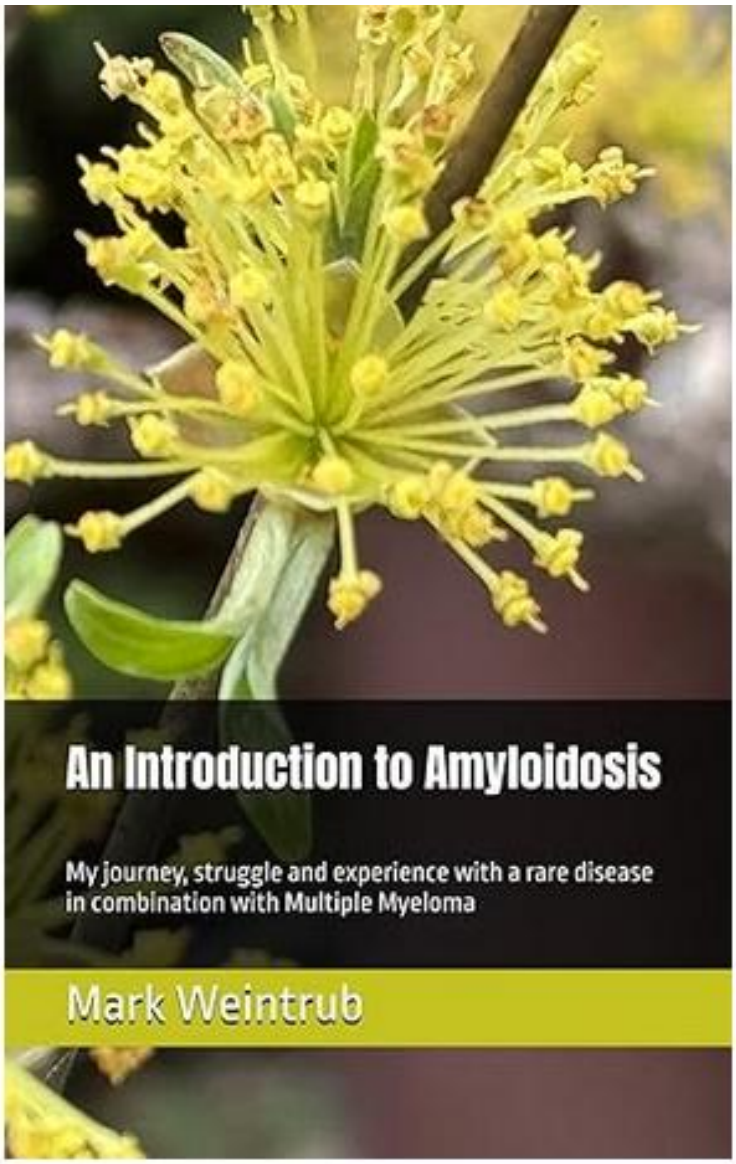
An Introduction to Amyloidosis
My journey, struggle and experience with a rare disease in combination with Multiple Myeloma
Mark Weintrub

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By Mark Weintrub

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This book is dedicated to Linda, my true love and partner in life.

Patience is her virtue, which she inspires in others through her acts of kindness.

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Prologue

Man, it is good to be alive and able to present you with my story and my journey along this rocky road.

This book is for those seeking some sense of commonality in a totally irrational and incomprehensible situation. My purpose in presenting this book is to provide others with helpful insights and information about a disease that, due to its rarity, lacks entirely too little generally available real-life information.

I retired from my day job formally at the end of 2023. That has allowed me substantial personal flexibility in the use of my personal time and has allowed me throughout 2024 to be reflective and to develop an increased sense of empathy and understanding for others that may be experiencing a range of feelings and questions in dealing with life-threatening illnesses similar to my experiences. I found myself thinking, if my experiences can in any way ease or comfort others (both patients and caregivers), then I should share those experiences. While I considered a blog, or postings on various topical websites, I found that most of the materials online were limited (most commonly pointing to trends in treating ATTR/TTR Cardiac Amyloidosis) and not very current (most up-to-date information on trends and studies include data through 2019). And while some were insightful, my knowledge about these two very serious diseases continued to increase over time (it's hard to absorb these things when you are actually going through it), and with this increased knowledge my desire to share what I have learned with others.

It's now spring of 2025. I turned 64 in January of this year and after more than 6 years of living with severe illness having been diagnosed back in 2019 with Multiple Myeloma (MM) and

Systematic light-chain AL Amyloidosis (AL) (recognizing there are several other types of Amyloidosis as well), I have written this book to be available to a larger audience. It is both cathartic and with compassion for others that I want to share my experiences, including emotional highs and lows, life-altering decisions, work-life impact, the impact on my family and the angelic level of care provided by my wife (of nearly 40 years), Linda (who is prominently featured in this narrative).

Many of these events that took place are after the onset in December 2019 of the Severe Acute Respiratory Syndrome Coronavirus 2, which came to be known as the COVID-19 Pandemic (COVID-19), and declared a global pandemic in January 2020. More on this later, regarding complications encountered because of COVID-19.

To be candid, this book is not for everyone, particularly for those looking for a light touch on such serious topics. I think you will find my prose to be straightforward, nonsensical, and unvarnished, perhaps even uncomfortable at times. For that, I make no apologies, as the intention stated is to provide insight into what you may expect to experience (or have experienced) in your own life (ranging from patients, caregivers and family members). Also remember this is not a scientific or medical paper, I am simply referencing things to the extent of my knowledge in lay terms or with explanations that I have come to understand (which I am sure many can be improved on or corrected by a medical professional). For purposes of respecting personal and professional privacy, all the names of my physicians and health care professionals referenced in this book are intentionally fictious names that I created. The facilities that I mention are factually correct and have not been altered.

1

The diagnosis

Let's jump right in with details around my actual diagnosis and then work backwards on the historical chronology of events as detailed in subsequent chapters. My memory is often distorted and foggy at times, as you can imagine and will come to understand. In 2019, my physical state had deteriorated to a point where I knew I was sick and I knew it wasn't good, but I had no idea what was coming down the pike. Linda knew a lot more as she had done so much research and reading on assorted topics that she pretty much diagnosed my Amyloidosis before any set of doctors had figured it out. I should pause to explain that not only is Linda smart, curious and extremely knowledgeable, she has been a health care professional (a pharmacist with a PharmD degree) for more than 40 years.

My day of infamy occurred in October 2020. This is Day 1 that I will never forget. Funny how at the time I thought this was without a doubt the worst day of my life. Little did I know there would be many more of these to come, and many would be worse. As it turns out, there would be 4 other specific days that I will also never forget (as identified in later chapters). But on this day, Linda and I had our first appointment with a new doctor, Owen Bass, MD (more details in Chapter 2) that I had been referred to following initial consultations with my oncology doctor, John Cross, MD (Cross). Cross was my first experience dipping my toe into the oncology waters, which consisted of extensive blood work and related testing culminating in a bone-marrow biopsy in August 2020 prior to my first visit with Bass. So here we are, me feeling like shit and not knowing what was coming and hard to imagine what's going

through my mind at this point (or yours for that matter once you start down this path).

