

# Seeking Shelter in His Refuge.... Finding, Facing and Fighting Amyloidosis

**Andrea Barshay Williams**

Greetings!

God put a desire on my heart to capture the last several years of my life and all that it encompassed on paper. When the spirit within you moves the process flows, and the result one would hope will be productive. Who will I offer this project to I wondered? It became clearer as time moved forward. There are three audiences listed below that I think this writing may serve. So, if you are choosing to continue on and take this journey, I sincerely wish that your investment in time proves to be a blessing. The journey of life is comprised of a web of obstacles, learning, opportunities, and growth in the following areas: physical, psychological, emotional, social and most importantly spiritual. Amyloidosis and my writing about it has certainly affected each of these areas in my life.

- 1- To my family and friends- I was very grateful for the many people who stood with me in whatever capacity, some from the inception of my hematology problems, others just catching wind of my issues at the transplant stage. I hope that reading my story will capture the lessons learned in my journey and that it will draw us even closer as friends and family while emphasizing something I never thought possible, that you can grow even in the belly of the whale.
- 2- To fellow patients and caretakers- I want to have something tangible to offer others who are and will be diagnosed with my disease, or a related blood disorder or go through a stem cell transplant. Sick people seek to find good doctors; being a strong productive patient is very important as well. I hope this personal story instills hope, encouragement, a little bit of wisdom, and practical advice for those patients reading it.
- 3- To medical professionals-The final purpose may be a fantasy but if said illusion ever materializes I want to make sure I am ready. I am so grateful that my disease was discovered early and it almost was not. When you read the story you will understand how the big picture was missed repeatedly. The difference between a late and early diagnosis with Amyloidosis is

literally life and death. In an effort to help more doctors be attuned to this fact and more apt to think about amyloidosis and concomitantly act on it, I will offer them Seeking Shelter in his Refuge... Finding Facing and Fighting Amyloidosis.

If after having read this story, you have any further suggestions as to how this writing could be used in a productive manner, please share your ideas with me. I remain very open to any potential positive uses that this story can generate.

It is the sincere hope of my heart that you will be unable to separate my story from the inextricable role my faith played in it. Many have remarked upon hearing what I have gone through that I am strong. I am not. Many have said that I am courageous. I am not. Whatever strength and courage on my part you may sense is simply a function of my getting out of the way and allowing my faith to sustain me.

None of us know what the next chapter of our lives hold. This becomes too real when you live with an incurable disorder. The future becomes just a bit different when you know the name of the adversary gunning to steal your life and also after you have done battle with him up close and personal. But whatever lies ahead I hope you will stand with me and pray that God gives me the courage, grace and strength to not only face it but to help others along the way. The depths of my soul and spirit wants nothing more than to pay forward all I have been given and all I have experienced.

Blessings,

Andrea

A.K.A. #TeamAndie

This book is dedicated to the handsomest man in all the land

This book is in memory of Ma and Pa Webster. Two every day Christian people who were obedient to the leading of God in their life and who loved a broken women into wholeness. Without them there would be no story to tell.

This book is written with the hopeful spirit and purpose that others will achieve early diagnosis and treatment for Amyloidosis.

Psalm 27

I am still confident of this:

I will see the goodness of the Lord in the land of the living.

And I did. I really did.

Andie B.

## Gratitude

How do you begin to say thank you to the many people who supported and prayed you through one of the most difficult times you could imagine? This seems an even larger task than the stem cell transplant I went through! There are some who were in my corner and whose names I don't even know. As the word spread people took my cause to their local church and laid me on the altar for the prayer warriors. There are people who continue to care and want the best for me. People who may not have known what to say but were cheering for me all the way anyway. I would hope that the way I will live my life and try to pay it forward will offer the greatest degree of thanks. I will try to acknowledge you guys with a collective thank you and some specific shout outs:

The Casteleiros mi familia por veinte y siete anos, The Otways and Alarm Ministires, the Williams' clan, Jenk, who held my hand in her heart and never missed one minute of each upswing nor one minute of each downturn from 1500 miles away (if they charged for texting we would be bankrupt), my Jenkins siblings especially Father Bill's Catholic Church, Linda ( who jumped in to love and pray) and Erik Sampson and their church, mi amiga Guiomar, Uncle Willie Boy and Ms. Claudette, Anne my favorite nurse and wedding planner. Noodle (who texted me to check every day) and Larry, Marcy, Marsha and the girls, The Lighthouse Church yes that means you Johnie, Garland, Eric and Kelly H., my MGUS pal Frances and brother Mike G., my Smoldering bud and mentor Dana, my amyloid mentors Kathy, Kim, Joanne and Barbara, Laila's mom, my NBA pal Lee, cousin Karen, cousin Abbe and Shelly, cousins Carolyn, Meechie and Lynn, Mini-Kitchens, my brother in law Kippy Boy, Denise and Beau, Linda from South Miami, the whole Racki family, Brian, Lidia, Tiffani and Lisa and all my adult Kids friends from Kids, Steve and Genna, Lesley, Charlene, Aznak, Burnie, Jimmy and Claudia Cool, Mr. and Mrs. Cromer, Sequim Carolyn (and her faithful letters in the spirit of Mom Buck) and Harlan, the Hines, Mumford and Graves family, Eric the master

Christian kitchen constructor, Eric the condo maintenance guy, some of our condo neighbors, all the Barshay cousins, Michael and Jackie Mumford their church, and everyone in Valdosta who joined in for prayer, Drs. Hoffman, Pereira, Wolinsky, Sandy, Pyle and Greenbaum, U. of M. transplant nursing team, The UPS Store in Weston, Christine and Paul, Jen my hairdresser who cut off all my hair with grace, love and mercy, Beth the money lady, Desouza and Alva, BG Mitch and Debbie, and all my new and old Facebook buddies who followed and rooted for me faithfully!

No one helped me more than the guy who never missed any of my doctor appointments who thought I was still pretty when I was bald, who washed away my terror with laughter, who after countless hours of listening about a disease that is super hard to understand, grew only to understand it simply because of the love he had in his heart for the person who had it, who was and is my caretaker, lover, friend and husband. He is the person who celebrated and cheered with me, consoled me in the dark moments, and kicked me in the butt when I wanted to run. In short when I dipped he dipped. I want to spend the rest of my life trying to repay him. Before this whole saga I thought I couldn't love him more. I was wrong.

It absolutely took a village.

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## CHAPTER 1 Could I Really be That Sick and Still Feel Okay?

I am grateful to tell the story of my journey in and through the world of hematology and blood dyscrasias. As I read the plight of so many of my comrades with amyloidosis, to be truthful, I have a bit of survivor's guilt. Had I not been blessed and guided in the manner that I was, or not had a really dedicated physician pay attention to my subtle signs and symptoms, then perhaps my story would have taken a much more dark and negative course. Hopefully I will be a case study or model of hopefulness, attesting to the merits of early detection and diagnosis. Though I will walk you through the journey, please take care to listen for the insights learned along the way for I believe that there is much learning here for both physician and patient.

Although I am 63 years old at the time of the telling of this story, the back story of my book started in 2012 when I was a young lass of 59. I had been a Christian for many years. My mind had never changed about my spiritual beliefs but my faith had grown cold from lack of use. I hope no one will be offended when I say I was not particularly fond of doctors and chose to have as little to do with them as possible, instead subscribing to an organic diet, regular exercise and managing several chronic conditions through lots and lots of supplements. The baggage I learned to carry every day was chronic Epstein Barr Virus, a multitude of orthopedic issues, (I was a former distance athlete in years gone by and had the injuries to bear witness to that), celiac disease, and other multiple food allergies, as well as bowel issues. **LESSON #1 There is a time for supplements and prevention. There is a time to fight disease with medicine. Know the difference.**

None of this stopped me from swimming laps for an hour and running three social service programs single handedly. I required a lot of maintenance to keep going but my compulsive personality lent itself to developing the necessary structure to keeping my problems at bay and functioning well. I had an older doctor nearing retirement who was very passive, never ran any lab work unless I requested it and never got very involved with me clinically. The mainstay of our relationship was



that he wrote notes to have me excused from hurricane duty. As a county worker I was required to work extensive shifts in a crisis, but was unable to because of my nightly need for 10 to 11 hours of sleep, rigid dietary needs and bowel problems. My relationship with this doctor, or so I thought at the time, was just perfect.

The first perfect storm occurred in October of 2012 when my doctor suddenly retired and left his patients hanging in the wind with no referral. This also coincided with the last vacation I would take for some time, wherein I felt very unwell and could not keep up with my husband. We decided I would see his doctor when we returned home. His doctor was very thorough and rigid, the former turning out to be my first miracle, the later a problem, as this MD was not compatible with my, at that time physician/ patient world view. This doctor insisted on running extensive labs. I had probably not had a CBC for 5 to 7 years. The results came back all out of whack and it was agreed that I had probably been fighting some type of virus. Several weeks later as I was feeling better the next set of labs had corrected themselves with one glaring exception, my urine protein was still elevated. At that point I had already decided to look for a doctor who was a little less controlling. I found a doctor in my neighborhood who seemed more flexible and to my liking. She had me redo the labs as it was now several months later. Again perfect labs with only one deviance; the urine tested positive for protein. She was extremely puzzled as my other kidney markers, GFR and creatinine were excellent. I was of normal weight, normal blood pressure, no signs of diabetes, so in essence there were no risk factors for kidney problems. She began to suggest a visit to a nephrologist. Not really believing I had any kidney problems, (man I drank a half gallon of bottled water daily), I tried to buy some time and convinced her to run the test in several months one more time. When the test came back positive for protein I knew it was time to go.

