to get away from this, my mental state was tearing me apart physically, having my stomach in a knot, not sleeping well, thinking about this all too often, etc.

My next challenge in the spring will be to schedule my next hematology visit and blood tests, two weeks before I get another colonoscopy, which was required after my gastro-enterologist found three polyps in my colonoscopy in April 2022. I had to be sure I had enough of various blood components to minimize my risk of doing a colonoscopy.

January 5, 2024

We are in Florida, and have been now for five days. Our daughter Sara and her two children came down for a four-day visit, and they just left to go back home.



(Toasting being together in Florida, left to right, me, Sally, our daughter Sara)

We had a very busy and enjoyable time, and we showed them the four best places that we go for dinners, plus visited a wildlife garden, and a children's museum. They swam most of the time in the afternoons, although the weather was unseasonably cool. Now that they are gone, it is very quiet again, but we do need some quiet and down time to recharge our energy levels. Having kids around of their age is draining to someone as old as us! But we love them dearly and will miss them, it was a wonderful visit that we enjoyed tremendously.

As for my mental state, I have not had much time to dwell on my illness, I still feel fine, and there are chores plus golf to keep me busy. I have slept rather well the past few nights, and being in the sunshine and not in gloomy Ohio makes so much of a difference! I hope this mental state lasts. I have even had a few positive thoughts of late.

But during the past 5 days, Sally has been in touch with family a lot, as her mother was in the hospital, and just returned home. Her care is becoming an issue, as living independently is becoming harder for her. I can relate after going through this with my father last year.

January 9, 2024

The weather continues to be bad, lots of rain, wind, and cool temperatures. I will be playing golf this afternoon in a tournament where the wind will be blowing in gusts as high as 40 – 50 mph. This should be interesting!

After golfing with my group on Thursday, one of my friends who knows what is going on with me, asked how I was feeling. Someone else overheard the discussion, and asked about my health. This guy, in his 80's, said that his son has had multiple myeloma for 10 years, and they thought that they lost him twice over that period. But he said that his doctor keeps telling their son that he has to have faith that they will keep finding chemo to give him to keep him going. He said he gets three hours of chemo each month. The golfer then told me that he had thyroid cancer two years ago, and that over the summer, they found head and neck cancer also. He said he had surgery, chemo, and radiation, and at times, he just wanted to give up, but that he made it through and that here he is, playing golf and feeling better.

It had not struck me how it might feel if one of your children had cancer, and a serious cancer to boot. That must be the worst possible situation, and made me realize that we should count our blessings if those younger in our families are OK and not dealing with anything serious health-wise. This guy gave me the name of his son's doc, at NY Presbyterian Hospital, and he said the guy is fantastic if I need him.

I think I will stay with *my* fantastic doctor for now, but who knows what sort of expertise or specialty may be needed in the future? As far as my mental state, it wavers day to day. It seems that the busier I am, the better I am, but those long lull periods are not good, as the bad thoughts creep back in. I guess I need to just stay busy!

January 12, 2024

I heard last night that a good friend found out he had significant artery blockages, and he underwent a multiple artery bypass today. He is doing well by all reports. It made me realize how lucky we all are to have good health even for a day, and to enjoy our time here.

January 16, 2024

As I was playing golf yesterday, the guy in the cart was asking about my health. He said that his sister had leukemia and battled it for 10 years before she passed. He told me that maybe I could live another 10 years too, and hell, that would make me 76, and we don't live forever you know! Just a note for future reference, that comment did NOT make me feel any better or make me re-frame my mental outlook, that I should be happy if I live for just another 10 years. I know he is right and he intended the comment to encourage me, but somehow, being grateful to live to 76 does not seem comforting to me.

As I drove home, I noticed a voicemail from a friend back in Ohio. He wanted me to call him right away. He had been through a heart attack of late, and I was worried he was calling me about that. It turned out that he notified me that I was being inducted into our county Golf Hall of Fame for amateurs in May. This was nice news to hear, but I would gladly give up all the hall of fame honors in the world for some good news on the health front.

January 17, 2024

Last night, while watching the last episode of Virgin River on Netflix, my phone binged, showing a new email. It turns out that one of my friends had a medical event over the holidays, and ended up at the hospital for four days, while they tried to figure out what was wrong.

They diagnosed him with Acute Myeloid Leukemia, or AML. This disease is the one that a good friend had at age 61, and she got through a bone marrow transplant and is doing extremely well today. That email just made me go back to my problems, realizing that in a few months, or a year, this could be me going through what my friend may be going through.

I reached out to him this morning, and shared my story of our friend who did so well. I also shared what I am going through, thinking that maybe if he knew there were others going through blood issues, he might find some comfort. He responded pretty quickly, but said that he is starting a clinical trial, having chemo one week, followed by pills / chemo for three weeks, then repeating the process. He said that his doc was still evaluating if he might be a candidate for a bone marrow transplant, but he did indicate that his age might be working against that as a solution. He said that the anxiety he and his wife are going through is difficult, and that maybe my next book should be about the illnesses that Boomers may get as they grow old.