Cross is an oncologist at Texas Oncology, a large and leading provider of cancer treatment services in the State of Texas. I met with Cross the first of several visits in late summer 2020 in his Plano, Texas offices right down the street from my home. While an experienced oncologist, Cross had very little direct experience and limited knowledge of AL. His initial thoughts were that I had MGUS (monoclonal gammopathy), which is a common diagnosis of patients presenting as I did as it also like atypical proteins. However, there apparently was more to it in his eyes and ours (as Linda's research had already convinced her that it wasn't MGUS) and he therefore referred me to Bass, who happened to be a highly regarded local oncologist specializing in treating Myeloma cancers and conducting stem cell transplants with more than 20 years of knowledge also treating this rare affliction know as Amyloidosis. Bass runs a highly specialized practice as part of Texas Oncology in collaboration with Medical City Dallas, where he has only 2 other partners (at the time) and a highly trained and experienced staff to manage patients with these delicate diseases. Since 1994, they have offered both autologous (using your own cells) and allogeneic (using a donor's cells) stem cell transplant services (Autologous stem cell transplant or "ASCT"). My recommendation to anyone that is looking to choose a provider for these procedures is to consider the best and most experienced practitioners and facilities, regardless of geography. Easier said than done, as extensive travel and lengthy stays can involve quite a bit of expenses outside of medical care that may not be covered by insurance. However, I found that even the most well known cancer treatment centers in the US (MD Andersen (Houston), Mayo Clinic (Minneapolis), Johns Hopkins (Maryland), Sloan Kettering (New York) who treat AL and

provide stem cell transplants were not the absolute best for my treatments (and may not be the best for your needs as well). Do your research in depth, ask questions, get multiple opinions (most institutions offer virtual consultation these days to start your research process) and don't limit your choices by simply settling for the convenience of local doctors or hospitals in your region of the country. In my mind, the clear leader that establishes the leading protocol for innovative AL treatment and ASCT is the Amyloidosis Center at Boston University. I was so fortunate to find Bass in my backyard as I was prepared to travel to Boston for treatment (even with MD Andersen just down the road in neighboring Houston). But after getting to know Bass, understanding his extensive level of experience and knowing that he follows the protocol from Boston University made my decision that much easier to pursue my treatment locally. Plus, this was all during the COVID-19 pandemic (as discussed further in Chapter 3). Medical City Dallas and Texas Oncology maintain 2 isolated floors in the hospital with a group of highly trained and specialized nurses and staff who only handle patients on these floors and are solely dedicated to stem cell transplant patients (I came to understand how it is necessary to keep transplant patients segregated from the general hospital population).

Linda and I arrived at Bass's offices and were shown into a small room with a round conference table and chairs, not a typical examination room. My recollection is that we waited an hour or more (maybe less) for Bass to arrive. I would come to learn that when with a patient, Bass's sole focus is on the patient, he does not look at the clock or his watch. He takes whatever time it takes to be with each patient, every time without exception. It's just one of the many things that make Bass special (more on that later) and you get used to that level of commitment for all of his patients over the course of working with Bass. At any rate, Bass walked into the room

with a thick file of papers and introduced himself. He is of slight build, soft spoken and dressed formally while wearing his typical double mask (it would be years after this before I ever saw Bass face to face without a mask). By that time, my physical presentation included what are referred to as "Pupea" on my face, or in lay terms what I call "Raccoon eyes". It looked like I had 2 black eyes, with dark, nearly purple coloring under both eyes. Armed with my bone marrow biopsy report (that was completed in August 2020) and a file inches thick, Bass took one look at me, and best as I can recollect, stated in his typical direct fashion that it was clear to him that I was "text book" and definitely had AL even though he was seeing me for the first time. That was before we conducted any tests related to AL to confirm the presence of the disease. The bone marrow biopsy had however confirmed that I had MM, which I would learn is a blood cancer that develops in your bone marrow. Your bone marrow is critical in producing white blood cells (which fight infection) and once the cancer enters an advanced stage, and without treatment, your body/your bones will eventually cease making white blood cells and then the all-important red blood cells which is the lifeline of plasma in your bodies blood. At any rate, Bass then proceeded to diagram and explain to us the unique "markers" in my body which are the starting point not only for treatment protocol, but this is how they basically assign your stage of progression (i.e. Stages 1, 2, 3 or 4, with 4 being the worst). Bass explained that I fell into Stage 4 and when I pressed him for a more definitive position, asking him straight out how long I had left to live, he indicated that without successful treatment I was looking at 3-4 months left. What? Did I hear that right? This doctor is telling me that I am going to die. I can tell you that at that moment, at that very moment, the shit hit the fan like never before. My head was spinning and to be honest after that first meeting I don't really recall

much else about the conversation details except a discussion on the next steps. Wow, talk about getting hit on the head with a 2x4 and not knowing what hit you, but as I said, this is Day 1, and my reckoning had arrived. Bass ordered a fatty tissue biopsy, which is a technique using Congo Red staining to medically and scientifically confirm AL. It was, as suspected, positive and confirmed that I not only had MM, but AL as well. In many cases AL is simply fatal, even with treatment, as it is highly underdiagnosed and often too late in the process.

Linda and I left Bass's office that day and headed home. Dazed and confused, not knowing whether to laugh or cry, it was right then that I realized how serious this was and only confirmed that I might very well die. I thought, wow, I am 59 years old, and this isn't at all what I had planned for my life. So much for feeling invincible up to this very moment.

Understand that it is not typical to contract both diseases simultaneously, far from it. While MM is the second most prevalent type of cancer after Hodgkin's lymphoma (about 365,000 cases/year in the U.S.), my research today confirms that AL occurs in something like 1 in 12 million patients annually, let alone in patients who also have MM. It does turn out medically that both diseases originate in bone marrow plasma and are related (beyond my understanding) or at least can occur at the same time. Yes, you can have either MM or AL standalone, but not me, I only do things that are complicated and never take the easy road (that's been the case all my life), but did I really deserve this?

2

Here's your Sign (precursors and failing to connect the dots)

Now that we know my diagnosis, I'll attempt to work backwards and to lay out the chronology of events that led up to this diagnosis. It goes all the way back to 2015 believe it or not. And it's a wild, crazy trip that like a lot of science and medicine, you become aware of by accident or incident. There's perhaps more detail here than the reader requires, but I put it all down with the hope that if any of these phases or experiences are something someone can relate to or that helps them to seek out more answers, then I have accomplished my goal of simply exposing this knowledge to others.

In 2017, I had decided to apply for an additional life insurance policy. It was part of my long-term plans unrelated to health status, to ensure that my family was financially covered in the event of an expected and sudden death. For larger coverage policies, it typically requires filling out forms with an agent and undergoing a basic medical exam (height, weight, blood pressure, blood test, etc.) for underwriting purposes. In the past, I had always been given a preferred rating for prior life policies, which gets you the lowest premium possible. However, the agent came back to me after this had been submitted to inform me that the insurance company had rejected my application for this new policy. They had not simply rated me higher than preferred but emphatically denied my application. They issued a brief report/explanation, focused on the fact that my BNP levels were higher than normal. At the time, I had no idea what the fuck a "BNP level" was. I had never heard of this and thought it was bullshit as a felt just fine (boy was I wrong). I had been living with hypertension/high-blood pressure since my mid-twenties (as it runs in my family), and I see my doctor annually

to run blood and urine analysis routinely. BNP is short for Brain Natriuretic Peptide and is measured in a blood test (which was required for the insurance policy application). Higher levels of BNP can be a sign of heart failure and make your heart work harder to pump blood. Normal levels are 100 pg/ML, high levels of 400 pg/ML would generally trigger you to see a doctor. My BNP in 2017 had come back at around 355 pg/ml. The very first sign. Guess the actuaries at the insurance company knew more than the rest of us, including the doctors. My BNP levels would continue to increase over time, peaking at 8,000-12,000 pg/ml. For comparison, today my BNP stands at around 3000 pg/ml (still high but down considerably year over year and manageable given my congestive heart failure). If you haven't considered outlier measurements and fall within some of the descriptions in this book, you should consult your physician and have this analysis included as part of a blood test.

I took the rejection letter and information and presented it to my internal medicine practitioner, Guy Mann, MD (Mann). Mann had been my doctor for several years before this and in fact has been treating me now for over 25 years. I have gotten to know him well over time, but he presents himself in some ways that can be irritating to those who don't know his style (like many doctors). He is straight forward, highly confident and often acts like he is the "smartest person in the room" (which he may be), truth be told he comes off a bit arrogant. But hey, he's my doctor and I know after all these years he is looking out for what's best for me. At any rate, he took one look at this information and brushed it off noting that BNP is highly misunderstood (or words to that effect) and that is often misinterpreted as an indicator of a cardiovascular problem. I took his word on this, but I now refer to this event as "Strike 1", a missed opportunity.