My husband had some mild kidney issues so I again took a referral from him and went to his nephrologist. A low key guy this doctor was puzzled as well. His summary speech went like this, "We may never know why you are testing high, or you could have had an insult that mildly damaged your kidneys or this could be the beginning sign of one of 5 dread diseases. I will run tests", he told me. When I returned he told me I was fine and since the protein was less than 1000 he would monitor me every 6 months. Relieved to be okay I glanced at the labs superficially

before just filing them away. It was not until much later in the game that I would go back and review those labs and see that there was a B cell irregularity that should have prompted further testing. Instead he buried the lab work in my folder and either ignored or missed the results that would eventually rock my world.

**Lesson #2 Review your labs and confront your doctor directly with anything that is not in the normal range.** (I don't know why I neglected myself in this way as actually my husband's doctor had buried his abnormal PSA labs without reading them and it was my diligence to review them that revealed he had cancer in 2003). But not knowing this at the time I continued to see the same nephrologist. Had I just stayed put with this guy he would have continued to test my urine protein and because there would be an absence of other signs, delay my hematology diagnosis by years.

However it started to gnaw at me that something was wrong with my kidneys. There was no progression in symptoms or protein levels. However, I started feeling that it was not normal to be leaking protein. I never leaked protein before and now I was 60 years old and I wanted to take good care of myself and didn't want anything to happen to my kidneys. I thank God I yielded to those inner stirrings and did not dismiss them. **LESSON #3 Pay attention and honor your feelings. If something doesn't feel right don't dismiss it, act on it.** As a side note since we are telling the truth here, I did not return to this doctor after several months with him. Instead of calling me to ask why I had stopped coming, he sent a letter to my primary doctor stating I had 4<sup>th</sup> stage kidney disease and was missing in action?? Excuse me check your chart buddy, I am the lady with great kidney function. And when it eventually came to light that I had a blood dyscrasia and he had missed the telltale lab I wrote him a respectful letter to inform him. But Mr. I'm so concerned about you but have all the wrong information about you, failed to respond or take responsibility for his costly error. **Lesson # 4 Do not, I say do not stay with negligent inadequate doctors** I felt really angry with this guy but guidance from the Lord coupled with the pursuit of my health enabled me to move forward and let go of my bad feelings. No time for negativity.

This prompted me to contact my friend who is a nurse and she referred me to a nephrologist at the Cleveland Clinic. In the summer of 2013 I met with the Cleveland Clinic doctor and she told me she would do her best but might not be able to discover the etiology of the mysterious leaking protein. I remember the

day well Friday September 20, 2013. The day when your life as you knew it no longer ceases to be. My plan was to run into the Cleveland Clinic, receive my lab results have the doctor tell me that I was leaking protein and she couldn't figure out why. Then I would dash to work and continue on. The mind of man plans but God directs the step.

When I arrived, the doctor pulled my chart up on the computer and stepped out for a minute and curiously I walked over to peer at my chart. Nothing prepared me to read Rule out Multiple Myeloma with my name on the page. Multiple Myeloma is an incurable blood cancer. I was traumatized in an instant and would not return to the self I recognized for a very long time. The doctor came in and told me, "We got some results we weren't expecting. You have a hematology problem not a kidney problem." I had landed in another universe and no one had even given me a passport. I was so unprepared for this news I found myself screaming at the doctor in disbelief. I would be convicted about my behavior and apologize many times in the future to which she graciously understood and accepted.

Although I have advanced degrees, my first of many new words was added to my vocabulary that day, Kappa free light chains. This new word haunted me and would become an integral word in my life, determining if I was to live or die in accordance to the level of the light chains. She gave me a referral to a hematologist and I made my way to work in shock. I locked myself in my office and tried to process this news. Did I have cancer? I couldn't have cancer. I ate all organic, didn't smoke or drink, ate no processed food, took a ton of vitamins, and had exercised all my life. I could not see clients that day but started a full court computer press to research multiple myeloma.

I shared the shocking news with my husband and close friends. I responded emotionally with abject terror and anxiety. The hematologist at Cleveland Clinic could not see me for 3 months and did not respond to my nephrologist's attempts to push me in earlier. The level of angst and dread I was experiencing would not allow me to wait 3 months for an appointment without serious loss of my remaining sanity. My old reliable nursing friend found me a local hematologist who would see me in several weeks. His office was a factory for hematology patients. I was repulsed by the patients lined up to have their fingers stuck with

no privacy and the toxic waste can overflowing. My terror increased as I walked by the chemo wing with the masses all lined up like they were giving something away. The doctor broke down the difference between MGUS, (MGUS is not as serious as myeloma) and myeloma. He thought I had MGUS not myeloma but could not be totally sure unless I had a bone marrow biopsy. "Do the biopsy", I shouted, scared but needing to know.

In the meantime I had resumed working but found myself very preoccupied, detached, unfocused and nervous. Not very good characteristics for someone in the helping profession. I started seeing a counselor. It seemed this recent news coupled with the stress of the many disorders I was already managing was just overwhelming and I felt myself slowly toppling. A normal workaholic I had about 12 weeks of sick time and knew I needed a break. I could not continue to deal with a very draining client population while I was riddled with fear about my own welfare. It was too much for me to carry and remain emotionally present for those who needed me. I was so out of mind, all I wanted to do was research my condition. **LESSON #5 Take care of yourself. Only you can ask for and do what you need to do for yourself to take good self-care. Do not delegate this responsibility to others.** I stopped working in early October of 2013 and went on a medical leave; the bone marrow biopsy was set for the end of October.

Meanwhile my husband was becoming increasingly critical. I did not realize at the time it was difficult for him to see my normally powerful demeanor crumpling into a basket of tears and fears. We turned the corner when I had to come up in his face and curse him out for judging my flailing coping skills. "That's my girl", he responded with a smile. Now I understood him a little better. A bone marrow biopsy seemed to be very invasive as I had only had a D and C previously, no other history of surgeries or hospital admissions. Tensions were running high the day of the test and my husband overslept and could not accompany me but got yelled at royally when he eventually showed up late in the doctor's office. The procedure was a piece of cake.

The next 2 weeks after the bone marrow biopsy matriculated me into my PHD program which included a major in waiting for test results. I was pleading with God for my life, but drawing closer to Him spiritually, surrendering whatever was left of my formerly boring routine life that seemed to have been blasted out of

hibernation. My spiritual surrender led me to rededicate myself to my faith, the best decision I could have made. That faith would sustain me in this new race I was running. My spiritual life consisted now of cleaving to God in fear. However, I have learned that if you hang tight with God, He is faithful to peel the layers and bring you to deeper and better places of spiritual relationship. I longed to be better in that way and I am pretty sure that counts for something. That was the best I was capable of at that time.

Constant labs and other testing becomes the hematology patient's life. The waiting period for results to come in can be excruciatingly tense. Not skilled at this the first year of my disease, I was actually making myself sicker by the pre-result terror I was inflicting on my mind and body. I was withdrawing from others until I could get a grasp on what was happening to me. I had no idea how long that would take. The hematology patient must develop skills to deal with the waiting period between giving a specimen and receiving the results that determine if you are moving a little closer to life or a little closer to death. **LESSON #6 Accept the hole you have fallen in. Stop doing self- defeating behaviors that make things worse.**

For an academically bright person I was being reduced to a kindergartener's level of behavior. It must have taken me a full year to realize that panic, which seemed to be the innate right thing to do, was not helping me nor changing my circumstances. In fact these behaviors were causing me to deteriorate. Upon realization of this, I determined that I couldn't change a lot about my situation. But I resolved I would do everything to get out of my own way. From that point forward, I realistically evaluated each of my reactions and purposely determined to stop the negative self- defeating ones.

## CHAPTER 2 It Has a Name

In mid- November the biopsy results came in. I did not have myeloma. I had MGUS (monoclonal gammopathy of an undetermined significance). Leave it to me to have such a complicated name for my condition! I was elated. The doctor gave me a bare bones dog and pony show about the differences between MGUS and myeloma. It seems MGUS was a precursor state requiring no treatment just monitoring. MGUS could or could not evolve into myeloma which as previously discussed is a blood cancer. Curiously no mention was made of the smoldering category, amyloidosis (especially since I was a light chain only case), or the three tier risk strata for progression. I had a chromosome 13 deletion as I was told, whatever that was supposed to mean. I was placed on a 3 month recall and we left the office cheering.

It was at about the same time that I enrolled in an online MGUS Facebook support and information group. These guys would educate the crap out of me and lead me to another miraculous occurrence. I was learning so much from these groups and free to ask them anything on my bottomless list of questions, and oh by the way, did I say they were not just knowledgeable but supportive and caring. For

the next 6 months I would see this same doctor. My disease markers stayed stable with the only 2 signs I had that something was wrong, protein in the urine and an elevated Kappa free light chain level. It is sad to say that the doctor was kind and pleasant but did not think it was his job to educate me about my condition and even refused to let me tape our sessions. **Lesson #7 Do not mistake a kind gentle approach for an intelligent current effective doctor. Find yourself someone who is caring, well versed in current trends and a wellspring of information. You deserve this; your disease demands it.** This would have prevented me from advocating for myself had I stayed with this doctor. It is sad to say that I was learning and growing much more from my participation in my on line groups than with my doctor. But at this point in the ballgame I felt safe with this doctor partly in fact since he had delivered the good news that I only had MGUS.