I felt sorry for him, as I could only imagine what his mindset now was. I have been through that in my imagination over the past year, thinking through the worst scenarios for me. I thought about Sally and what she would do through this period, I would not want her driving to the hospital every day, and her anxiety would just be terrible for her.

Then I started thinking again about the Covid vaccine, and how I am considering that this was the cause of the falling of my blood numbers. I could not prove it, but all the normal causes of my blood problems and/or MDS were (1) exposure to radiation during some health treatment (2) exposure to chemicals working in a factory or near chemicals (3) blood cancer running in my family. All of those were big NO's for me. So, what would cause this? Of course, my second Covid vaccine was just before I went deaf in both ears (happened the next day), developed tinnitus which has become permanent, and right before my blood numbers began to fall.

Every doctor I talk to about this, when I tell them my hypothesis of how I developed this blood disorder from the vaccine, says the very same thing – “It is possible but not likely.’ It just gets my goat that it is possible that these vaccines *could* cause my death and the death of many others, all the while, they pat themselves on the back as to how they saved the world from Covid. What about the heart issues that have been documented? What about the thousands who developed tinnitus? What about blood disorders? I am not saying that the vaccines did not save many lives from Covid, but nobody seems to want to discuss the side effects and other implications of the vaccines.

I asked my AML friend to keep me posted on his progress, but I suspect he won’t, and maybe I don’t need frequent reminders of what I may have to go through soon. I was feeling better mentally until I got the news about him, now I am back to where I was a few weeks ago.

January 19, 2024

I heard back from my friend with AML twice in the past few days, he actually replied while he was at the hospital, preparing to have his port installed in his chest. He was also waiting to talk to the head of oncology there. I have not heard back as yet as to what the discussion was or if he was a candidate for a bone marrow transplant. He did say that the anxiety from all of this is just overwhelming. I get it!

My mind alternates between positive and negative thoughts. Yesterday, I looked at my latest blood numbers again, and it struck me that most measures were within normal ranges, except my platelets (126 vs a normal range of 150-450) and neutrophils, which were actually in range but at the very low end of the normal range. Monocytes were high, but my hematologist did not even discuss that with me. Kappa free light chains were high, and that is likely the most worrisome to me, as it increased from the prior test and everything you read about this says that this is not good, it could be damaging my organs. But had it not been for the hematologists running tests for autoimmune disease (thus the kappa number), I am guessing that most GP's would have told me, based upon the last blood test only, that I was in great health and that there was nothing to worry about, just a slightly low platelet count.

But then I remembered something that a workplace friend said about life. "The bad things that happen in your life prepare you for the *worse* things that will happen in the future." It seems that way with health. In my younger years, the only health issue was getting the flu or a cold. Then later, high blood pressure, a few lumps and cysts that had to be surgically removed, and two knee repairs. Then in my early 60's, prostate cancer and that whole treatment scheme. Could it be that even though 2023 was a bitch of a year due to my anxiety over my blood issues, that it was just preparing me for worse things in 2024 and years thereafter? That is, in the past 9 months, I have had virtually no blood disease symptoms, I can continue to do all the things I enjoy doing, I still feel healthy, etc. If the blood numbers continue to degrade, then I know that symptoms will appear, such as tiredness, weight loss, bruising, etc. Maybe my prior 9 months will be the best of the years I have left! Wow, I can certainly think myself into a depression!

I contrast the difference between our time in Florida just a year ago to what we are experiencing in 2024.

Last year, we were both healthy, Sally's mom was doing well, I knew NOBODY with blood diseases. I was not worried about much at all, I could drink wine every night, etc.

This year, the anxiety for both of us is dominant due to my blood issues, Sally's mom is not doing well at all, needing help daily, I now know 5 people with blood disorders, the weather is cloudy and rainy just about every day, I stay away from wine except for a small glass once or twice per week. BUT, I can still do other things such as golf, exercise, go out to eat, swim, walk with my group, etc.

Hmm, maybe just God's way of preparing me for what is ahead? I just wish I could shut off my brain and the anxiety for a few days, but I'm not sure how to do that. I feel pretty stupid on this front!

February 9, 2024

It is hard to believe it has been three weeks since I wrote in my journal, which is encouraging, as it means that I have had other priorities other than HCL. However, outside events keep bringing me back to my health and disease.

In the last three weeks, I have communicated with my friend about his AML disease and treatment (no response of late from him, which is worrisome), had our next-door neighbor here in Florida call me last night to let me know that his wife had passed away over the prior weekend, and I keep hearing about new stories of those I know who are battling a variety of health issues.

For some reason, however, I have finally been able to relax a bit here in Florida. It most likely has been due to two things: the weather has gotten better with a lot of sun and warming temperatures, and we have been very busy socially with dinners with friends, trivia games at the club, dinners outside listening to music, playing golf, etc.

We are very fortunate to be able to afford spending parts of the winters in Florida. For those who have not had that opportunity, the Florida winter climate and environment for retirees is just amazing. It is a series of sunny days, warm temperatures, and an amazing number of social activities to participate in every day, or at least several times per week. Dining outside is the norm, and there is just something about having dinner or lunch outside, with a large number of menu choices of fresh seafood plus other options, that makes meals so enjoyable. You can go outside at night in the dark and just walk in a t-shirt and shorts, or go the local pool and talk to others your own age about a variety of topics, pick a new restaurant for dinner, and never have to repeat going to the same place again that winter. There are so many enjoyable restaurants within five miles of wherever you live.