Just before this, in 2015, and in what seemed unrelated to anything else at the time, I developed what they call "trigger finger". That is where your finger not only doesn't bend, but it locks up at the joint and you must use your other hand to get the finger to "unlock" or fold down. What is happening is that the tendon is inflamed and gets stuck in the tunnel (bone) as it feeds through your wrist/hand, etc. I visited a local orthopedic hand specialist, Ethan Laraby, MD ("Laraby") who eventually treated 3 of my fingers (2 thumbs and a ring finger) for "trigger lock" in 2015 and 2016. It's a local procedure where they shave the tendon in microns to allow it to bend and operate freely. I chalked this up to the fact that I spent most of my working hours typing on a computer keyboard/using a mouse, and that I played both guitar and piano in addition to be a home handyman, so I presumed it was simply correlated to my personal activities. I never thought anything more about it. But after fixing these fingers, I started to experience extended periods of numbness in my hands, for example while holding up a newspaper to read (after just a few minutes) or playing guitar (mostly in the left hand as I am right-handed) or typing and having to take a brake to get the blood flow back into my hand and reduce the numbness. Following lunch with a friend, I mentioned the problem I was having with my hands and that I thought it was emanating from my neck. Describing some of his own back/neck issues led me to follow up with a visit to the orthopedic office where Dr. Laraby practiced seeing a neck and back specialist. He examined me and conducted a simple test tracking the response time to electrical impulses sent from your forearm/wrist area to your fingers. Turns out I had no response. Nadda. Zero. It was like the impulses were not going through to my fingers. Not good, I thought. And apparently the neck doctor had the same thoughts. He said I needed to see Laraby immediately, and more to the point he

proceeded to walk down the hall to speak with him and within 10 minutes I had a follow-up appointment booked for Laraby later that week. When I visited with Laraby and following a set of hand X-rays, he informed me that I did indeed have "severe" carpal tunnel syndrome (CTS) in both hands to boot and asked when I wanted to undergo surgery to fix the problem, saying he was available the next day. Tomorrow? Really? That never happens and to say the least I was a bit shocked. I guess this was serious. I couldn't process this so quickly, but we scheduled the procedure for the following week. When you have CTS in both hands, you can only do 1 hand at a time. I had my first CTS procedure in February 2019, followed by the second procedure in April 2019. All healed without incident and life went on. I never saw Laraby again and learned that years later he had retired.

What does this background information have to do with anything related to my diseases? Well, it turns out that in a medical paper published in 2020, CTS was identified as just one of the many precursors in people with AL (it's now somewhat more commonly known, but still not as widespread as it should be). Who would have thought! Certainly not any of my doctors, including Laraby. Another sign and "Strike 2" as they say.

3

Can't See the Forest for the Trees

(an endless pursuit to cure my A-Fib)

During or about 2017, I started to experience heart issues, which I didn't recognize as heart issues at the time. All I knew was that I was exerting myself in trying to breathe comfortably after eating a large meal. I just figured I had eaten too much. I continued to feel this discomfort and at times felt like my heart was beating through my chest, literally. I went in to see Mann and started to experience one of these episodes while in the office, wherein he immediately performed an EKG and confirmed that I was experiencing Atrial Fibrillation (A-Fib). He prescribed Eliquis (a blood thinner that is intended to avoid blood clots and potential strokes). He also referred me to a cardiologist, John Shuman, MD (Shuman). Shortly after, I visited Shuman, who ordered an echocardiogram (Echo) stress test (this is not just your ordinary echocardiogram but is done after walking on a treadmill at an incline in order to elevate your heart rate and then hopping off to have the Echo done immediately). That Echo did not provide Shuman with adequate views of my arteries (to determine if I had any blockage), so I underwent a heart catheter procedure, which confirmed no clogging of any arteries. After that I thought I was good to go. But this damn A-Fib kept reoccurring and after some research online and reviewing several articles, I learned about a technique known as an "ablation", for which there were several alternative technologies. Ablations are used to treat various heart cases, such as flutters and arrhythmias as well as A-Fib. The discomfort continued and the episodes of A-Fib became more frequent and to the point that I became determined to fix this problem. I was 56 years old at the time and could not fathom

living with this condition for the rest of my life. I was still in the mode and mindset that I was pretty much indestructible. Drinking alcohol and smoking cigars was a favorite pastime. I quit smoking cigarettes in 2007 after 15 years. I pursued my first ablation after meeting with a new cardiologist known also as an electrophysiologist (as I learned cardiologist handle the "plumbing" and an electrophysiologist, a specialized cardiologist, handles the "electrical" work). I knew that these procedures were at the time controversial within the medical community with data indicating about a 50% success rate. So, I went for it. And it didn't work. After that, I identified a national expert, Jean Batiste, MD (Batiste) who had pioneered techniques for ablations using cutting edge technology through catheters and applying radiofrequency to the heart muscle (as opposed to my first ablation using a Cyro ballon technique). This technique attempts to pinpoint areas of the heart triggering A-Fib and zapping it with radio frequencies, basically you are intentionally scarring your heart with this method to redirect or interrupt the abnormal electrical pattern causing A-Fib. Batiste was based at a specialized Medical Center in Austin, Texas where nearly an entire wing had been devoted to this practice seeing patients from all over the world. For me, it was a no brainer as Austin was just 3 hours down I-35 and so I scheduled my first appointment. In all there were 4 radiofrequency ablations starting in April 2019 (you can see I was more than mildly obsessed and continued to plunge further down the yellow brick road with blinders on). Some were mildly successful, but none ever resolved the problem, although the final ablation in April 2020 did bring relief for a period. In hindsight, the reason for the lack of success is that A-Fib wasn't the real problem (even though I clearly suffered from it), AL was. But Batiste could not see the forest for the trees on this one, as many doctors simply focus on the problem you bring

and not necessarily the root cause. Another swing and a missed opportunity. The count now stood at Strike 3. I have learned since that many heart specialists are not informed or aware of AL, again just another indicator of how difficult it can be to identify this diagnosis (and confirms the lack of relevant information among the medical community in general). I finally abandoned the hunt to cure my A-Fib, but the damage had been done.

After this, and going into 2018, I do recall over some period experiencing continued discomfort, feelings of sluggishness and fatigue that culminated in 2 vivid and memorable events. The first one was in June 2018, during a trip to several places including Switzerland, Croatia and coastal Italy. It was in Croatia during a group walk through the local town, up a lot of steps and then up a hill (literally not that much of a hill, but with a pretty good incline) to a historical fort at the top. The hill part was maybe a 10-minute walk. It was warm, I recall, and as I am walking up with Linda and the group, I felt lightheaded, I looked as her and said, "I'm going down" and collapsed to the ground. Luckily, I could feel myself fainting as I slowly went down (fortunately a soft landing and I didn't crash my head on a rock). I may have been out 10 seconds, not sure, and opened my eyes surrounded by Linda and others in the group. I thought I was just hot and dehydrated (which I probably was). But nothing like this had never happened to me before. The second event occurred later that summer over the 4th of July weekend while playing an outdoor game with my family at a lake. Its July in Texas, and as usual it was very hot and I'm sure I was drinking a few beers. While squatting down I suddenly felt lightheaded. I quickly headed up the stairs of the deck to the house (and the air conditioning). I didn't quite make it. I went down on the deck and passed out, eyes rolling up in my head. Everyone thought I was having a seizure and nearly called 911. However,

once they helped with into the house, a cold press and liquids helped me to get back to normal. No seizure but dodged another bullet this time. Another sign of heart issues that soon I would not be able to continue to ignore.

I limped along into 2019, my state of health digressing but not realizing or appreciating what was happening or at least the extent to which I was declining. Linda noticed though. As I mentioned, she had already started doing her research to figure out what was wrong with me.

I typically undergo my annual wellness exam with Mann in the summer. I went to see him in June or July of 2019. He conducted the usual blood and urine tests. Nothing really stood out as we reviewed the blood test results during my visit, but he noted that my urine had indicated elevated levels of proteins at 2+ (above normal). My recollection is he simply said we would watch this. Looking back, I cannot for the life of me figure out why neither of us suggested that we revisit this in 6 months (or less) to check on the levels. The following year in 2020, again around June or July, I saw Mann for my annual exam. This time the urinalysis confirmed increased levels of proteins (2+) but to the point now that Mann was "concerned" and ordered a 24-hour urine collection test (this involves catching your urine for a full 24-hours straight, storing it in a refrigerated container and then turning it in for analysis). Following up, Mann referred me to a specialist known as a Nephrologist (apparently, I had Nephrology as I was continuing to "leak" proteins from my kidneys). I had no idea at the time what all this meant.