It was now November and I was due back at work before Christmas. A period of serious reflection ensued. I weighed the following factors: I was now at risk for an incurable blood cancer (multiple myeloma). I was almost 61 years old about a year away from full retirement in my work system. I still very much loved being a therapist. I had done psychotherapy for 34 non- stop years and although I could still hold a full time job down it was getting increasingly more difficult to do so. I faced the fact that I was slowly running out of gas. I really didn't know if stress versus a rest and self- care approach would make a difference in my outcome related to progression. But I decided to err on the side of caution and knew slowing down could at least strengthen my beleaguered immune system in case I had to gear up for a fight. I prayed and prayed. I had a strong peace in my heart that retirement was the right option. In fact whenever I entertained even a brief notion of returning to work a darkness would engulf me. It felt like returning would be going against the grain. The Holy Spirit was making my path very clear. I had several licenses so the option to re-enter the work force part time would still be open to me. In early December with tears in my eyes I informed my employer I would retire from my beloved profession. In just 3 short months the face of my life wore a very different profile.

My research at this point in time was focused on natural approaches to warding off progression. Thinking about future medications or chemotherapy is a tough nut for anybody to swallow but for an organic purist it is blasphemy and

sacrilegious. My readings initially took me into the world of curcumin a natural herb known to do many wonderful things but most importantly decrease light chain activity in people with blood disorders. The studies said that eight grams daily was the recommended usage for people in my situation. That my friends is a ton of curcumin. I could not stomach that much. Also, I rationalized that I was not sick yet so 3 to 5 grams daily seemed enough. I would save the big guns for later if I needed it. Anyway because curcumin has poor bioavailability, it is recommended to take the capsule immersed in fat. I had to open the capsules and mix them in oil. What they neglected to tell you is that curcumin stains everything bright yellow. I mean bright yellow and I mean everything! For the two years I would take this substance, my countertops, computer devices, hands, underwear, floors, socks etc. were yellow. My grandkids came for a visit and were very puzzled over the yellow tinge they found everywhere. My good natured husband never complained, in fact he always joked about it. Both of us believed that the yellow stuff was possibly saving my life. I also did a lot of studying about proteolytic enzymes following this protocol from a famous alternative cancer treatment doctor. I began ingesting up to 50 enzymes daily. I took other things known to have good effects on my condition such as green tea, B12, Vitamin K, resveratrol, wheat grass, butyrate, and a prescription for low dose naltrexone. I had confidence at this time that my strategy could keep me on the positive side of my disease. I was to learn what I stated in Lesson 1 earlier, know the difference between when to use a prevention protocol and when to implement medication to fight disease. Prevention was not going to be able to get me all the way down the road.

Somewhere in the spring of 2014 we hit the second perfect storm. The doctor at the hematology clinic was leaving. In his place I was assigned to a doctor new to the field of hematology, a recent convert from internal medicine. Next, upon returning from a visit to Tallahassee in April the strangest thing occurred, both of my eyelids hemorrhaged and I looked like I had 2 black eyes. My husband who is black joked with me, "Don't you pull the race card on me as someone will think you are a victim of domestic violence." We laughed. We thought it was funny. It certainly couldn't be anything serious. We rationalized it was a product of my dry eyes, coupled with blepharitis, and allergies and the tremendous pollen in Tallahassee. We went back in May and it happened again. Still not unnerved by



this new symptom, I then read in my online information group that peri- orbital purpura which was described as exactly what my eyelids looked like was a sign of amyloidosis. Now I was concerned. The timing of this on line revelation and the occurrence of the new eyelid symptom, in retrospect, were not coincidental they were to me miraculous.

I had been waging war the past 8 months fighting progression to myeloma and now I could have amyloidosis. I DID NOT WANT TO HAVE AMYLOIDOSIS. In my mental economy I reckoned I had my fair share of problems, but apparently I guess I had not yet reached my ceiling. I ran as fast as I could to my new hematologist. He reassured me and told me there was a very low likelihood that I did have amyloids. He told me there were other etiologies for peri-orbital purpura apart from amyloids, but he couldn't tell me what they were. My research in the coming months told me amyloidosis was the only etiology for my eye symptoms especially in a person with light chain plasma problems. But my terror and fear and denial just wanted to hide inside the doctors uninformed reassurances. During the next few months I had my bone marrow retested for amyloids, a special cardiac test looking for amyloids, as well as an eyelid biopsy searching for the same demon. All the tests were negative. The tests however, only owned a 50% accuracy rate. The exhale of relief I breathed only lasted for a minute.

The hematologist kept reassuring me I was okay. But although I was afraid to verbalize it, my mind could not delete the file that continued to tell me there was no other cause for my eyelids apart from amyloids. I clung to my novice MD and co-signed his ignorance... If he wasn't concerned why should I be worried? My denial blocked out what my gut couldn't shake off. Seeking answers I was not getting from my hematologist, I went for consults to a dermatologist and an ophthalmologist. Both dismissed my eyelids as allergies telling me it was not amyloidosis. **LESSON #8 Don't allow your fear to blind you from facing what is happening to you and knowing the truth. Nothing is worse than having this disease than having it and not knowing it.**

My labs continued to stay stable but other incongruences started to surface over the questionable mastery my M.D. had of his chosen specialty. When I asked him why I had albumin in my urine and not just bence- jones protein he said I probably had kidney damage. The nephrologist said there was no damage; I had excellent

kidney function. Later I was to learn that albumin in the urine is an associated sign of amyloidosis. This hematologist did not know this. I asked him about the three tier risk of progression that all MGUS patients are evaluated on. The doctor told me there was no such thing. Why had I read 12 journal articles on this topic? Why was it common knowledge amongst all MGUS patients? I did not understand when I asked about having a fat pad biopsy to rule out amyloidosis, (which had an 80% accuracy rate as opposed to the 50% rate of the tests I had done), he wanted to defer until I had cardiac symptoms. I was so afraid of having amyloidosis that at that time his strategy actually made sense to me!! The last straw was when the doctor began to tell me that he could not answer a lot of my sophisticated questions because his responses would be beyond my comprehension. But if I was bright enough to formulate the question why would I not be smart enough to understand the answers...or as I started to realize he just did not know the answers.

God sends us help in many forms. It is not easy to keep an open mind to assistance that may knock on your door in a form you never anticipated. Thank you Dana Holmes for banging down my door. You were an integral piece of the pie in saving my life. Negotiating a serious disease also requires one to use discretion to weigh input and advice that may be wrong or incorrect. It seems to be a cruel trick that in the midst of our most stressful periods we are also required to grow and come out of our old patterns and hiding places. The stress of serious disease and all the existential issues it brings has a way of causing this. My disillusionment was growing with my current physician. I was concerned about my eyelids. I developed a band aid solution by applying a ton of Vaseline to my eyelids daily; this did not cure them but prevented me from facing the hemorrhaging. My protein and kappa light chain levels remained steady so I gleaned an undue level of confidence from that and bragged to my support group that I am light chain only. Dana one of the most dedicated and knowledgeable soldiers in the fight against myeloma and amyloidosis wasn't buying my story. In fact she had the nerve after listening to me discuss what was happening to strongly suggest I seek a better doctor. This lady is a loveable pit-bull who will dog you until you take proper care of yourself. I fought her tooth and nail on the outside but inside I slowly realized she was right.

I had no idea where I would go to look for a better doctor. What about the hematologist I was first referred to at the Cleveland Clinic who had a 3 month waiting period? I called and checked into that and she was available in September of 2014. Perfect. When the hospital sent me instructions on how to prepare for my appointment with this doctor they neglected to tell me to wear a full set of armor. No one let on that my appointment would include a full fledged verbal assault following the bomb that the doctor would also detonate. Unarmed and unaware of what I was walking into I came to my appointment as scheduled. I was like a lamb being led to the slaughter.

Cold and rude from the onset she made negative remarks about having to shake my hand. She began speaking so rapidly I could not understand her and when asked politely to slow down, she began to roll her eyes back in annoyance. This was a behavior she would continue throughout the entire appointment. She did not slow her speech and seemed to care less that I could not understand her. Although I appeared to be a stable MGUS case, she referred to me as a myeloma patient. She seemed resigned and even arrogantly anticipating that I would be a cancer patient soon. In fact, although up to this point I had been given a positive prognosis, and had many stable months of lab tests she told me I would get cancer. She seemed so sure I almost expected her to drag me back there right then and hook me up to chemotherapy. When I tried to object and tell her of the other positive opinions previously offered to me, she began to yell at me over and over, "You can't handle the truth." Each time she barked that phrase at me it felt like she shot me right between the eyes. It wasn't very pretty. In 45 minutes she seemed to beat me down emotionally and spiritually. She robbed me of any hope and crushed my spirit in just one visit. She walked out of the office leaving me a casualty of her horrible ethics and aggressive and abrasive bedside manner. Her nurse tried to glue me back together. She wanted to see me again in 3 months. Did I look that crazy to actually return and pay another 50 dollar copayment for a second round of abuse? My thought process was I may not be able to control what happens to me with this disease but I damn sure will not choose to voluntarily place myself under her watch. Hell I was still relatively healthy and she destroyed me in 45 minutes. Can you imagine her impact if I was already ill?

It took me a full week to recover from the trauma this woman unnecessarily inflicted on me. To this day I remain conflicted about my decision not to report

this woman. At the time, I wanted to let go of all negativity and press on refocusing on me and my health. But I must wonder about all the innocent patients behind me I failed to try to protect. Hard decisions. **Lesson #9 No one has the right to treat you in a negative, disrespectful, or condescending manner no matter what their credentials are. Never let anyone rob you of your hope and integrity. Being sick demands better behavior from others not worse.**

I would like to mention that I had also stopped around May of 2014 seeing the counselor I had started with a year prior. He had held my hand through the initial crisis period, but my sessions with him revealed no growth and I felt locked into a pattern of just venting and going nowhere. I began to dread seeing him and knew it was time to move on. I had also decided that I wanted a faith based therapist, one with a working knowledge of the Scriptures. I was determined not to leave God out of the equation. My thrust into the world of hematology had caused deep issues to surface and I wanted to seek answers with the Scriptures as my guide. I began to experience a hole in my spirit that was only being filled by voraciously reading the Scriptures. This nasty doctor ignited the fuel in my desire to return to therapy.