When we go back to Ohio, we tend to just stay home in the evenings, as we don't have the opportunity to see others every day, other than my playing golf. There are no walking groups, no pool groups, little outside dining, few musical acts for free, no trivia games, and very volatile and windy/cool weather. The parts of our winters in Florida truly represent the 'golden years' for us, as life is everything you could ever want it to be. Maybe we should call them the 'golden months' of each calendar year! We have been blessed to vacation here together for 10 years, and not many other couples have that many years together in retirement living the 'good life'. I am so thankful.

February 24, 2024

It is Saturday night, and we finally had a night at home for dinner after going out with friends and for events all-too-often this week. It was nice to relax here and just chill. I have had a good run of golf with my group, and am finally making some birdies which helps a lot. However, we did buy plane tickets to return home on March 23, and that event sort of changed our mood. It hit us that we will be going back home soon, and will be facing the doctor visits and tests that I have been thinking about all winter.

I still feel OK, with no new symptoms, so that is a bit encouraging. I am not tired, nor have I encountered any of the health issues that my doctor said was possible to develop. The full-scale worrying has not yet returned, but as March gets here and we start to count down the days until we fly home, I am sure my friend 'anxiety' will revisit.

For now, I am trying to enjoy every day.

March 15, 2024

It is Friday morning, and we are counting down the few days until returning home to Ohio. Last night, we finally had dinner with our friend from home and his girlfriend at our club. It was a beautiful night with live music and dinner under the stars. He is 83 years old, and amazingly, just two months ago, had open heart surgery to replace two blocked arteries. Three months before that, he had some sort of food poisoning from bad fish, and almost died and had to be intubated.

He was in the hospital due to the fish for a week, and took a long time to recover. One day before he was to fly to Florida for the winter, he had some problems and ended up at the cardiologist, and they discovered the blockages. We heard his story last night that after arriving in Florida, after recovering from a heart bypass, he had to be admitted to a hospital again for high blood pressure. We had the discussion that for the rest of his life, he probably just wants to block out the past six months, as they are bad memories other than the great health care he had, and help of his family and girlfriend. He seems to be doing well, but told me that they are telling him that it might take a full year for him to feel 100%.

It was sort of like my thoughts of the past 10 months for us, only the difference is that my situation likely is not going to improve going forward. Rather, my best hope is that I stay where I am health-wise, with my current blood count. The reality of being back home in a week facing blood draws, the hematologist appointment, and seeing the bloodwork test results seems a bit distant right now, but only because of physical distance. It’s interesting how being geographically far away from home and your healthcare team can relieve worry and anxiety.

Speaking of being removed from reality, I have no idea what is going on, but my golf continues to amaze me. My last 8 rounds have been 72, 72, 76, 73, 74, 73, 78, and 73. These are scores which would have been impossible in the past three years since beginning to play at my club. Yesterday, I hit all 14 fairways, hit 14 greens in regulation, and only due to two bad swings on two of the easiest holes on the course, avoided shooting 70 or better. I missed some very makeable putts, but made some nice putts also, having 4 birdies.

It just seems of late that I am not stressed about playing the last few holes well. Now, I don't worry if I start poorly, because I know I can make birdies and get back on track. Yesterday, after messing up two easy par fives, I hit a great drive and hit an 8 iron to a foot from the pin, on the hardest par 4 on the course. I keep telling myself to quit thinking about how to finish the round and what score I need to shoot, instead to just think about the next shot. Even though it doesn't mean anything to me, the commissioner keeps track of gross winnings for the season, and I just moved into first place.

I don't care about the money, it just makes me feel good that finally, I am playing much better and seem to have some sort of control over my game. Nothing that will change the world, or mean all that much, but to me, to be able to do something well that I have worked my entire life to do well, is rewarding.

I keep thinking that maybe this is God's gift to me in my final year or years, that we have had a wonderful winter here with friends, good golf, great food, etc. Last week, as I was driving home from another good round of golf, out loud, I said something like 'Lord, thank you for this wonderful life we have enjoyed here over the years during the winters, we are so blessed, and thank you for the good friends that I have made here.' It was sort of like a beautiful sunset that ends the day. I hope there are many more seasons, but of course, we just don't know, do we?

I have made my peace that if it is my time to go, I have lived a wonderful, wonderful life. It has been so much more than I ever dreamed possible. A wonderful childhood in a small town, a wonderful career, a wonderful wife, children and family, good friends, and living in a great country. There are so many others who are not as fortunate.

I keep asking myself what I should be doing with the rest of my life, how can I serve God and help others, or if maybe God has other plans. It seems like he would want me to plan my next few steps to make the world a better place, even if I don’t get to do that. All I can keep thinking about for now, is to continue to write about my health issues so that others someday can read my story, and find some solace, understanding, and relief in their own journeys. Beyond that, there are many other opportunities to help others, which I can focus upon in the future.

For now, I have one week remaining here before returning home, three rounds of golf, a few more nice meals out with friends, a few more trips to the pool and getting some sunshine, and a few more precious moments with Sally. I plan to enjoy them fully if I can!