I also noticed (and have a picture to remind me) that I started to develop these small blood spots or what resembled bruises on my

face. This was around July 2020. I may have had them and asked Mann what he thought when I saw him, but I don't remember either way. However, I was at a Dermatologist appointment later that summer and asked the doctor what these unusual spots were. The doctor had no idea and suggested I put some skin cream on it. Swing and a miss.

During this same summer on a follow-up visit to Shuman, we discussed how I was feeling in terms of fatigue and heart issues. Shuman was concerned. He had read my most recent Echo which by now was showing a reduction in my ejection fraction (EJ), which measures the effectiveness of your heart pumping blood into your system from the left ventricle. I was also showing signs of the thickening of the walls of my heart. These were all indicators supporting the diagnosis that I had congestive heart failure. Shuman suspected something but could not quite put his finger on anything specific. He ordered me to undergo a special nuclear test specifically for detection of ATTR Amyloid, or Heart Amyloid. The tests results in August 2020 were negative. Good swing, another miss (but not for lack of trying).

Recall that all of this was happening during COVID-19. Although the rules in Texas were less stringent that in other parts of the country, the Nephrologist I was referred to, Dr. Susan Wells (Wells), wasn't holding regular office hours, but with some begging and prodding and Mann's referral, I was able to schedule an appointment for the one day a week that she was seeing patients (like so many things in this story, timing was not only fortunate but critical). Donning her mask and protective garb, I met with Wells, and she ran a full range blood panel analysis. We waited for the results and the next week I revisited with Wells, and she informed me (this is July 2020) that my blood panel revealed a protein level

of 3+ and that I had immunoglobulin (or monoclonal free) Lambda light chains (high level) and evidence of Bence Jones protein in my blood. Detection of Bence Jones is a suggestion to MM. I had no clue what all these medical terms meant, but when I returned home and delivered the results, Linda knew exactly what this meant. After she explained things to me, I knew this was not good. It felt like a death nail, and although I was still ignorant on these topics, I was smart enough to know that this meant I had cancer. Call it serendipity or what, but Wells's nurse said she had a good Oncologist to refer me to (I had no idea where to turn to at that point) and behold my introduction to Cross (who I first met with in August 2020), which then lead to a referral to Bass, which in turn saved my life, literally (more on that later). It also started me down a path for which I could never anticipate what was to come and how my life would be altered. It was a dark day indeed. But finally, someone connected the dots.

4

Wait, what did you say?

I know I have cancer (MM) and some other supposedly rare disease that I can hardly pronounce, and I feel like I am swimming in the dark as I am way outside of my knowledge and comfort zone. Linda is my guiding light here, as always and with everything both in my life and on this journey,

Besides all these fancy medical terms, I'm thinking, and maybe you are wondering as well, what the hell is AL? In addition to my attempts to define AL in Chapter 1 (the folding of proteins), here is a little more information that I have learned over time. Proteins are basic to life in all living organisms. Proteins are generally "assembled" in the body or folded in a normal way. As I touched on before, with primary AL, proteins can become "misfolded" or "sticky" through mutations. Defective proteins that have mutated by misfolding enter your blood stream and basically "stick" to your organs, of which those most often involved include the heart, kidneys, nervous system, and gastrointestinal tract. Simply put, without further treatment, the organs will be compromised and eventually shut down. Signs or symptoms generally agreed by the medical community in these organs can cause shortness of breath, fatigue, edema (swelling of ankles and legs), dizziness upon standing, a feeling of fullness in the stomach (especially after eating), diarrhea, weight loss, enlarged tongue, numbness of the legs and arms, and protein in the urine. Heart conditions are one of the most common denominators or indicators, which was true for me, in addition to the manifestation in my kidneys (again, quite common). I had also experienced swelling (Edema) many times, which first surfaced during an overseas airflight (pressure changes

often bring this about) and eventually I learned I had an enlarged liver as well. How does this work in combination with MM? To me it sounded "doubly" bad. And as it turns out, it is. While some of the treatment protocols are the same for both diseases, it truly has a multiplying effect both in terms of the pre and post ASCT treatments as well impacting survival rates.

At this point in time, and as Linda would describe it, I could no longer exercise and merely walking across the room was difficult while walking up the steps of my house was like climbing a mountain. I struggled most days to get up those stairs to my office as our Company had transitioned fully to a remote workforce because of the COVID-19 pandemic. It was a busy and challenging time, both personally and professionally trying to work together with our executive team through this unchartered territory of online video calls and remote work while trying to run a global based business. The transition to working 100% remotely was both a curse and a blessing. Frankly, I would not have been able to adequately perform my job duties if I had to undertake the rigors of commuting and working in an office all week. And it served as a welcome distraction for me given what was coming. Looking back, I have to acknowledge my long-term employer completely supported my situation as I continued to work and never missed a beat either before or during my time in the hospital. If not for this incredible support, both morally and financially, the hardship on me and my family would have been unbearable.

I mentioned in Chapter 1 that during our consultation with Dr. Bass he presented his analysis and a straight-forward delivery about my status. I didn't really get it at the time and still don't quite know what the details really mean. But my bone marrow biopsy showed 25% clonal plasmacytosis (a significant level) and further analysis

showed my FISH panel translocation 11:14 in 78% of my cells (highly significant). This FISH panel is designed to detect the most common, and/or prognostically significant abnormalities in MM and related plasma cell neoplasm. I distinctly recall Bass diagraming this all on the back of some papers, showing us that I fell within Stage 4 (again this being the worst out of 4 stages) and ended with his prognosis that I had 3 months to live (without successful treatment). I was truly struggling to understand what was happening at this point.

Driving home that afternoon following this visit and trying to digest this information, as I mentioned previously, was surreal. I just couldn't have imagined in my wildest of wildest dreams that I would not only have to deal with this overwhelming situation, but now I had to consider the very real possibility that I might die. It was simply too much to handle.

After our initial appointment there were follow-up consultations regarding the next steps. I was assigned to, and we met with our "planner" who would communicate with us going forward regarding my immediate pre-transplant treatments and prepare me for my anticipated admission to the hospital. She handed us a full 3-ring binder with an overload of information and procedures to follow including details about preparing for the ASCT and limited information on what to expect. Overwhelming once again, but at least our road map was becoming clearer.

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The Calm Before the Storm: pretransplant process

So it began, the first introduction to bi-monthly blood labs and intravenous treatments at the Texas Oncology location near my home in Plano, TX. The office is unassuming and located next to another Medical City hospital in the suburbs. Bloodwork is a highlight efficient in-house process (with probably close to 100 patients/day) and analysis is typically available within 24 hours. After they took the multiple vials of blood (by now I was getting used to this even though it was just starting and would go on pretty consistently for the next 4-5 years), I had a brief appointment with Cross or it may have been with his nurse practitioner, we'll simply call her "W" here (no intentional reference or likeliness to former President, George W. Bush). W became and continues to be my primary contact that I have seen for nearly all of these past years and has been more than a welcome pleasure in terms of her cheerful demeanor and her high level of care. Then it was on to the "transfusion room". There is no way to prepare for this first experience, even scenes from TV can't do it justice. This room is quite large, holding, in my estimate, up to 50 chairs that are lined up in rows facing each other. Walking in and seeing all these patients with some form of cancer who are receiving various types of transfusion treatments is mind blowing and surreal. As you walk through the room to your designated seat, you see mostly older patients (+50), in all stages of life and physical condition, many bald and with caps on and most covered with blankets as cancer patients tend to experience a lower tolerance for cold. These chairs are pretty much like a Lazy-Boy lounger you might have in your home. They are wide, leather seats, which recline to a full flat condition with electronic controls and some even with internal heaters. Very

comfortable and most were well broken in. Couldn't think of a better place to spend 4-5 hours (not kidding) every other week. Treatments were (as discussed elsewhere) based on protocols established by Boston University. They included a combination of drug therapies, a mixture of chemotherapy, commonly referred to as CyBor D, which included Cyclophosphamide, Bortezomib (a shot delivered into your stomach) and Dexamethasone and immunotherapy of Daratumumab (a transfusion branded as DarZalex) and Methyl prednisone (pills).