I could not find a Christian therapist on my insurance plan. I got a lead to find some Christian counseling through 2 former church friends whom I had reconnected with on Facebook. I poured out my case to the counseling pastor my friends recommended. The church did not take insurance and I was already 47,000\$ out of pocket for medical costs. They would waive the fee as a reciprocal gesture since I was in the field. I had spent my life caring for the wounded and now fitting that description myself, God had provided refuge. Thank you Jesus! I would form a good bond with my new counselor and would find a better sense of Godly direction as well.

After I regrouped from the Cleveland Clinic consult I was lost as to what direction to go. I had ruled out returning for further abuse with the last doctor who beat me up and did not want to return to my current hematologist as with all due humility, I was beginning to feel as if I had more accurate and current information than he did. You have to kiss a lot of frogs in life when you are dating and looking for your prince. I guess the same is true as you search for the right doctor. The only difference is the stakes are much higher, and the clock may be ticking as far

as progression of your disease goes. Be mindful of this while you hunt around for the right doctor. Be aware that as disease progression occurs you may not have the stability and wherewithal to endure the courtship process. So in some cases the search for a good doctor may take an urgency, but never let it be a task you put off or procrastinate doing. Placing yourself under the wrong doctor's care could also be frustrating, draining and counterproductive with possible negative consequences.

Not knowing where to turn I opened up to the one person I knew who had a solid knowledge base and excellent intentions and motivations. Dana Holmes. Dana told me about the Mayo clinic in Jacksonville some 350 miles away. But she also mentioned one doctor she knew of, who was local and had a very good reputation. That doctor was James Hoffman. That was the lead that would change my life. I researched this James Hoffman and I was impressed with his credentials and his knowledge base. He was attached to the University of Miami another good selling point. But what locked up the deal were the reviews I read on line about this man. Each one detailed his compassion, genuineness and direct caring approach. I knew I would need those personal characteristics just as much as his expertise in the field of hematology especially if I were to progress. Since I recently had taken labs and all appeared stable I set the appointment for December 18, 2014 some 3 months forward. From the moment I made the appointment I knew I was headed in the right direction and a peace came over me. I was beginning to rest in a well-made decision. Maybe just maybe I was about to meet my partner in the war against my blood dyscrasia.

## CHAPTER 3 Toto I Have a Feeling We're Not in Kansas Anymore

I was both excited and nervous about my first appointment with Dr. Hoffman. The experience in person proved to be every bit as good as it had looked on paper. Personable, kind but real, smart, current and sharp, not threatened but impressed by my knowledge base, Hoffman was a great score. Unlike my very first doctor, Hoffman did think it was a part of his job to answer all my questions and establish a partnership with me in this treatment process. To that end he sat focused and determined to address every question and issue on my lengthy list. He took so much time with me I was tempted to offer two co-payments that day. While you can afford to have mediocre doctors in some circumstances when you hit the big leagues of hematology problems nothing but the best most up to date doctors will suffice. Because of my fears of amyloidosis I minimized my inner concerns while briefly mentioning my eyelid situation. Hoffman showed no dire concerns about my condition at this point in time. At the end of the visit I was to be kept on 3 month recall labs and face to face visits every 6 months and deemed to be stable.

**LESSON #10 Trust in the Lord with all your heart. Lean not to your own understanding. Acknowledge Him in all your ways and He will direct your path.**

Sometimes, you may not know in advance that the road will go south before you reroute into a better direction. If you have contracted with a Good Driver to take the wheel the stress will be much less and maybe just maybe you can even find some peace in the free fall moments.

During the next 5 or 6 months life seemed to be as “normal “as I had experienced since that fateful day in 2013 when I learned of my MGUS condition. I felt safe and protected under Hoffman’s wing. My anxiety was markedly less and I had some degree of joy and engaged in planning of future events. My behavior and attitude seemed to suggest that I was starting to believe that maybe I wasn’t going to die, maybe at least not right away. The February labs came and with it

came hand in hand my usual surge in spiritual intensity. Hitting the floor, seeking God, and finding the courage to just open the results remained my usual pattern. I must tell you that I had memorized every lab value for every testing period since my inception to this disease. But the labs remained stable. I had received another 3 month reprieve to live.

The next visit to see Hoffman was for June 4, 2015. In mid-May I attended the birthday party of a set of twins who were turning 10 years old. I absolutely love these girls. I love their sister Jojo too. We were at a loud venue and I lost my voice and for weeks my voice would not return. I also started to have minor difficulties swallowing and a dry mouth and throat that woke me up all night long. I saw an ENT who scoped my throat and told me the problem was NOT amyloids. That made me feel a lot better but I had no idea what was going on. I now had 4 doctors telling me I did not have amyloids. I spoke a lot less and my husband became happy. The labs for the June 4<sup>th</sup> visit were done in late May. This time my harassment of God was not as successful, as my kappa free light chains, the little demon clonal population causing this problem in the first place rose about 100 points. I was in a frenzied panic. My security in life had become the serum level of these light chains rather than the God I served. All my success in learning to live in the moment eroded as I opened the Quest results. June 4<sup>th</sup> could not come fast enough. What would Hoffman think?

Little did I know that things were really going to heat up. Several things happened at the office visit on June 4<sup>th</sup>. First Hoffman was not concerned about the 100 point rise as all the other markers were stable. I convinced him to retake the test again in June and not to hold you in suspense the results indicated that the light chains dropped the 100 points and returned to their former level. Yay or so I thought. Dr. Hoffman at our office visit casually asked me to open my mouth and took a look at my mouth and tongue. He did not mention a small change he observed but told me it would be a good idea for me to get a fat pad biopsy before I returned in December. That small change he observed was some mild ridging starting on the sides of my tongue. In the current medical climate there are doctors failing to make or even think about an amyloidosis diagnosis when gross symptomology of the disease is screaming in the doctor's face. I had a physician so in tune with the subtleties of amyloidosis he could sense its' presence blindfolded.

Please recall that a fat pad biopsy is the most accurate test to test for amyloidosis. He told me getting the test was not an emergency and led me to believe it was just protocol. "Let's just be thorough as you are a light chain case", he instructed me. Who could fight with that? I left the office that day totally unaware that Dr. James Hoffman had just saved my life. In retrospect, I believe that God had ordered my steps and authored the events that led to this point in the story. Response to prayer takes many forms.

Being a compulsive personality I wanted to get the test off my plate so I set it up for July. I went to Memorial Hospital on July 27<sup>th</sup>, 2015. I joked with the technician and the doctor that this was my 4<sup>th</sup> test looking for amyloids. "The first 3 were negative", I told them. The medical team there declared, "And so shall this fourth test be." You cannot simply wish something into existence. I did not know how long it would take to receive the results from the fat pad biopsy. An ominous cloud hung over me as I waited for results. You would think that two years into this process I would have gotten a little better doing the waiting thing. You do get used to it; maybe the fear and dread diminishes as time goes by but the tension is difficult to dispel. When I actively rely and focus on the God of Psalm 27, Wait for the Lord, be strong and take heart and wait for the Lord, I am better no matter the outcome.

On July 29<sup>th</sup>, 2015 at 10AM the phone rang and I just knew intuitively it was about the fat pad biopsy results. It was Hoffman's assistant on the phone and in a matter of fact voice, as if she was informing me they were out of Snickers and I would have to eat Milky Way, she delivered the news. "You have amyloidosis, the test is positive for amyloids". My heart sank, my brain went numb, and my body flushed from head to toe with anxiety. All I could think to say was, "Are you sure?" "Yes they were sure", but she said they would get the specimen from Memorial and test it again. She tried to tell me it was not a death sentence but I did not believe her. Hoffman called me later that day to confirm the results and inform me he was going on vacation. An appointment was scheduled for August 24<sup>th</sup> as soon as he returned. He echoed it was not a death sentence. He asked me not to go on the Internet while he was gone, a promise I would break almost as soon as I made it. In the back of my mind I had always suspected I had amyloidosis, because of my discovery that there is nothing else that can cause eyelid purpura. Thinking you may have a disease and then actually being



diagnosed with it are two very different things. Amyloidosis is not only a very rare blood disorder but creates another big problem. Because the amyloids are insoluble, they can damage major organs in the body. It is not cancer but it is treated like cancer. **LESSON #11 Procrastination is not a good thing when dealing with Amyloidosis.** I was a very long way away from realizing that something good had occurred that day in my not putting off the test and finding out when I did that I actually had this dreaded disease. You could have never convinced me at that moment, what some time and space would eventually help me to realize.

The next week was a blur. As I fell apart in my husband's arms, his cool and caring demeanor informed me we would meet this mountain together and fight it. I knew this guy loved me the past 17 years but the coming year would show me his depth of strength of character, commitment, devotion and love previously suspected. Now what I believed about our relationship would become indelibly inscribed in my heart and personally experienced in many awesome ways. What had I done to deserve such a wonderful man to be my husband?