March 17, 2024

It is St. Patrick’s Day! We plan to hit the breakfast buffet in an hour, and certainly wear green. Yesterday, another amazing round of golf with a 72. We had dinner at home, then played euchre with some good friends in our neighborhood.

The TPC (golf) is on TV this weekend, a tournament that is always fun to watch. But the ‘downer’ of returning home in six days is starting to hit, with the packing, chores, cleaning, checklists, etc. ahead of us. I never am happy to go home in the spring to Ohio, mainly due to the questionable weather, and due to fantastic weather in Florida in late March and early April. But this year, obviously it is more, with the upcoming blood tests and another session with the hematologist. I still feel OK, so the ‘no new symptoms’ is a good thing, but your blood can be changing and you might not be aware of the struggle going on inside. My future life can go in one of two very different directions after that appointment.

But I am also ready to go home. I do miss the chores outside and inside, and witnessing spring with trees eventually coming out, grass starting to grow, and the rain and gloom? Sally likes to go home, and we both like being closer to our family, but she also fears what is ahead health-wise.

I guess all we can do is enjoy the time we have left here, and get back home and prepare for a family get-together on March 24 the day after we get back home.

March 22, 2024

This is the final day in Florida before heading home tomorrow. My last three rounds of golf continued to be some of the best golf of my life. Saturday, I shot a 73, Tuesday a 77 that felt like an 87, and the last round, I was two under par with four holes to play, on a course where I had never broken par. Of course, I went bogey, bogey, birdie, bogey, with two three putts and a drive 50 yards offline that flew into a lake, to shoot 72. The day before that last round, I just had a feeling something special was going to happen. But golf can always humble you, and it did, with the last green leaving me with a 50-foot birdie putt, and I hit the putt FAT, hitting it maybe half way to the hole! I had to make a four-foot putt to three putt! I said goodbye to my very good Raider friends with handshakes and back slaps, while in my mind, I was struggling not knowing if I could ever come back.

Today is chore day, with lots of work and prep to do, including a run through the checklist, and looking ahead to facing whatever is going on with my bone marrow and blood. I guess it is about time to face the music, one way or the other.

April 2, 2024

Living back in Ohio is SO much different! I have been working my tail off with yard work, chores, playing a little golf in cold weather and mud, and preparing for health appointments. My magic is now gone as far as golf goes, and my back is hurting again as it always does when I start walking and golfing in the cold.

Three days ago, I woke up in bed feeling confused. I was not sure what was going on, but just thinking about what day it was and what I had to do that day, took much longer than normal. Once I got up, it took me twice as long to make coffee, make breakfast, clean up after breakfast, etc. It was as if my mind was in a fog, and I could not recall what I was supposed to do in order to get some simple things done. Where was the coffee stored? How did I go about making a smoothie? I knew I had to go pick up some meds at two different drugstores, and planning the path from one to the other was a challenge, I could not recall how to get there exactly. By the time I got back home, my fog was gone, I was feeling more or less normal again.

Maybe this ‘fog’ happened because I began taking papaya leaf extract two days before, and this is something I had never consumed before. It is supposed to boost your platelets. But I think I will stay away from that in the future!

The blood draw is in two days, and I am going to drink some wine that evening after the bloodwork, before the emails start being sent to me with blood work results. I DREAD opening up the results, as they are usually bad news. At least I will get to experience the total eclipse crossing the heart of America before heading to the hematology appointment on April 10 with my new hematologist. I keep thinking that between the three weeks of fantastic golf, the total eclipse, and sharing the news about my golf hall of fame induction, God is giving me some wonderful gifts now, before the next chapter. In a way, I am expecting that with my next appointment, I will be headed down a slope I am not looking forward to walking on.

April 4, 2024

The blood draw is complete, this time only two vials, I am not sure why. Wine will get consumed tonight! I guess there were no tests this time to check for rare reasons why my blood may be messed up, such as zinc shortages, AIDS, etc.

I have had a few weird things happen in the past week physically, besides the brain fog. For the past six months or so, I have had strange sensations on my upper right arm, sort of tingling, but less noticeable than needles when your arm goes numb from laying on it, more like a fluttery feeling. When it comes on, it is only for a few minutes. It might happen 4-5 times per day, but 95% of the day is normal. Two days ago, I had the same tingling in my feet and hands as I watched TV. The same thing happened in bed for the night. When I awoke and got up, it all disappeared, but this was definitely something different, and concerning. I searched online about the sensations and saw Multiple Sclerosis listed as a possible cause for this. But other symptoms for MS I did not have, except it did say you can have confusion, which is sort of what I experienced with the brain fog incident.

Then I read today about a celebrity that has MS, and read about her journey. It sounds terrible, with strong pain, weak legs, inability to function well, etc. I have no idea what is going on, and part of me is debating whether it would be better to have MDS and get a high-risk bone marrow transfusion, or have MS and live in pain and lose my mobility. We don’t get to choose what we have, but I can’t stop thinking about which one I could have, or could this be something else? There is not much to do but wait for the emails to start flowing with blood test results. I am not sure I want to review them; I may wait until just before my appointment on the 10th.