After completing 2 months or so of pretreatment through September 2020, I was feeling a bit better, but still not able to exercise or walk any substantial amount without getting short of breath. I had responded well to the drug therapies so far. We had received our treatment plan outline and expected we would be going to the hospital in October sometime. So, with Bass's permission, in September 2020, we were able to take a nice long weekend trip to the Smokie Mountains in Tennessee. It was gorgeous, a well needed escape and even with my limited scope of physical activities we managed to get around more than I would have thought and packed in as many activities as we could. At least for a few days we were able to escape our focus on what was coming or how bad (and fast) I was deteriorating.

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Checking In: stay 1

As I keep saying, many of my recollections remain cloudy, but certain things I am quite sure of. Its mid-October 2020, back from our quick trip to Tennessee and now having completed all the pre-treatment protocol, I would sit at home and work during the day waiting to hear from our "planner" at Bass's office as to when we would be admitted to the hospital. The initial calendar planner we were provided with indicated that once we checked in, there would first be the stem cell harvesting or the collection stage, followed by chemotherapy (Melphalan), followed by the actual transplant. After that, there was an imperfect estimated timetable for recovery (you are not released until your blood cell counts had reached a minimal level) and then I would go home. Checking in the end of October meant that I could expect to spend basically the month of November in the hospital.

As it was, things didn't quite go according to this plan. Everyone's experience will be different here, but in the end, I would spend a total of 46 days in the hospital (I affectionally refer to my 2 stays as "Stay 1" and "Stay 2", separated by a 3-week hiatus).

We got the call to pack our bags and show up for admission on October 26, 2020. This is Day 2 that I will never forget. Linda had already decided that she would stay with me in the hospital room for the duration. While my first inclination was to strongly discourage this (I didn't want her sleeping in a chair or on a couch for an entire month), this was not up for discussion and in the end thank God she was there daily during this entire experience for more reasons than I could have ever imagined. It's critical to have a

caretaker to oversee things ranging from making sure your daily pills/dosages are correct, helping you shower, get dressed, order food, question changes that were constant with each different nurse or staff that would come in for something or another. With the expectation that we would be there for a month, Linda and I each packed a large suitcase that you might use for a multi-week vacation for example. We also each had a "carry-on" or "carry-with" bag with accessories and our own pillows (absolutely necessary). I also packed my briefcase with my laptop for work (I knew I would have quite a bit of idol time to occupy). I did not take any blue jeans, regular shirts or shoes for that matter (except what I wore that day to the hospital). I packed only loose fitting, soft and comfortable clothes. I had purchased 5-6 pairs of sweatpants and long sleeve soft shirts to sleep in, underwear, socks and my house slippers. Thank God I took those slippers as they would become the only thing. I could eventually squeeze onto my swollen feet to walk around. I lived in those slippers (and I went home in those slippers). Don't overlook the little comforts of home that you will miss extremely or end up needing. With Kindle, iPad, iPhones, cables, toiletries, etc. in hand, we showed up at the hospital. You cannot bring your own prescriptions or over the counter items as they provide your pills or whatever you need every day/night (and yes, they charge for this of course). And, unlike a hotel, there is no one to greet you or a trolley to load your luggage. So here we are trying to balance all this "stuff" as we walk into the admitting area. We processed the paperwork and waited to be shown to our room.

Looking back now, I had given little thought to what it would really be like during our hospital stay and had no real point of reference. I had only experienced 1 or maybe 2-night stays in a hospital for vastly different procedures than what was coming now. I had visited people over time in hospital rooms, but really didn't give

much thought to what it would be like or how difficult it would prove to be for many reasons. On the list of things they don't tell you, or that's not addressed in the binder of information provided, is since there is a major pandemic and at this point still no vaccines, once you check into your room, you will not be allowed to leave (and no I'm not using a Hotel California metaphor here). But that's right, you can't even walk out the door to get some water or juice. For anything you need, you must call a nurse who will bring it to you (when they can, since now, they are waiters in addition to their multiple other duties). Linda couldn't even get a cup of coffee upon waking up in the morning without catching a staff member or nurse to bring it to her. You were not allowed to walk around your own floor without proper masking and permission and only a limited number of people at a time (there are only like 12 rooms on a floor). You cannot leave your floor. Linda could not leave and go for a walk or to exercise. The list goes on, but by now you get the point.

At first, they stuck us in a typical small hospital room. Our first thoughts were that although this might be appropriate for an overnight, I could not imagine staying in this room for a month. We were later assigned to a different room and breathed a sigh of relief as we walked into a much larger space with a standard hospital bed, reclining chair, sofa type couch (vinyl covered which apparently turned into an "oh-so-uncomfortable" bed that Linda would sleep in for the month), a desk, a TV, a mini-fridge (again, thank God for small miracles) and a separate bathroom with a shower (more to come on that lovely shower).

We settled in and became acquainted with the room and things started to slowly sink in. My nightmare had begun. Among other things they don't tell you, or at least I wasn't prepared for, is that for as long as you are there you can expect to be interrupted every

4 hours, 24/7 for blood samples, taking vital signs, administering drugs, whatever it was, it never stopped. What else they don't tell you, or even if they did I wouldn't have known how to visualize or anticipate, is that you are going to be hooked up to 24/7 monitoring, which involved similar electronics to taking an EKG, sticky pads on your body hooked to rubber covered chords (you could stretch about 8 feet), hooked to the monitor next to your bed. Another reality is if you are a side sleeper, as I have always been, you can forget that from now on. You will learn to sleep lying flat on your back with monitors hooked up for the duration. The only saving grace for me was that they do provide you with a sleeping pill each night (optional) which helped put me down. But not for long, only 4 more hours until the next interruption for vitals!

I also discovered that I would no longer be allowed to take my daily Eliquis (blood thinner) doses orally. Apparently Eliquis was not compatible with what we were going to do. Instead, I was to receive daily doses of Lovenox (a substitute blood thinner) by way of shots to my stomach (which you get used to extremely fast). Add to the list of things not previewed or discussed, is that for the duration of your stay your "output" of urine will be captured and measured every day. That's right, you are no longer going to pee in the toilet, but into a plastic container (which I had several strategically stationed around the room). This was collected throughout the day/night and output posted on the whiteboard in your room for the doctors and staff. This whiteboard contained many other data points and communications for each shift as well.

You would think (and I did as well) that I would read books (which I did little to none during the entire Stay 1) or watch TV, again, which we did very litter (except maybe Wheel of Fortune and one or two shows at night) or sometimes a DVD movie (yes, this is

before Netflix and streaming), all of them old. What I wound up doing, and this depended on the day and how I was feeling, would be to do emails and video/Zoom meetings to occupy time during the day and then I began to enter what I call a meditative state, where I would just sort of check out and not do much of anything. Linda might be reading or browsing online, but if we weren't talking about things (and you could only do so much talking every day), this was my default state. It proved to be beneficial and got me through some rough times during both Stay 1 and Stay 2.

Locked in the hospital for Stay 1, I started to receive growth factor injections to stimulate my cells for harvesting. This was done through injections in my stomach (yes, just another stomach shot), multiple times a day. Within the first few days I was wheeled down in my bed to a surgery room to have a central venous line catheter placed in my body. This involved inserting a long, thin flexible tube just below my collarbone on the right side (I believe there can be other locations for other purposes as well) up to the large vein that empties into your heart (the vena cava). This reduces the need for an external IV (i.e. on your hand or arm) and avoids hundreds (overtime) of needle sticks. On the outside of this tube are 3 tails or ports each with a 4-inch-long external tube that has glass encased (for sterility) connectors that allow for easy hook up for various purposes. These are amazing as they function both ways, taking blood samples directly as needed without a needle insertion and administering drugs directly into your blood stream (which allows multiple IVs to run simultaneously). Weird and a bit cyborg like, I would have this little gem in my chest for about 5 months. While it is quite an ingenious tool, now I have all these chords attached to monitor my heart rate and this other thing on the right side of my chest with dangling connectors, further complicating movement in general including the ability to roll over and sleep in any position

other than flat on my back. One saving grace, during the midnight and late night check in by the nurse (remember every 4 hours), I got to the point where I didn't even have to wake up past a groggy state to have them take my blood. Some of the nurses were so good, they would take my blood pressure (with the cuff) and the blood samples through the central line ampules and not even wake me! Some patients often have these catheters inserted in advance as an outpatient procedure.