My step daughter texted me giving me permission to fall apart but to then get up and fight. Confused I asked myself is that what you're supposed to do? A sucker punch of this magnitude leaves you dazed and bewildered. When I informed several of my best friends, they committed themselves to pray me through this. My anger started to rise in the infancy of processing this amyloidosis news. Don't pray I wanted to scream just change it. As I stumbled around in shock trying to live what used to be my life for the next few weeks, it was a dear friend who is my massage therapist whose advice put a dent in my tailspin and helped me to start the process of landing back on Earth. "It is already here", she would tell me repeatedly. If it is already here then there was no sense in struggling. Apparently I was not getting a vote in whether or not I had this disease. This advice helped me to begin to shift gears from the watch and wait world of MGUS. The denial and fear that had previously served me would no longer be appropriate skills. The enemy had arrived and declared itself in certainty. I would need to accept, fight, and press forward.

The few weeks I had before Hoffman's return coupled with the advice I received, started to prepare me for the action I would need to take. My prayer life took an

active turn graduating from passive prayer and Bible reading to an active letting go, surrender, reliance and a trust for this God I had pledged myself to so many years before. I was to learn that truly connecting with my Creator would be all about my heart not my words. While in the MGUS stage I still had the illusion that I had some control, that perhaps my supplements and self-care could affect the outcome. Maybe that belief was the source of my anxiety that if I did the right things I could make a difference. I don't know. Now I was so far out of my league buried in a problem so big I had no thoughts of self- efficacy. I was squarely in God's hands and wherever we were going we were going together. So although the stakes had risen considerably this was the start of a peace I would experience that I still do not fully comprehend. I believe this same peace is more than adequately described in Philippians 4 verse 7 of the Bible, as the peace that passes all understanding.

You won't believe what happens next, in the middle of this great turmoil. We had been saving for years to have our 35 year old kitchen remodeled. The remodel was due to start 2 weeks after I received my earthshaking diagnosis. Needless to say we were very mixed up about whether or not to proceed. This was a 3 to 4 week project. I was uprooted emotionally and physically by my health problems, why not have the house match my situation? One factor that weighed heavily in what we would do, was we didn't know for sure if the treatment I was facing would make me sick. We wanted to have a clean kitchen for that reason. The future was up in the air and we didn't know when we would be able to reschedule. Maybe it would be just the perfect distraction until Hoffman got back. By default it was a go. The contractor who is a consummate kitchen remodeler had to deal with me in my very raw state and did just as well with that task as his cabinetry work. Eric Bright, the kitchen contractor, is my old Christian buddy from my first church some thirty five years ago. We had been looking forward to this job helping us catch up with one another. It was a very different experience between us than what we first anticipated but Eric handled me with grace and kindness. Thank you buddy.

During this interim period between diagnosis and my August 24<sup>th</sup> appointment with Hoffman, Dana again was an invaluable resource. She hooked me up on Facebook with two new support groups; I definitely had outgrown the MGUS world. I asked questions in my new group with an insatiable thirst. I met what

appeared to me to be the most incredible women who jumped right in to support, assist and care for me. They did not know me but their concern and commitment felt a lot like love. Although I was not anywhere near my normal self I was perceptive enough to sense a deep sense of wanting to pay it forward motivating each of my newfound friends. You could call on them anytime, ask them anything and they would do their very best to respond in full. I wondered if I could ever become like them. They set the bar very high. Were they all such solid characters to start with, or had the amyloidosis coupled with the stem cell transplant process itself molded them into vessels of gold? I promised that if I was granted the opportunity to continue to live I would do my best to help others who suffered with my disease.

Before I proceed with my medical and treatment path I would like to pursue a side road and talk a little bit about support. I am certainly old enough to have experienced and know that drama and tragedy in life have a natural ability to selectively purge the outliers from one's resume of family and friends. People who are very marginally concerned about you may just naturally drift away when you are not able to fulfill your usual obligations or if they perceive you might be in need of or require more of them than they wish to give. But my current dance with amyloidosis would school me in other ways.

We all have people in our lives that are toxic for us but we continue to try to deal and manage. In times of normal everyday living perhaps the drain from these types of relationships is tolerable. When a serious disease knocks on your door and a potential fight for your life follows you can no longer allow folks who are toxic to you and for you to continue to hurt, damage or abuse you. It becomes a matter of survival and good mental health practices. So to prepare myself for his usual caustic remarks, I waited a month to inform my very nasty and mean spirited brother of my new circumstances. He responded in the same hurtful, uncaring and belittling manner that he does whenever I am vulnerable. It seems almost blasphemous in my code of ethics to be frightened about what course your disease will take your life in, but unable to focus on those very real concerns because you are nursing unnecessary wounds inflicted by someone who doesn't like you or care about you. It didn't seem fair for him to do this now but on the other hand his treatment of me has always been consistently painful. My only sin was informing him of being ill and facing treatment, not requiring or asking

anything of him. The gift I got from amyloidosis was the realization that there is no room for people in my life anymore who cannot offer me a minimum of human decency. I determined that when I came through this I would say goodbye to someone I should have said farewell to at least 20 years ago. And just to let you know that, I did so in March of 2016 in a very respectful but firm manner. This enables me to keep a clean spirit towards him and wish him well in my heart. It feels good to take care of yourself.

**LESSON #12 Be prepared to lose some people but realize that the people who truly love you are not going anywhere.** But on the other side of the coin your disease if you allow it will open some doors to bring some fantastic people in your life. I must share with you how many great people I have met through this journey. I am a little sorry I had to run into them through shared grief but it is the path we are on. Also, a further blessing is renewed past relationships that came to offer tremendous levels of support thru all my current difficulties. My old buddies Janet and Linda who I met in my 20's came back into my life with a fierce strength and devotion, and walked me inch by inch through every step of what I am writing about. And though I lost a brother I gained 2 sisters. Other relationships that were good became stronger. Lizzie my Cuban sister never missed a minute, Noodle my friend of 49 years checked in by text daily. Carolyn my sister on the other side of the country sent long letters bathed in love and encouragement. I found myself covered in a level of prayer and support that brings me to tears. At times there were so many people praying for me I thought God might have to take out a restraining order. I learned that support is a wonderful thing but I could not hide behind it. God and my disease would require that I put my big girl panties on and face Him and my problems on my own two feet.

Another aspect of hematological disease is that there are both true crisis points as well as a chronic aspect of this disease. Why am I mentioning this? I started a habit of texting about 10 to 15 people from the start of my first diagnosis asking for prayer for every lab test every time. They all responded in the affirmative and held their breath with me collectively until I got the results. Although most of them didn't understand the details of all this light chain crap they all had one characteristic in common, they cared for me and wanted me to be okay. After some time my own perceptions told me my prayer requests and need to talk amyloidosis were becoming tedious; I had lapsed into the chronic aspect of this

condition and I was still relating in the crisis mode. If I did not change I would wear my support team down and risk alienating them for the times I truly needed them. My brother's total absence of any care or concern for me as a human being motivated me to appreciate any support others brought to my table. I wanted to be a good steward of people's concern and protect and value it in return. His unwillingness to even acknowledge me or my illness, instilled in me the gratitude to accept whatever amounts other had to give. Not everyone would be Janet, Linda or Liz in my life. I am glad to report that I realized this in a timely manner and made my adjustments the best I could. All of the 15 people I started the texting process with are still positively connected to me and my life.

There were also other friends who no longer wanted to share the issues in their life deeming mine as way more serious. This could be true presently, but allows an imbalance in relationships to occur. If that persists it will keep me overly focused on self and denies me the opportunity of giving. Although without a doubt I was in a position to need help, I didn't want my diagnosis to render me to be just a taker. Try not to let this happen to you. **LESSON #13 Try not to wear people out. A terrible thing has happened to you but life still goes on. It is good to the degree you are able to be there for others. You will sustain your self-esteem, remember you are more than your diagnosis, and create a healthier balance in your relationships.**

Now let's get back to our central story. August 24<sup>th</sup> finally arrived. Hoffman was caring but ready to get down to business. My prognosis according to him was pretty good for this serious disease. We had found this very hard to diagnose disease in the early stages. I had seen my cardiologist and nephrologist while he was gone and obtained some testing. Both doctors had declared both organs strong and functioning, well capable of sustaining a stem cell transplant. Dr. Wolinsky and Dr. Sandy were super supportive of my fragile emotional state. They both pledged to be a part of Team Andie. I had mixed emotions. On one hand I was glad to know my heart and kidneys were not damaged by the amyloids. On the other hand I had lost an excuse not to press forward with a very scary stem cell transplant. Please understand I am 63 years old never spent a night in a hospital and only had one minor surgery years earlier when I lost a baby. I was in virgin territory.

In fact it was a stem cell transplant that Hoffman was recommending as my best treatment option. It was believed I was strong enough to endure and survive a transplant; only about 20% of amyloid patients are. An alternative was cycles of CyborD, (chemo), but he felt that the transplant afforded me the best option of beating this baby back into remission. Amyloidosis is a very rare disease and as such there are not a lot of treatment avenues; there is still much that is not known. The potential for disaster in the amyloids attacking vital organs, make the need for treatment an urgent, not a watch and wait deal. Unfortunately the statistics regarding success are a hard nut to swallow. Some obtain full remission, some very good partial remission, some partial remission and some no effect. I could not imagine going through everything that a stem cell entailed and getting absolutely no benefit. Despite this, in my gut from the get go I knew this was the correct direction for me to go in. I did not commit at this point to the transplant, but in order to move forward, an appointment with Dr. Denise Pereira one of the University of Miami's transplant doctors was set up for September 3, 2015. Another bone marrow biopsy was scheduled for August 28th, 2015. It was explained that over 10% plasma cells in the marrow required chemotherapy before transplant and under 10% went straight to transplant. I would see Hoffman again on September 10<sup>th</sup>, 2015 to seal my fate.