Oh, today the local Canton newspaper published the announcement about the county amateur golf hall of fame, and my induction, but I am not sure I care that much about it, to be honest. It is just not that important to me relative to health issues.

April 6, 2024

I got the bright idea yesterday that before we went to see some friends (in a band) play at a bar, I should check my blood numbers, which had arrived in an email on the 4th. I had not opened the results on purpose, as I was not ready mentally for whatever it said. But it seemed a good idea to check them in case my neutrophils were low, as that meant I should avoid crowds. If that were true, if I got an infection, such as the flu, I may not be able to fight it off and may have to go to the hospital.

We were sorry we opened the results! The numbers went to hell from just 4 months ago. After we digested the numbers, we tried to eat dinner, but were not hungry. We sat and talked for a long time, cried a few tears, as we both knew that I definitely had some sort of blood cancer and that treatment of some form would be in our future, which meant chemo, maybe radiation, hospitalization, etc. and all the side effects. I think we were both in shock, as we were hoping for the numbers to be stable as they were last time. Instead, platelets fell below 100 for the first time, and lymphocytes and white blood cells zoomed to very high levels never seen before in prior bloodwork. Also, kappa free light chains increased again for the third time in a row, which can indicate some very bad diseases and organs being affected such as kidneys and heart.

Neither of us slept, maybe we got two hours of sleep. We are both in shock. I am trying to stay positive, but it is difficult. I texted a few family members and close friends as to what was going on, but have not told our kids yet. That time will come, but for now, I just cannot burden them at this point.

We pretty much know what the appointment will look like at the hematologist, they will recommend a bone marrow biopsy, hopefully they can do it that day, then we wait for days to get a call to explain what they found, and recommended treatment plan. I am not sure I am ready for all of this, but I guess you never are. I am trying to do as much as I can now before ‘the crap hits the fan’. Ugh, what a day and night!

April 9, 2024

Well, the solar eclipse of 2024 came and went yesterday. It truly was spectacular in its own way, as we never get to experience such an event, and when the full corona showed, it was just amazing. I yelled ‘There it is!!!’. My few photos taken were duds, for a variety of reasons, but my memories are clear, sitting in the back yard with my dear wife and just experiencing the changes.

Today, I had my dentist checkup, and while cleaning and examining my teeth, she was commenting to the assistant that this area was bleeding, that area, etc. I asked ‘Do you mean my gums are bleeding NOW?’ ‘Yes, they are.’

Then I asked if they were bleeding when I got there, or if her pushing in different areas may have caused this. ‘Yes, they started bleeding after I pushed the gums in certain areas.’ It sort of hit home, since one of the symptoms of low platelets are bleeding gums! I made a mental note to mention this to my hematologist tomorrow.

We also signed off on some changes to our trust documents, then I had lunch with a friend who I was asking to help with a relative who might be seeking another job at some point. Then I hit some golf balls as our driving range finally opened for the year. But after I got home, I had a bit of a pity party for myself, which I hate to do. I went back to the things that keep gnawing at me about my blood disorder. First, these blood cancers are very rare, maybe 1 in 10,000 of any population can get these in a year. Also, everything I read says that these blood cancers are usually linked to a family history (nope, not for me!), or working near caustic chemicals most of one's life (nope, office job here), or having radiation earlier in life due to some other cancer. (nope, my prostate cancer was treated surgically, with zero radiation)

Also, I can sense that I am probably a real dud around my friends, as I just cannot shake what is going on with me, while they seem to be doing great and having fun and joking around. When you are struggling with deep anxiety over what you fear is coming with a disease, it is very difficult to hang out with others and be your normal self. I hate that in a way, I am jealous that they are living their lives without a care in the world, and they don't really understand what I am dealing with, nor should they have to! But few if any ask me how I am doing with my blood problems, and I attribute that to them not wanting to broach a touchy subject.

But I have to remind myself that there are SO many out there who would gladly change places with me, and who are struggling with much worse than I am, at least to this point. I had a lengthy prayer session this afternoon. Admittedly, I don't pray enough, but occasionally I 'get serious' and have a long discussion with our Lord, and of late, I keep asking for strength to do my best through this ordeal, mainly for Sally. But this time, I prayed for healing for myself. I want to stick around this world a bit longer, as I am sure that I have some sort of role to play in this world, even as I get older.

I remembered today that when I was most anxious about my prostate cancer, I was at work one day, years ago, and I was alone in the office at 7:00 a.m. My mind was completely on my cancer and if I might die from this, feeling very high stress. Then, something happened that never happened to me before, nor since. I did not hear a voice out loud, but I heard a very clear voice IN MY MIND say 'Be calm, there is a plan for you.'

I was shocked, as I am pretty sure that voice did not come from MY mind, but I immediately calmed down and the stress literally flew away in that moment.

That convinced me that something more was at play in the world than just people and things and this earth. Since then, I have had this confidence that indeed, there was some sort of a plan for me, and after retirement, I became convinced that writing my first book was part of that plan, to help others by sharing lessons learned by myself and others.

Later on, I developed a passion to write about the generational divide, again as a way to calm the waters of friction between younger and older, and to educate those younger as to why the older generation thinks, acts, and behaves as they do.