The schedule called for me to initially harvest cells the second week, followed by administering the chemo and then the ASCT. But like so many other things in this process, this was not to be. My heart continued to present a challenge, and every time it would go over 90 BPM, it would trigger a beeping in my room and at the main nurse's station. This became a frequent occurrence (and annoyance). They eventually adjusted the in-room monitor alarm so they wouldn't have to come in each time to reset and check on me. At some point during the second week into Stay 1, I was notified that they were ready to start harvesting my cells. This was like a field trip, sort of. They wheeled me down in my bed (that is how I traveled anywhere in the hospital) to the 4th floor (from the 11th) to the "harvesting room". This is quite a large room with space for multiple beds (around 5-8 beds) and several chairs for non-patient donors to sit in during the process. There was a threshold number of cells they were looking to harvest (millions) and there was no telling how long it would take, but at least several days. Each day I was wheeled into my bay where I had a private TV screen that dropped down in front of me and a hospital phone nearby. There was a main nursing station where they could see and monitor all the patients in the room. I was hooked up to a machine next to me, which is best described like a Kidney dialysis machine, that spins your blood and removes your cells in a process called "apheresis".

A session would run for about 5 hours, so it was a full day for me (as they would wheel me down shortly after breakfast). I was on my own to order lunch and they would deliver it to my bed. This also provided Linda with a break during the day, which she would take advantage of to exercise in our room (go figure how she did that in a 12x12 room with a bed and all the furniture), get some quiet time, talk on the phone and have a meal by herself. All in the comfort of our wonderful room. November had come and it was dreary outside most days, but at least on our floor we had a view to gaze out. I believe it took a total of 3 days to hit my target. Once completed, there are no more trips to the harvesting floor. They would now take my cells and "clean" them for the time when I was to receive them back during the actual transplant (and freeze the rest in storage).

Relieved to have completed this process and thinking we were at least on track to move forward, Bass and the staff continued to pump me with fluids (through IV) to keep my heart at bay. Bass was monitoring me literally 24/7. He visited daily during his rounds with his "team" (sort of like you see on TV shows). He visited me every day without exception, even when he wasn't doing rounds (another partner would do them), even when he was on a day off (which Bass didn't ever really do), even on a Sunday. I never knew when he would show up, but he did every day. And we were all concerned as I was continuing to retain fluid, put on weight and swelling just about everywhere. I no longer had ankles, only kankles and could hardly get my slippers on my feet. Despite this, I never spent a single day lying in bed. With Linda's encouragement and insistence, I would get up each day (I was also expected to shower each day..ugh…more on this), get dressed in my loose-fitting clothes (which by now were a necessity) and mostly sit in an armchair next to my bed (often the couch was harder to sit on

and lean back). Also at Linda's insistence, we would go for a walk around the floor every day. I would have to get permission from the nurse, unplug from the monitor, take my portable IV pole on wheels with me, put on a robe and proceed to walk around the floor as many times as I could muster. At times I was even required to have a strap around my waist (to prevent falling), and a nurse accompanied me with Linda always walking next to me. It went on this way as I waited for the word to move forward with the ASCT. That didn't happen though (again plans change). Due to the fluid overload and swelling, somewhere around November 16 or so, Bass came in for his rounds with his team. After the team moved on, he stayed behind to talk to us, which he did on several occasions, so this didn't seem odd at the time. I sat on the couch with Linda and Bass sat in the desk chair across from us. Bass is soft-spoken, deliberate and sincere in his discussions and delivery of information. It is done in a matter-of-fact manner with little if any emotion. He would be a good poker player. Plus, since he always wore a mask, I could never really read his facial expression except looking into his eyes. He then told me that he was "sending me home". I thought "what the fuck?" (and wanted to shout out loud). I asked why and what this meant. I know inside I was spiraling downward. He explained that I needed to shed some of the excess fluid and weight before I could be considered to proceed further. I knew he was concerned about my heart condition as well. This is Day 3 (November 2020) that I will never forget.

Bam! What an unexpected shocker. We proceeded to pack up, they unhooked me, discharged me and wheeled me to the car and Linda took us home just before Thanksgiving. I can remember that once I got home, certain things were wonderful. I could sleep in my own bed, no more monitoring, I could sleep through the night undisturbed, eat my own food at home (or order out), shower in my

own glorious shower! But it was still COVID-19, and in my condition, I was confined to the house. I could hardly (or maybe not at all, I can't remember) make it up my own steps (15 steps) to the office upstairs. But I recall thinking my only shot at survival is drifting away. I had no idea if or when Bass was going to re-admit me or perform the ASCT.

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Stay 2: live or die?

When I arrived home after Stay 1, I weighed about 180/190 lbs. I had gone up to as much as 215 lbs. in early November (my usual weight before all of this was steady around 207 lbs.). On November 26, I weighed 190 lbs. (and after my ASCT, I would swell up and weigh in at my top weight of 233 lbs.).

I was able to finally shed the fluid and hold my weight steady in the 180/190 lbs. range. I had maybe 1 or 2 follow up visits with Bass. Just after the Thanksgiving holiday, we received the call (or we may have been informed during one of the follow up visits) that I should prepare to check into the hospital again, which we did on or around December 1, 2020. What a huge relief. Stay 2 (and the real work) was about to begin.

I didn't really have a lot of time to think about it back then, but this entire up and down process was truly unforgiving for my family. Our son, Matt, had recently relocated back to Dallas from the West Coast while our daughter, Leah, had just relocated to Austin to start her first semester of law school at the University of Texas. Our last get together as a family was early in October when Leah came home to visit and we took a series of family pictures (hey, nobody knew what the future would hold or frankly how much longer I would be around at that point). It would be nearly 3 months after we took these family pictures without seeing my kids. They were not allowed to come to the hospital, in fact no visitors were allowed at all (COVID-19). Linda, my doctors and hospital staff were the only people I could see during this time frame.

We packed up to go back to the hospital as my anxiety increased in anticipation of getting the ASCT done. Things moved quickly at the beginning of Stay 2. I received high doses of Melphalan chemotherapy intravenously that are commonly used to treat MM and for conditioning prior to the ASCT. Melphalan is very powerful stuff. It puts you down like nothing you have ever imagined or experienced before. It interferes with the growth of cancer cells and at the same time kills off growth of your other cells. White blood cells, red blood cells, hemoglobin, platelets, etc. It can also cause sever issues to your heart, particularly when you are vulnerable as I was having congestive heart failure (I was running an abnormally high heart rate with unusually low blood pressure). Bass was also filling me with drugs to counteract the fluid overload (which again they were "pumping in" as well) requiring what they call IV diuresis (same as in Stay 1). I proceeded to lose my hair and felt the full impact of this drug in every inch of my body. If I thought I felt like shit before, this felt like I was hitting the bottom of the bottom (if that makes sense). Getting out of bed each day was an ever-increasing challenge, but with Linda there urging me to get up, I continued to sit in the chair everyday and refused to lie in bed (I was determined that I would not get bed sores on top of everything else). We would still walk around the hospital floor as permitted, but often I was physically limited to doing just a single loop before needing to head back into the room. I was required to rinse my mouth twice a day with an awful prescription mouth wash to avoid mouth sores and pain (which I luckily avoided). I was also required once again to shower daily in this god-awful shower using this god-awful medicated soap and then required to use medical sterile wipes. This shower merely trickles out and you can only make it Luke-warm even though I am freezing and often I would have to sit in a chair while showering with the handheld spray. Plus, for every shower I

had to remove the sticky pads for my monitor chords and take my portable IV pole with me (as it stood just outside the shower) since you cannot unhook from your IV fluids. It's a challenge to try and turn to rinse your body, but you do get the hang of it eventually.