The ship was out of the dock sailing ahead. Even though I had settled down in one month since the diagnosis and understood that stem cell transplant was indicated I still had difficulty processing that this was actually happening to me. On August 28<sup>th</sup> I went to see the doctor I was referred to for the bone marrow biopsy. I had such a positive experience two years prior with that procedure I was not concerned. I should have been. The doctor was cold and sterile, she barely spoke to me at all. That's fine I told myself, I only need her to have some good technical skills. She had me lay in a tight fetal position with my back to her. She was silent except to chastise me that I wasn't scrunched up enough. A very flexible person doing my best, I wondered how older heavy sedentary patients would fare with her rigid requirements. She made one attempt and I jumped in excruciating pain. She became angry that I moved. She asked me if she should stop. I was determined to have this done that day and not have to go through this again. "Continue", I responded as I grasped the side of the bed with all my strength. The second attempt yielded more pain and another jump. Why had the first bone

marrow biopsy been so painless? She then informed me she had finished and left the room. The nurse would then tell me the third attempt was successful. Why hadn't I felt it at all? "Oh, she realized she had not numbed you and when she did it was a piece of cake", I was told. Bleeding all over the table and bruised from her butchered attempts, I felt pretty pissed off. Not even a word of explanation or apology from this doctor. I had a fleeting thought to report her. But I would let it all go, the gift of amyloidosis recognizing the difference between the important and the unimportant battles in your life.

September 3<sup>rd</sup>, 2015, University of Miami outpatient stem cell transplant floor. The scene of the crime. I was nervous like a tight rubber band about to snap. I had done my home-work. Through my stem cell Facebook buddies I had generated a list of questions. My list which read more like a dissertation was 3 typewritten pages. They would be interviewing me to see if I was an acceptable candidate, but I would be interviewing them as well. I had mentioned to Hoffman going to Mayo in Rochester, Minnesota the premier Amyloidosis Hospital. He was cool with the idea, (the sign of good medical professionals are those who do not get defensive when you want to go elsewhere because their main concern is your welfare). We reached the same conclusion though, that I would really not need specialized care as I had no major organ damage. I also was concerned with the impact of dragging my husband halfway across the country with no support for him with the daunting task of being my sole caretaker. University of Miami I was hoping would work out. I was so tense I became irritated with the nurse for asking so many mindless questions while I was overly eager to jump into the meat of things with the doctor. This nurse would eventually become one of my favorite people down at University of Miami.

Please realize that I thought I had met the best doctor ever in James Hoffman but I had not yet met Denise Pereira. That day because of my preoccupation with what I was facing and my rigid controlling behavior I would not be able to fully absorb the depth of character, personality, and professionalism that embodies Dr. Pereira. But I will never forget this lady who sat on a chair for 2 full hours determined to answer every one of my questions in full and to my satisfaction. I looked for signs I had overwhelmed or exhausted her. I could find none. Her dedication to me as a patient penetrated any defenses I was wearing that day. A doctor with excellent credentials, she possessed the humility to seek consult on 2

matters she wasn't sure of. You don't see that often. Dr. Pereira believed I was an excellent candidate for stem cell transplant. She also broke the really great news that my bone marrow biopsy had come in with only 5% plasma cells so I would be able to skip the chemo and pass go, collect \$200, and go directly into the stem cell transplant. I was elated but getting scarily closer to the 4<sup>th</sup> floor (stem cell transplant floor). There was nothing preventing me from committing to the stem cell transplant that day but I wanted to see Hoffman one more time. I would see Hoffman on September 10<sup>th</sup> and return to Pereira on the 24<sup>th</sup>.

On September 10<sup>th</sup> Dr. Hoffman was eager to hear my thoughts about doing the stem cell. I knew I needed to do this, and I knew this was the right time. It really was a forgone conclusion. I told him I would commit to the transplant at my next Pereira visit. Hoffman praised my decision and was very hopeful we would see good results. I was hopeful but I had to go one step at a time and surviving the transplant was higher up on my list. I wanted to continue to see Hoffman until the transplant but he was releasing me to Pereira's care. Just when I was starting to feel secure. When I left his Deerfield office I realized it would be quite some time till I saw him again at that venue. I made a mental commitment to myself that I would survive this transplant and make it back to Deerfield to see him. The coming days would see me hang blindly onto that vow to make it through. In fact I saw him there on March 17, 2016 back in Deerfield for the first time, about 4 months post-transplant.

In September my phone started to ring and Humana my insurance Company was trying to tell me they were giving me a transplant case manager to support and assist me. Still not comfortable being in the patient role and feeling competent to manage my own affairs, my response was, "What do I need this guy for?" Reluctantly I accepted the help. It would not take very long at all for me to change my attitude welcoming the assistance from Dave. The last thing people need to additionally take on is the business aspect while preparing for a serious medical procedure. Unfortunately many patients are not granted that kind of support. Dave from Humana was a great asset on my team. The gravity of my situation was sinking in. I am glad that I learned to make adjustments when I needed to and not remain stuck in the mud of my former patterns and behaviors.



I hope you can tell that I really like to write. Around this time I would start to use Facebook to express myself and inform friends and family of my status and progress in preparing for my stem cell transplant. This generated a lot of support which I hungrily absorbed while it also provided an outlet for me to share. Though a lot of people say a lot of bad things about Facebook, it would truly prove to be a lifeline to me in the coming days.

On September 24<sup>th</sup> I authorized my execution, well at least the death of my clonal light chains if I became lucky. I had at this point in time a well- developed understanding of the stem cell procedure. The conversation between doctor and patient took a more specific turn from the generalities discussed in the last meeting. Although I had no major organ problems, I was very concerned as to how I would fare regarding my Epstein Barr Virus and my bowel situation. I also had celiac disease and a host of other food allergies and I would require nutritional help. The pharmacy department would have to screen all potential medications so as not to induce an active celiac state. I couldn't imagine being sick from melphalan, (the high dose chemo they used for the transplant) on top of the dead rat syndrome I experience in my gut when my celiac is triggered. I am aware that albeit unintentionally, I am not an easy person. Not everyone was on board with my needs initially. I made it my responsibility to get them on board.

**LESSON 14 If you are going for a stem cell transplant do not be a passive passenger be an active partner.**

My people skills at this juncture were rough, but as time progressed I was able to cultivate rapport with 2 people that I had initially alienated. **LESSON #15 Give yourself some room to wig out a little, to not be yourself. Take responsibility to clean it up when you can. It will help you in the long run and go better for you.** I wanted to do everything to be successful. I had a fragile little body in normal times, this would push the balance to places unknown. I had great respect for the knowledge and skills possessed by my transplant team, however I had 62 years of experience with the nuances and oddities of my physical self. I was informed that my kidney and cardiac testing were sufficient. I would also need pulmonary clearance which would be a piece of cake as I was swimming laps an hour a day. Next I needed a dental clearance, not a problem as I was meticulous about cleaning my teeth every 3 months. But would I pass the psychiatric I joked to anyone who would listen just to cut the tension. Unbelievably, the psychiatrist

said I had a short term memory deficit because I couldn't, let me correct that and say I wouldn't, memorize a laundry list of meaningless words. Can you spell I'm a little preoccupied here lady? She worried I would forget to take meds on my own. How do you convey to someone that you have been coordinating the ingestion of over 100 vitamins daily for 25 years and never missed or mixed up a dose? The following will reinforce the comical aspect of the psychiatric assessment. When I saw Pereira later that day I amazed her with my ability to recall my kappa free light chain levels and ratios and the concomitant dates for every lab taken since 2013. Pretty impressive. I guess I can remember the things that are important to me.

Pereira was drawing 11 tubes of blood testing me for everything and anything. On October 15<sup>th</sup> I came in to sign the informed consent. I was too familiar with the document and each of the unpleasant side effects as well as the list of life threatening possibilities. It was a scary necessity this informed consent. My tendency is to obsess about possibilities. A new online friend who has POEM's disease another blood disorder and is also a brother in the Lord gave me the best advice that I eagerly substituted for my obsessive worrying. "Andrea", Mike said to me, "you can worry about the 15 things that might happen or you can choose to wait and deal with the two that do happen". Right on Mike. When I implemented this advice it made me less dilute, not all over the map and allowed me to save my strength for the battle that would occur but not until it occurred. You feel me now? **LESSON #16 Living in the moment means you deal with what is not what might be.**

On the 15<sup>th</sup> I asked to take a tour of the transplant unit. I was taken aback with how small it was, coupled with the knowledge that I would be up there for a good 3 weeks. I was told there was a window in each room. When I returned home I became preoccupied with setting my life in order to prepare for being gone for a chunk of time as well as being incapacitated to some degree upon my return home. I busied myself with compulsive cooking and bill paying to lift those burdens from me for several months. More is not always better. No amount of distraction even in the form of productive compulsive activity could divert my growing underlying concerns. I started to wake up in the middle of the night in a panic that I could not get off of the small transplant floor. I was trapped. It was horrifying. This happened two times. I would text my supporters at 3 AM to talk

me back in off the ledge. Not having ever experienced this before I began to wonder if I would make it.

So on my last visit with Pereira on October 22<sup>nd</sup>, before I would be called for a bed, I begged her to allow me to leave the transplant floor and walk around the hospital or go outside after admission. No way Jose, I was told. Okay this was the deal. Not wanting to freak out I started the process of asking the psychiatrist for anti-anxiety meds and although I was not depressed, (just in case), anti-depressants. I did not follow through with this, instead deciding to wait. Let me fill you in on the state of grace that enveloped me throughout my hospitalization. I experienced absolutely no anxiety or depression. In fact please don't laugh at me, in the 18 days I remained on the 4th floor I never once, not once looked out of the window. **LESSON #17 The recipe is not the cake. The scenario that your mind dreams up is not the same as the experience. Stick to reality.** At some point my therapeutic background kicked in and helped me to realize and understand what the trapped feeling symbolized. That was that once the melphalan goes in there is not turning back. You can't change your mind there are no do overs. The ripple effect and recovery from that one infusion can last a year. The reality of that decision was manifested in the form of my trapped feeling. Once I understood that I relaxed some and became more ready to just do it.