Maybe I will have time to finish this, my third book about my battle with blood issues. But right now, I am at a pretty low point without a lot of optimism.

Tomorrow is the big day, but I am sure it will be just one of many future big days. I see my new hematologist, and she will discuss the blood numbers with me and likely recommend a bone marrow biopsy. Then, I hope to come home and wait for the phone to ring with results that I likely will not want to hear. But I know that I have to just take each day at a time and do my best with each day.

Golf is a lot like that, you can worry about the entire round, or the rest of the round, or you can concentrate on just that next shot, since it is all you can really control.

I worry most about Sally and how her life might change, and how she will have to learn how to get so many new things done, whether I am sick or whether I am no longer with her at all. Please God, help me and her through this in some way!

April 11, 2024

Well, it was another deflating experience at the hematology appointment. The drive up was not good, with so many tailgaters. One lady flashed her headlights at me, but I had nowhere to go, I was in the left lane following someone who was holding me up. She finally jerked her car to the right, and passed us, then swung back into the left lane right behind the guy who was holding me up! It was a dreary, rainy day, and my stress level could not have been higher. We had trouble even getting through the parking deck and finding a spot, as the aisles were so narrow, if someone was coming in the opposite direction, you could barely get by. We took our parking ticket inside with us, and walked the pedestrian bridge to the CANCER CENTER, then to the fourth floor to check-in. We had about 40 minutes until our appointment. There were so many people coming into the waiting room, all with frowning or emotionless faces. Names would be called, people would struggle to stand, then shuffle off. I felt that we seemed so healthy relative to these other people, but of course, maybe not.

When called into the office, a very nice nurse weighed me, then took us into the room. She tried to take my blood pressure, but it was terribly high, 160 over 110! It was never that high before. We told her that the drive here was stressful as was the past week after seeing my blood numbers. She took it again, about the same. I told her that in prior years, when I came to the center as part of my executive health program, it was always high, but they would put me into a private room that was dark, and a machine took my BP multiple times, and it always came down to the normal range. “Oh, OK, maybe you have white coat syndrome.” “Yep, I think I do”.

She told us our doctor would be right in, and left. Suddenly, the door opened, and two younger doctors walked in with very sour looks on their faces. I thought to myself ‘Oh crap, they are coming to tell me I am a dead man.’ One introduced himself as a ‘fellow’ which I think means they are doing their internship; the other lady was an intern apparently.

He did not explain why my doctor was not there, he just said that they were there to talk to me about my situation, and that they were lymphoma specialists.

Let me say upfront that both were very nice and professional, but you could tell they were not at all comfortable doing what they were doing, at least in talking with Sally and me.

Neither offered me a professional card so that I knew the names of who we were talking to. He asked what my thoughts were about the latest blood test. I thought to myself – "Holy shit, how would you feel about the blood test if it was YOURS? It sucked!"

But I bit my tongue, and explained I was concerned about the lymphocytes jumping up and the platelets falling down. He asked how I was feeling, I said fine, thank you. He did a quick exam, felt under my armpits and felt my spleen and liver areas. Then he said, "OK, you have had your say, and asked questions, now I am going to do the talking." Wow, I did not know this was a contest, especially since I did not ask him any questions! I told him to please proceed; I wanted to hear what he had to say.

This guy looked like he should be in the movies, he was handsome, tall, looked to be of Indian descent, perfect skin, perfect teeth. The more he talked, the more I realized that I was talking to someone very young, who was a little awkward broaching this whole topic of discussing that I may have blood cancer. As he talked to me, it was dawning on me that he was just now realizing the magnitude of the situation, in that he was going to be telling me bad news that could mean I was on my way to kick the bucket. I became certain that he had never done this before. He said he was most worried about my lymphocytes (he thinks HE is worried?) and that it was indicative of a lymphoma. He said that in order to identify what sort of lymphoma this might be, they needed to do a flow cytometry test. The young lady said nothing, but would nod her head in agreement at just about everything he said.

“OK, well your doctor will be in next.” I thanked them, but kept wondering what a weird process we were going through. We were expecting to see our doctor, but instead, these two people come in, total strangers, and I think now that this might have been some sort of assignment for them; to experience how difficult it is to tell a patient that they may have lymphoma or leukemia.

When our doctor came in (who we love, by the way) the other two followed in behind her. What was this all about? <u>*Now there were 5 of us in a very small room.*</u>

My doc: “They have told me that you are feeling OK?”

“Yep, I feel fine.”

“Wow, the lymphocytes really rose, huh?”

“Yep, I have no idea what happened.”

The next 20 minutes were a blur. We asked our questions, she answered them, we agreed to do the next blood test, and that she would call with the results in a few days. If the test was inconclusive, a bone marrow biopsy would be next. She did not hold out much hope that I did NOT have a blood cancer, just that it was a good sign that I was feeling OK. I blurted out a not-so-rational comment given that I just heard I likely had blood cancer.

“What do I do about the anxiety? For a year now, we have been worrying and waiting and not knowing what was going on, and the news keeps getting worse.”