Bass is now literally monitoring me hourly, whether he is at the hospital, in his office or at home. The level of care and concern from him is unprecedented. I was teetering back and forth in terms of my fluid levels and my response to the chemo. I felt like Bass was no longer on the fence about my condition, that he was past this point and thinking that my heart would not survive this process. He had told us before and reiterated that he expected I would end up in ICU (intensive care unit) before it was all over. Shortly into Stay 2, Bass came into our room (I can't recall if it was during his rounds or another one-on-one visit). Linda and I sat on the couch, Bass sat in the desk chair (we've been here before). He went through all his concerns about my heart and overall general condition. You could just tell that he was hesitant, and I sensed that he was ready to pull the plug on the ASCT. I remember this moment with utter clarity. I looked at Bass, nearly in tears, and told him that my heart was stronger than he could imagine and that I was tougher than he could fathom and that I was going to survive this thing (inside I felt a sense of desperation like grasping for air). I sensed that he was leaning towards sending me home, but my response to his reluctance to perform the ASCT was "what choice do I have?" I said, "we need to do this transplant!" So, despite his reluctance, he acknowledged my decision and said that we would go ahead and proceed. This is Day 4 that I will never forget (December 2020). Accepting my choice to proceed, Bass agreed to take a risk, that, in my opinion, other doctors in his situation may very well have rejected. But this is just another example of Bass' character and further confirmed his courage and respect for my decision as a patient. His actions

exemplified his dedication as a physician and his empathy as a human being. This man monitored my health status for 60 days straight, morning, noon and night, showing compassion and care unlike any other physician or healthcare provider I had ever met, or have ever met since. While it may seem dramatic to say, he clearly saved my life by allowing the ASCT to be completed, giving me the chance to continue to live and experience all the good things to come. Bass continues to be my treating physician to this day. My trust and faith in him are unwavering and my gratitude immeasurable.

It's December 9, 2020. This is the day. A specially trained nurse came into the room and wheeled in a machine (much like the dialysis type machine they had used during cell harvesting). I sat in the reclining chair and for the next several hours they proceeded to put my scrubbed cells back into my body. Nobody else was allowed in the room during this procedure. I remember that I was required to constantly have crushed ice in my mouth to suck on and alternated between the ice and popsicles they provided. This was (like the daily mouth wash) to avoid mouth sores from the high dose chemo. They completed the transplant and the nurse, and her machine left the room. It was (finally) done.

I didn't realize that this day is considered my new "birthday" (my actual or first birthday is in January). This is because you are basically starting out with no protective immunity cells like a newborn baby, after the chemo. Your "count' as they call it, consisting of measuring your complete blood count (DBC), white blood count (WBC), hematocrit (HCT), platelets (PCT), hemoglobin (HGB) and absolute neutrophil count (ANC) are at "zero" and the days are counted as D+1, etc. The white board in the room tracked my daily progress until I achieve the acceptable levels

before I would be "out of the woods" as my body once again began to manufacture all these critical cells. That afternoon, the nursing staff all came into my room with a decorated poster with birthday wishes and brought in a cake that said, "Happy Birthday". I was so surprised and overwhelmed to say the least. I had survived this ordeal so far. This is Day 5 that I will never forget (December 9, 2020).

Now it was a matter of waiting each day to see the count progression. There was little I could do at this point as I was very weak and still very swollen (further inhibiting mobility). I remember the anticipation each day, waiting for the morning shift nurse to come in and post my "count" numbers on the board from the blood taken during the night. Slowly, I mean excruciatingly slowly, with single digit increments my count was increasing and I was getting better!

During Stay 1 and Stay 2, there were a lot of rules imposed because of COVID-19, which complicated our stays in many ways. Linda was permitted to leave the hospital 1 day each week to go home for personal needs (laundry, rest, sleep in her own bed, take a bath, have a cocktail, check on the house, water her plants, etc.). She typically went home during the middle of the week and during Stay 1 it wasn't much of an issue as she would plan around any procedures or events. During Stay 2, and after December 9, I was still struggling as I had just started to "rebuild" my cell count and to get a little stronger, but I was still pretty much in crappy shape. On December 16, it was mid-week and time for a break for Linda to get her 1 day out of the hospital. Since I wasn't doing particularly well, I remember she didn't want to leave and even talked about going home just for a bit and then returning for the night. I really wanted her to get a break and some rest, it had been a long 2 weeks, and I

convinced her I would be fine, so she left for home late in the day. Although I spoke to her before I went to sleep, as it turns out things didn't go so well that night. Yep, the one night that she was gone (and had not wanted to leave). I remember waking up, maybe midnight or so, to go to the bathroom. I would do as usual, just sit up and then stand at the side of my bed and pee into the bottle hanging from the side. I woke up and I was literally soaking wet. You would have thought I took a shower in my long sleeve shirt (a dry wicking material). This had happened a few times before where I would simply wake Linda to get me a dry shirt to change into (I also remember keeping a dry shirt on the nightstand next to my bed so I wouldn't always have to wake her up when this happened). But this was soaking beyond anything I had experienced before. As I sat up in bed, I was sweating profusely and felt a little light-headed, but I was groggy and didn't give it another thought. As I started to stand up, my heart started racing and I quickly sat back down (thinking if I sat still for a moment, it would go down), but it just kept racing upwards and triggered the alarm bells at the nursing station. I was quickly over 100 BPM and climbing. When this happens, it also triggers hospital protocol. No matter what you say or do, the nurses go into full triage mode and the level of activity and number of bodies in the room just soars (I mean there are bodies in and out everywhere). They bring in a machine and take an EKG. They wheel in another machine and put a board under my back and take a chest x-ray. They give me some drugs, not sure what at the time. But nothing is working, as I am in A-Fib, my heart is Tachycardia and approaching something like 140 BPM. I remember that at some point they called Bass at home, probably around 1 a.m. He prescribed Amiodarone but I was still speeding down the highway uncontrollably. After something like 2 hours in this condition, and I know they were in constant contact with Bass

as he monitored my situation, he upped the dosage, and my heart finally kicked back down to a more normal level. I was able to sleep now for a few hours and left alone until the 7 a.m. morning nursing shift change without further incident. Yes, I had my cell phone and could have called Linda (I keep thinking the nurses asked me if I wanted them to reach out to her), but I decided there was no reason to wake her in the middle of the night as she would just come rushing down to the hospital. So, I waited until it was around 8 or 9 a.m. to call her and let her know what had happened. She was distraught and couldn't forgive herself as this happened the one night she was reluctantly gone. Just another wondrous experience to look back on and in hindsight just glad I didn't wind up in ICU or something worse. It did result in having the on-staff Cardiologist added to my list of doctors along with some heart medications. They weren't taking any chances at this point.

On December 20, I got another surprise (I say in jest) that falls under that list of things they don't tell you about (or at least I had no idea). As the nurse was checking on me, I stood up to pee (in my plastic container of course) and lost all control of my bowels. A quick reaction by the nurse to have me sit in a chair that had been put in the room with a catch bowl underneath avoided a complete catastrophe all over the room. I had apparently contracted "c-diff colitis", which is not uncommon during these treatments. This just added another layer of complexity to the situation. I was put on a drug regimen that requires you to orally shoot a liquid medicine into your mouth every day (it did not taste good) and catch your feces in a bowl that had to be sent to the lab every day to be tested until they determined I was improving and past the worst of this. It also meant that anytime, and I mean anytime anyone entered my room, even if only for a few minutes to check on me or to deliver food, they were required to "garb up" with a disposable surgical like cover/gown,

mask, hat, nets on shoes, etc. to protect the staff from contracting this disease. I gradually got past the worst and recovered from the c-diff.

Also, I was starting to experience a buildup of fluid in my abdomen and the swelling of my belly. I would later understand this is called "ascites". This resulted from my weakened liver and in combination with my weakened heart, their inability to process fluids normally. The fluids spilled out into the abdominal cavity and at some point, required me to undergo my first paracentesis (the first of several in December and many more over subsequent years). This is a common and mostly outpatient procedure that involves inserting a porous plastic tube (about a 6-inch needle like object) into your abdomen. It's just a poke (with a little numbing shot before) and it's hooked up to a tube that then hooks up to a vacuum jar that drains the fluid. Each bottle is 1.5 Liters (like a Coke bottle). I can remember that they would take anywhere from 3-5 Liters or sometimes even more from a single procedure. 1.5 Liters equates to 3.3 lbs. So, it was like an instant loss of 15-18 lbs. and an extreme source of relief from the internal pressure.