I had drifted away from my counselor for the time being and had delegated my need for guidance to a kind pastor from my church. Johnnie was armed with tons of comfort and support. I was at the right place. Garland another pastor from the church took an interest in me and my life. It was amazing to me how much they cared as we had only been attending their church for several months before the crap hit the fan. As a therapist I know that there are things a person faces in their life where there really are no answers. Another human being wanting to help can only cheer you on. It is your race to run. But the support I received did strengthen my courage. Being able to go into a big procedure like this well- grounded is a gift.

During our meetings I shared something with Johnnie that at the time I did not understand. Up till this point I had been studying the bible and praying quite a bit. Now in my somewhat shaken state when I would read the Scriptures it just seemed like a conglomerate of words screaming blah, blah, blah at me. I realized I was so overwhelmed that I could not absorb anything I was trying to take in.

Going back to square one I just identified several of the most meaningful scriptures and tried to actively apply them on a heart rather than a head level. I focused on my heart and spirit actively doing what the Scriptures suggested, rather than my brain just understanding the content of the matter. Something happened to me in the depths of my alone time where I began to understand and experience the shelter of God...His refuge. What a safe and secure place that is. In fact this accomplished a higher degree of trust, so much that while I would be in the hospital I would not pray much. I would just rest in the hospital in the peace that I had acquired earlier from my active application and practice of trust, faith, hope and belief. At this time I decided to give up all my little good luck habit and rituals. I was letting go of a lot of the superstitious lucky behaviors, I learned as a child growing up in Philly, which my current fears had multiplied. And for maybe one of the first times in my life especially during such a serious situation, I was able to not try to control the outcome but just trust the process. Whether or not I survived, whether or not I made it into remission, I had grown and no one could take that from me.

Okay so by mid to late October everything was set. I had planned the crap out of this transplant. **LESSON # 18 Do what you can to plan this transplant process. Don't be shy about asking for what you need** The pre- transplant meetings with Pereira had instilled a level of confidence and courage in her and in myself to face this thing, to survive this thing, and to be successful. I had scheduled it to begin for the second or third week of November to coincide with the period I would be starting to feel sick so that I could be overseen by my beloved Pereira. I timed it with her appointed 2 week rotation on the unit. I had prayed that the doctor who would be on the unit for the first week I was there before Pereira arrived, would be Dr. Komanduri, the head of the department and an expert in virology. And he was as luck would have it, the doctor slated to precede Pereira.

I was scheduled for a minor surgery On November 3<sup>rd</sup> to install my new life line, my catheter. I knew once that happened I would not be able to swim for about 6 months. So on November 2<sup>nd</sup> I went for my farewell swim, said goodbye to the pool and in my best Arnold Schwarzenegger voice said, "I'll be back". My husband and I booked a hotel right across from the University of Miami for the first week in November as we lived 40 miles away. After the catheter installation I was on schedule to harvest my stem cells for the next 3 days (November 4- 6<sup>th</sup>). The

surgery went fine except for a curious red blotch I awoke with on the opposite side of the catheter. Maybe they had bruised me I thought. I had heard them banging on my chest but the drugs they gave me rendered me to not care about anything. Fentanyl is a very good drug, said the substance abuse therapist. They finished with me late at night and I had to be up at 630AM the next morning to start the harvest.

I was off my schedule now and worried that the lack of sleep would trigger my Epstein Barr Virus. I normally sleep 10 to 11 hours nightly. But I was in too deep in this process and the hospital I learned is not conducive to my scheduling needs. I had to comply with their protocol. I had done my very best to change the time and couldn't even put a dent in it. After many years of working direct services with addicts I had my own set of manipulation skills. I was adept at outplaying the players. When I used this set of skills on the normal population, (the medical staff), I realized I had pushed too hard and people start getting pissed off. So I did what everybody does when they hit a brick wall I backed off. Miraculously I did not get an episode of Epstein Barr.

In fact I had an excellent experience with the harvest which is officially called apheresis .In preparation I had started nupogen shots the week prior to coax my stem cells out. Nupogen causes some pain for some, I only had a little bit of leg pain that was very tolerable. My goal was to collect 10 million stem cells for 2 transplants. I needed a minimum of 5 million to proceed. It took 2 days to collect the harvest and I collected 9.7 million stem cells, not bad for an old gal. My nurse Carmen, whom I would write a commendation about was kind, professional, very competent and informative. She made sure I understood every part of the process. It was a positive experience. I did not require a transfusion but some patients do to replenish their blood supply. One nurse on the apheresis floor kept warning me the worst was yet to come referring to what I would go through on the 4<sup>th</sup> floor. Not a really good thing to tell someone facing a huge daunting procedure. On behalf of myself and the patients that would come behind me, I confronted this nurse and redirected his negativity by helping him to understand the effects of his communication and the needs of a patient in my position. Who knows if it changed what he would say in the future but it feels good to take a stand for yourself especially in the disempowered patient position.

One issue that came to light during the apheresis process was my problem with the kitchen department. I had worked extensively with the nutritionist to provide detailed lists of what I could eat and what I could not eat. I am more than aware that my dietary problems make me a high maintenance person in this area. When they served me my meals at apheresis they were covered with gluten foods and eggs. I got exactly what I couldn't eat. It was upsetting. I had done my part why couldn't they do theirs? After 4 or 5 meals the kitchen prepared for me, that would have poisoned me had I eaten it, I came to the conclusion that they were totally unprepared to feed a special needs person. They agreed to give me chicken rice and a vegetable. And that is what I got on the 4<sup>th</sup> floor for every breakfast, every lunch, and every dinner for 18 days... chicken, rice and a vegetable. But remember when I shared with you not to worry about what might could happen, but rather do as I learned, just deal with what is? All this legwork was for naught as I would be so nauseated during my transplant I could not eat for 9 days and the remaining 9 days I could only eat a slice of my gluten free bread coupled with a ginger ale. However when I came home I threw out all of our rice and waited 2 months before I could face looking at or being able to eat chicken.

It is now November 6<sup>th</sup> and I was instructed to stay home, rest and allow my blood counts to rise and I would be called in about 2 weeks when my bed became available. I started to wean myself off of all the tons of vitamins I was taking as I had been informed they would not be permitted in the hospital. I was a little scared to do that but on the other hand I wanted to take a break from all my self-remedies. I certainly did not want any complications. I had a healthy respect for the compromised state both my blood and immune system would be in from the transplant. A home health nurse visited me three times weekly to service my unused catheter keeping it ready for action. My University of Miami nursing coordinator was a no frills all business type of lady. We clashed at first. I knew she was the boss. She didn't reveal to me till post-transplant that she was a Broncos fan. That piece of information earlier could have created some bridges. NFL banter is not respectful of person; it draws everybody just a little closer. I was already packed for the hospital in anticipation of the call I would receive. I had over prepared myself and as I look back I must laugh. I had 50 movies, coloring books, sewing projects, and puzzles. I had a 10 day supply of clothes so my husband wouldn't need to run back and forth. It looked like I was going off to

camp. The anxiety was gone I was a soldier awaiting the call to duty. It is the same sense I had when I was living in the class 5 Hurricane Andrew path of destruction. You prepare, you wait but you know this event will change your life.

While I was waiting I noticed that the red blotch on my chest from the catheter surgery was becoming infected. I was watching and waiting to see what it would do. I would not have to watch and wait very long. On November 9<sup>th</sup> while shopping at Publix the call from my nursing coordinator came. Apparently the guy ahead of me was not stable enough to take the bed and I was being called to come in on November 11<sup>th</sup> a week early for my transplant. Bed placement is a function of hospital availability and patient readiness and stability. "Okay, I said, but I need to let you know I have an infection on my chest." It was agreed I would text a picture of the wound for the doctor to see. The doctor did not see infection from the picture, but they asked me to come in the next day to be evaluated. Maybe the screaming red skin and the pus did not come through in the phone picture but my husband and I sure saw it. It was then that we decided that no matter what they thought, I would refuse the bed and wait until the infection cleared up. It just did not seem like anything I could possibly risk, having an infection in a situation where I would drink some melphalan that would destroy my entire army of infection fighting blood cells. Prescription for disaster. **LESSON # 19 Do not leave your common sense at the door. Always be prepared to advocate for yourself. Do not be afraid of what others think when you have to assert yourself.** I would like to mention that later on I learned of someone who went through with his transplant with a small infection. This created terrible complications for him.

When I got to the U. of M. they were surprised I had made this decision on my own to not take the bed. I would not delegate my responsibility to stop this process to someone else no matter what their title or credentials. They could readily see it was infected. They placed me on antibiotics and took a culture. Two days later they called to inform me it was a hospital based infection and switched antibiotics. They had given me the infection during surgery I assumed. How would they prevent this from happening to me after my transplant when my immune system was in the cellar and I had to return to surgery to have the catheter removed? I called U. of M. risk management and alerted them and asked for an investigation. Some people may describe me as a pain in the butt which I am not

denying, but in certain circumstances I am a very determined person to just do everything possible to protect myself. This I believe was one of those times. They now were requiring an ultrasound and an x-ray to see if the infection had gone below the skin. It had not.