“Once we know what you have, and get a plan, it gets better.” She said she did not prescribe narcotics for sleeping problems, but I should see my GP if I was struggling. She grabbed both our hands when she left, and was very empathetic. I am sure this job is tough on them especially when delivering bad news. Later, we found out that she was exactly right about having a plan.

The nurse came back in to try my blood pressure one last time, but it rose even more! She seemed pretty freaked out about it, and said that if we came there three times in a row with high blood pressure, they would ‘have to do something’. I said I would follow-up with my GP about the BP. She seemed to approve.

We did the next blood draw down on floor 1, then went to the cafeteria for some food.

The drive home was not great, raining even more, and difficult to see. My stomach was still in a knot, and I was very tired from not sleeping the night before. (make that the week before!)

I checked my BP at home, still sky high. But later after dinner, it fell to a normal level. I have had enough gut-wrenching emotions for this day!

April 12, 2024

The new blood test result from the flow cytometry and / or CBC showed up in my email early on the 11th. I refuse to open it and read it, as there has been too much bad news of late, I am sure this includes more bad news. It is tempting to read it, but I just cannot, I guess I am programmed to expect bad news since nearly all of them have been bad in the past year.

I reached out to that colleague of mine who is going through treatment for AML, a clinical trial, I think he is about in his mid-70’s. He replied that he is keeping a blog of his experiences day to day, and that I could sign up to read it if I wanted. I spent last night and this morning going through all his posts since his treatment began in January. The cold realization hit me that if anyone needs intense chemo or other cancer treatments, it is a challenge with lots of bad days and some good ones. The sequence of medical care he has received in just three months is mind-boggling. I cannot imagine the strain on him or his wife or children, who sometimes drive him to his appointments.

A friend, Jay, who was diagnosed with lymphoma four years ago, called me this morning to share his experiences. He was upbeat and told me all of these are treatable, and some curable. His experience didn't sound too bad, although there are still blood tests and checks to see how his blood numbers are doing. It was a positive to hear that he has not needed any treatments at all for 18 months, how wonderful! I am very happy for him. It is very nice of some people to reach out, but I think that most people do not know what to say, so they don't reach out much at all.

April 14, 2024

Today I turn 67, one day before I get a call from my hematologist who is to tell me what type of lymphoma I have. The stress is building about that call, as one part of me wants to know and is hopeful, the other part of me doesn't want to know and expects the worst. I played golf early with my regular group. On the first tee, one friend asked me if anything was new with my health situation. Others were within earshot.

I said 'Well, yep, some news, but it is not great news. I was told this week I have lymphoma, and I expect to hear tomorrow what kind I have.' There were a few comments, I don't recall what was said, but by the end of 18 holes, I became aware that all 10 guys who played today knew about it. It was hard sharing the news, but a bit of a relief that others were finding out and that they were praying for me and thinking about me, and were wondering how Sally was handling the news.

When I got home, I scrolled through all the texts and social posts wishing me a happy birthday. I didn't realize I had so many people who cared. It was nice, but I felt a bit guilty hiding from most of them that I was not having a good birthday and that all was not well with my world.

Later in the day, after dinner, my daughter Sara called me on Facetime with her two children Colton and Hayden, to wish me a happy birthday. Dan, her husband, walked over too and wished me a happy birthday. I just knew then that I had to tell Sara what was going on, as too many others were hearing about this, and I did not want two of the three most important people in my life hearing about this from somebody else. After talking for a while, I asked if I could talk to her by herself for a bit. She went into another room, and I suddenly realized how difficult this was going to be! I was able to keep it together for a while, but then she started to cry and asked what this was, she didn't know anything about it. "I thought you were doing OK, what happened?" The tears were coming out, and all of sudden, I welled up and couldn't say anything for a while. She said all the things that Sally and I had said to each other – this wasn't fair, I don't deserve this, I take care of myself, why me, etc.

I tried to tell her that from what I know, all of these types are treatable, some even curable. I told her I would update her tomorrow with whatever I heard. Maybe because it was my daughter, it was very hard for me to tell her and see her cry. I felt so bad for her, and felt so guilty that I had to give her this bad news. She was not at all expecting this, sort of the same as me, I was not expecting this either! I thought that maybe she would accept this and be positive, but she was just like the two of us! I could tell part of her was afraid of the worst. We hung up, then both Sally and I cried just over having to tell her! Then we discussed that we need to stop thinking the worst, that this is not the end. We have a journey to go through together.

But I also remember saying to Sally ‘When is this going to end? When are we going to know something, have a plan, and move forward? This past year has been hell!” (not the first time I said those words)

Then, I watched the end of the Masters, which is always such an enjoyable thing to watch, was happy that a class act, Scottie Scheffler, won, and that he is so modest and unassuming and a religious family man.

I worked on a list of questions for my doctor when she calls tomorrow, and Sally went to bed. She looked exhausted both physically and emotionally. I need to be strong for her and for me too! She has been so supportive, just there for me at all times, and I just don’t know how to thank her, other than I keep telling her that I love her and am so lucky to have her. But I know this is creating a huge stress for her, and I worry about her health too.