As December plodded along, it continued to be cold and dreary outside. I remember sitting on the couch and watching the moisture dripping down the windows from the difference in temperature inside the room. Every day we played the waiting game as my blood counts continued to increase towards that magic number. It seemed like an eternity now and we were just hoping for the day when Bass would tell us we could go home. I had reached the magic number (finally), but I kept having spikes in my temperature (considered anything above 90 degrees). Anytime you run a fever in the hospital it requires protocol, and they put you under close watch (and no Tylenol to bring it down as it must occur naturally).

The main concern with fever here is the risk of a bacterial infection. Every time I thought we were so close to being released; my fever would spike. There we sat every day on the edge of the couch, waiting for Bass to make his rounds (he might show up in the morning or not until the afternoon) and tell us we could go home.

We found ourselves on Christmas Eve still at the hospital. No real gift exchange, but one of the nurses was so kind that she brought us both wrapped little gifts (that were so appropriate after she had been with us over this period)> It was such a wonderful sentiment and feeling that this person did on her own accord. It's hard to say how much we appreciated this gesture as we never thought we would still be in the hospital, just the two of us at Christmas. We woke up on December 25, 2020, and after breakfast, Bass's partner came into the room for rounds with the team. I had not met him before. He is a big man, gregarious and wears cowboy boots and has a lot of character. He looked at me and said the magic words "how would you like to go home?" I could have kissed that man. This is Day 6 that I will never forget. We unhooked me (for the last time), packed up and checked out of the hospital. Christmas day. Hallelujah. We were finally home.

8

Home Again (and turning 60)

Once home, we were told I would have to quarantine for a few weeks. Still no kids or visitors. But it's great to be home. Great to be alive. Life was good, truly.

It's January 18, 2021 (my actual (first) birthday). I was turning 60. But on this truly momentous occasion, in my immune-compromised state, there was no venturing out or celebrating with friends. COVID-19 protocols remained in effect, but by this time our son Matt was able to join us in the house (all of us donning masks) and Leah joined us via Facetime from Austin (since it was during her final exams she was not able to join us at home). Our close friends Mike and Jill did a "drive by" birthday wish shouting from the car as I stood just outside the front door. As I walked into our family room, there stood a life-size cardboard cutout of my sister and brother-in-law (it was a little scary to be honest!) that had been sent to the house in advance (they had apparently conspired with Linda on this). We had ballons and decorations so we were able to celebrate together the best we could. Celebrating the milestone of turning 60 in such a subdued manner that I would have never anticipated before this journey, words can't express the gratitude and shear happiness of being home and the ability to see and be with my kids, knowing I was done with the hospital nightmares for now.

Turning 60 was just the beginning of a new lease on life. So many things to be thankful for, so many challenges ahead, but for 2021 all we could think about was getting back to some semblance of normalcy in our lives. This journey that started back in June 2020

had been long, exhausting and with a heavy burden. It was time to move forward.

I've talked about Linda throughout this book but merely scratched the surface as I never really go into all the harsh details and sacrifices, she made for me over these years dealing with this life-threatening turmoil (again, going way back to 2017). Looking back, I understand why there was this constant inquiry by medical staff from the beginning to ensure that I had an adequate and dedicated caretaker and how critically important this role is to anyone diagnosed with a life-threatening disease. I always say Linda is my "Rock", but she is so much more than that as my lifelong partner and without any exaggeration or stretch of the imagination I would not be writing this book today if it weren't for her efforts to be the first to literally identify my AL disease (before any doctors could reach a diagnosis), her tireless support, seeing me through all of the ups and downs and forcing me every day in the hospital to get up, get out of bed, get dressed and walk the floor (no matter what my mood or physical limitations were at points). For all these reasons and her support, I never quit being positive. I am eternally grateful to her and always will be.

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Why Me?

It didn't take long after I was home and adjusting back to a more "normal" routine when an old friend from my hometown (St. Louis) told me about another mutual friend that was diagnosed with cancer. This friend and I, we'll call him Sam, had known each other since childhood but we did not maintain any regular direct contact over the years. The time frame is around September 2021. I thought that if my experience could in any way provide some benefit to Sam I would reach out, which I did, first via text and then we spoke. During a call with Sam and his wife, I shared some of my experiences hoping to help them understand this crazy new world they were about to enter, things like how to prepare for what might be coming, treatment options, getting personal affairs in order and other action items they may not have been considering. Sam was diagnosed with a totally different type of cancer, a lymphoma, and was undergoing analysis and getting ready to start treatments using a vastly different medical regimen than what I had used, focused on a developing technology referred to as CAR-T therapy (chimeric antigen receptor or CAR) which as I loosely understand is used for a variety of conditions ranging from Autoimmune diseases to Large B-Cell Lymphoma and helps a patients T cells attached to a specific cancer cell antigen. This is done in a lab and then introduced back into the patient. Each CAR is made for a specific cancer antigen, so in rough lay terms it's customized for the type of cancer and specific cell treatment. This technology has developed rapidly over the past years and is commonly used today as a more targeted treatment protocol to treat a variety of cancers.

We kept in touch through the rest of 2021 and into 2022, mostly through text messages and some conversations as well. Linda and I were even able to visit Sam and his wife during a trip to St. Louis in March 2022, although with certain restrictions. Sam couldn't really leave his house at this point due to COVID-19, as well as being immunocompromised and fatigued, so we met outside and sat at a distance and talked. No hugs, handshakes or backslaps between old friends. But looking at each other it was heartfelt and enduring. After we left, I sensed things weren't really improving, and I couldn't help feeling that the prognosis wasn't great. Sam continued to decline over that summer, but I monitored his situation either directly or through other friends.

For over a year, Linda and I had planned a trip to Europe in September 2022 to take a river boat down the Danube River. We were maybe halfway through our trip and as would be typical, I would check emails, texts, etc. either late in the afternoon or evenings when back in our room on the boat with access to Wi-Fi. I got a text from my friend that Sam had passed away. Not surprising, really, but it hit me like a ton of bricks. I remember emotionally breaking down and saying to Linda, "why Sam and not me?" I wanted so badly to attend his funeral (which was 3 days later) but this would not be possible as our trip continued for another week or so. Unlike with other friends or people I had known who had succumbed to the ravages of cancer, I had been along for the ride with Sam, and it was just eating me up that I could not be present to honor Sam and pay my last respects. After this, I could not seem to get closure for the longest time.

Several years before this (2106), another friend of mine in Dallas had died of cancer. He was a colleague (a lawyer), mentor and friend for more than 20 years. Recalling our last conversation over

lunch just before he passed away, we were discussing some upcoming travel plans and I remember him looking me straight in the eyes and saying the most poignant and simple 2 words, “don’t wait”. “Don’t wait” indeed. The best advice ever when you think about it. I now find myself saying this to people all the time. Don’t wait to take that trip, to call that old friend, to go out to dinner with friends, get together with family, whatever it is you want or need to do. Don’t wait. I told this to Sam as well, but unfortunately in the end he would not be able to do all the things he wanted or would have loved to do with his family and friends.

After Sam passed away, my obsession with “why me?” never stopped. Why by the grace of God and all that is good in the universe was I spared and allowed to live? Why, I wondered, was Sam, this man who was my same age, had 3 adult children, a devoted wife and a successful business not spared and left to die? That question has haunted me since Sam’s death. Why are any of us (or those we know and love) plagued with these horrible diseases spared to live another day indeed? All these years after my personal journey through this uncontrollable jungle, and several years after Sam’s death, I now understand that there is no answer to my question.

It has taken me 64 years and a lot of “stuff” in my life to get me to the place I am today and to borrow a phrase, I have learned to “love the journey, not the destination”. As I read over and over in one of my favorite books about life perspectives, (again to borrow a quote) “today is not a dress rehearsal; it’s the only guarantee you get”. These days I’m just hopeful that there is another sunrise on the horizon and the gift of tomorrow.

About the Author

Mark Weintrub is a survivor of Multiple Myeloma and AL Amyloidosis and grew up in St. Louis, MO. He is a retired executive and attorney living in Plano, Texas, with his wife, Linda, with his wonderful children, Matthew and Leah both close by.