April 15, 2024

I slept terribly, and when I did, I had aberrant dreams, always situations where I had no control and others were screwing me over. In one dream, a car dealer was stealing my car, and I could not get it back. It was late at night and I got lost in the city, and could not find the dealer again. To try to find them, I had to walk through mud and wet concrete to get there. At the end, I was yelling at them to give my car back. I am sure there is a link there to not being able to control or effect my health situation, and how others seem more in control of my life and health.

Anyway, lying in bed, deciding to get up at 6:00 a.m. or not, I realized that I needed to check my latest blood numbers online, per the test that was taken when we were at the center. I said to myself that maybe there was a 1 in 100 chance the earlier test was in error, but hey, it was worth a shot. I got up, checked the numbers, and wouldn’t you know the lymphocytes that were extremely high, fell back into the normal range, all in a matter of 6 days. Unfortunately, my platelets fell again from 98 to 86 in 6 days also. In the past year, they have fallen from 135 to 86. Once they get close to 50, I would be in trouble and would need treatments to try to get them back up. Ugh. I'm not sure what this means. Here I am after 10:00 a.m., and still no call from my doctor. I cannot see the results of the flow cytometry test, so am hoping that will provide some information to help us move forward.

ABOUT THE AUTHOR

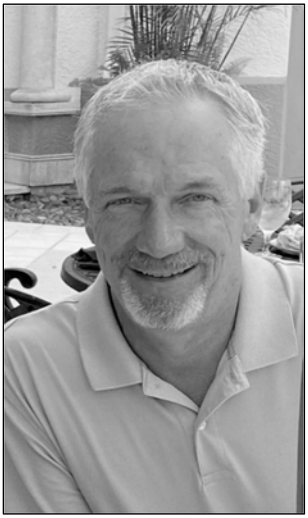
(www.danielmullerauthor.com)

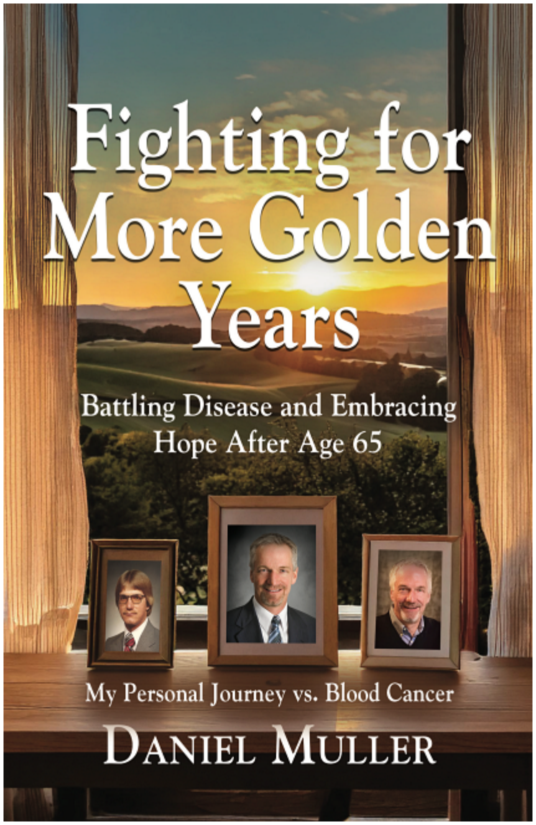
Daniel Muller grew up in a family of five, in Brewster, Ohio, a small town in Northeast Ohio. Athletic and academic success paved the way for a scholarship to Kent State University, where he became the first in his family to attend college. He lettered four years on the varsity golf team, and succeeded academically as well, graduating Summa Cum Laude in his undergraduate (BBA) and graduate (MBA) programs.

He spent most of his career in the business world, with various responsibilities taken on during a thirty-five-year career in a Fortune 500 company. He ended his career as a Senior Vice-President / Chief Information Officer, and also held other senior roles such as leading corporate strategic planning as a senior vice-president, and becoming president of a major division. He retired from his fulltime executive role in 2014.

Muller is now an author, and president of his own consulting company, DEM Consulting, LLC. He wrote and published his first book in 2019, entitled “CHANGING COLLARS: Lessons in Transitioning from Blue-Collar Roots to White-Collar Success”. His second book, entitled “SEX, DRUGS, ROCK and WAR: The Boomer Generation” published in 2023, was written in an attempt to capture the life stories of various Baby Boomers, and to explore the sources of generational friction between Baby Boomers and Generations X, Y, and Z.

He currently lives in Massillon near his early hometown in Northeast Ohio. He was inducted into the Fairless High School Hall of Honor in 2016, as well as Stark County’s Amateur Golf Hall of Fame in 2024. He continues to serve as a guest speaker for various organizations, sharing insights about the generational wars, aging, and lessons related to being more successful in the white-collar world. He is still an avid golfer, winning 10 club championships over his career. He is married and has two children and five grandchildren.





Told in journal format, this is the author's true personal story about being diagnosed with, and fighting, leukemia. The author relates all the treatments and side effects from his battle, while trying to find hope throughout the process.

Fighting for More Golden Years:
Battling Disease and Embracing Hope After Age 65

By Daniel Muller

Order the book from the publisher Booklocker.com
https://booklocker.com/books/13837.html?s=pdf
or from your favorite neighborhood
or online bookstore.