The following Monday I came in to have the wound re-evaluated. The infection and wound had healed. The results were presented at the round table of the medical team. And the call came shortly thereafter that I would get my bed on November 18<sup>th</sup>. This was no Braxton Hicks call. This was labor. I was excited, there is only so long you can sit on the edge of the diving board without jumping in. I knew through and through that my life would be changed as we drove to the U. of M. I had so much stuff it looked like we were moving in. As I left the sidewalk to enter the hospital I said goodbye to the outside world but not to God. He was definitely coming in with me

#### CHAPTER 4 And Now onto the Execution.....Excuse Me I Mean the Resurrection

You will have to bear with me now. Once the melphalan comes, and it does come the very first day, my recall becomes a bit blurry. My husband had already agreed to stay with me the first 4 days to make sure I was acclimated to my new environment. I am so grateful he was there. He is not the most nurturing



character as you will find out, but I know there is no more loyal, dependable, strong man in all the land. His lightheartedness has always been a welcome buffer for my intensity. I was happy to be on the unit buzzing around like a bee. The medical people started to swarm and it soon become evident this was their house and I would just be along for the ride. My port was hooked up to the pole, (my companion for the next 18 days). I was, after 62 years, working a pole and never had to take my clothes off! I received a brief in service to the blackboard which would post my daily blood counts. Their version of the New York Times. Hematology appears to be about blood but trust me it is all about the numbers... all about the numbers.

I expected the melphalan in the afternoon it would not come until the evening. On my mind were my two biggest concerns: my bowels and my Epstein Barr virus. Would the virus wreak havoc over me once the Kool Aid stripped away my immune system? Would my bowels shut down as they had so many times before, and I would be as they had informed me unable to do my home grown protocol? But just as I had signed informed consent so had they. I had alerted them of all my medical problems and they accepted me and also promised to keep me alive. My problems were their problems now. A very strange experience for a normally very controlling person this was. Peace comes with insight and trust.

The melphalan arrived, I was more than ready. I kept ice in my mouth as I was advised for the entire infusion to avoid mouth sores. And thankfully I did not get mouth sores. Forty minutes later the empty melphalan bag left. No flashing lights, no parades, no nausea. It was sort of anti-climactic. I went to sleep as I was now on hospital time requiring an early wake up after a night of blood pressure checks every 4 hours. I wondered who dreamed up that protocol for sick people.

I awoke and felt fine. I was taught that whenever I left the safety of the room I had to glove up and mask up. To this day I feel much more secure when my gloves and mask are in place. They urge you to walk so I got up and did laps around the small unit talking my head off to anyone who would listen. I looked at the other sick patients and felt smugly superior. I was going to ace this test. My cockiness as you shall see was short lived. This was the day of rest I was given. The following day I was instructed would be my new birthday, the infusion of all those stem cells. 4.95 billion of those suckers disease free coming in for a landing. The

entire transplant process mimics the spiritual principle of life emerging from death. In Christianity salvation is a picture of death to the fleshly nature, which brings new life arising from the birth of the spiritual nature. In hematology the melphalan kills the diseased blood supply, while the stem cells resurrect life planting a healthy blood system.

The stem cell infusion required a staff of three. It was technical for them but a routine drip only for me. I understood they had mixed a bunch of prophylactic drugs with the infusion to prevent allergic reactions through my catheter. It seems that the storage of the stem cells requires preservatives that can be noxious. The nursing staff on this unit was more skilled, intelligent, competent and sophisticated than any other nursing unit I have met in my many years on this planet. I was so impressed with some very young nurses who were holding the weight of this very heavy unit on their shoulders. Most people at age 26 or 27 are drinking beer and trying to find themselves. These women were working 14 hour shifts, never sitting down for even a break, definitely had found their calling, and were sharing pieces of their soul and selves with some very blessed patients.

**LESSON #20 It is good to notice and appreciate the positive things around you even in a difficult situation like this.**

I had thought the melphalan would make me immediately sick. I was wrong. The stem cells did. Before the stem cell infusion was even over the nausea set in and that puppy would hang on for days and days. The vomiting did not start for a bit. I was aware this could happen but didn't think it would grab me so soon. I had determined not to complain about nausea or vomiting because after all they are only unpleasant, it was the serious side effects and complications like blood clots, kidney failure, infections pneumonia etc. that I desperately wanted to avoid. So I said nothing about my nausea for a day or two until I finally broke down and asked for some help. **LESSON #21 Sometimes real strength comes in the form of humbling yourself and asking for needed help.**

I was such an anti-drug person I actually wanted to limit the amount of meds I was taking. Finally I realized when in Rome do as the Romans do. Dr. Komanduri was not nearly as flexible as Pereira and we started to go at it as far as medication choice. I let him win as if I really had a choice. Anyway Pereira was coming on Monday, I would be fine. I had lost my appetite and even the smell of or seeing

food made me sicker. To illustrate how the effects of a stem cell vary from person to person I want to share with you that the guy two doors down from me was receiving the same exact protocol as me and never missed a meal. His appetite was better than ever. I looked at him in disbelief as if something was really wrong with him besides his blood disorder! But for me as the days went on, and the gastric distress persisted, my motto became if someone would tell me I never had to eat food again, I would be just fine. Really fine. And I really meant it.

Pereira came on Monday. Her demeanor care and presence are just well therapeutic. She also actually listens and takes into consideration what you think. I'm not kidding you. I actually would eventually write her a letter telling her that even if eventually they find a cure for amyloidosis, she will still never get rid of me. My husband wants to put up a billboard on Interstate 95 with her, Hoffman and me saying how we kicked amyloidosis' ass, but lest we get ahead of ourselves I must actually do that. I don't know which day the vomiting started but boy believe me it started. Since I was not eating it would be the dry heaves most of the time. And trust me, I was heaving like a champ shaking me and my little body to its core. My husband would sit there reading his newspaper while I was violently preparing to die, hanging over the toilet or the trashcan or this specialized bag they give you just for the occasion. I actually had to school him on how to act as if he cared and come over and comfort me. This was first met with his objection, "I'm here aren't I?" I guess he thought he should get points just for showing up. Though he could never really appreciate my need for kindness, he did start to come over and superficially pat me on my back. Just sayin' nurturing is not his game.

The meds they were giving me for nausea really were not getting it. The doctor informed me that Ativan which is a tranquilizer could bring some relief. I was allowed 4 doses a day. I took only one dose judiciously, as they are highly addictive and I am by trade a substance abuse therapist. Somebody should have reminded me I was not at work. So the one dose of Ativan was giving short term relief. They then talked me into trying some Zyprexa which has been known to help nausea. Zyprexa is an anti-psychotic. Now I may have some neurotic tendencies but I am not and was not psychotic. Believe that! At about the same time sick and tired of being sick and tired I decided to throw caution to the wind and ask for my allowable 4 doses of Ativan. After 2 days of taking both the Ativan

and Zyprexa, (while singing all day about the virtues of Ativan in a funky little song I made up), I got up from the bed and fell flat on my face. I gave up the Ativan and now would wear the label Falls Precaution for the duration of my stay. I tried to protest stating, "You try taking 4 Ativan and a Zyprexa and see if you can stand up!" This protest fell on deaf ears. I was now labeled, felt targeted and would be asked questions regularly about my ability to ambulate for the rest of my hospitalization. My ability to ambulate, by the way was just fine as long as I wasn't drugged out of my mind! The Ativan and Zyprexa part of my stem cell saga was now officially over. I would gut the nausea and vomiting out with Compazine.

The nursing staff was a bunch of super personable and competent people. We liked each one better than the last. Barbie one of the night nurses was pregnant and ready to burst; she became like an adopted daughter. She had the patience, demeanor, and strength of a saint. Another nurse and I would tease and pick at each other over the Dolphins (her team) and the Patriots (my team) rivalry. The banter got brutal but it helped me feel a bit like myself. Another nurse who was in training was assigned to me regularly and we became fast friends. Out of all the nurses that served me there was only one who I had difficulties with.

Nausea and vomiting and low blood counts do not lend to happy enthusiastic moods. This nurse would come in and pick at me for not smiling and being happy. She seemed to mock my difficulties. I am not a needy person and wanted no sympathy but she seemed to be indifferent to the patient's experience. I was not having my toenails clipped lady. It came across and affected me badly. I am sorry to say I didn't let her have it or ask her how happy she would be in my situation. And even this nurse apart from her demeanor was super competent and smart. I believe the nursing staff on this floor is a bit overworked and lower patient to staff ratios would be a very beneficial move for everyone. University of Miami 4<sup>th</sup> floor transplant floor... great nursing staff.

I did not engage with any movies or projects for the full duration of my stay and would take home eventually 50 unwatched movies. A full day was taking a shower, brushing my teeth, changing my clothes, recovering from the vomiting episodes, and drinking fluids. **LESSON #22 We tend to think we are growing when we are doing good and our lives are blooming. The reverse is true we are growing when we are in our worst places and we just hang on and refuse to give**

***up even if we don't look very pretty.*** However, I could not help practicing my craft with some of the nurses as we got to know one another. By the day of discharge I had successfully helped one mom with parenting strategies and assisted another nurse in relieving relationship distress by clarifying the motivations of someone in her life and then helping her lay down the appropriate boundaries to resolve said issue. Another nurse going for her masters in psych nursing would engage with me in conversations about diagnosis and pathology. I was a stem cell transplant patient yes I was, but I was still a good therapist.

The duration of my stay was projected to be about 3 weeks if there were no complications. I was taught that the first week I would gradually deteriorate in how I felt, the next week I would bottom out as my blood counts hit the basement and the last week would be the upswing where after my stem cells engrafted I would start to feel better. Engraftment means the stem cells have started to work and are creating new supplies of everything the melphalan wiped out. I engrafted on day 11. Though I had worried about not engrafting before my hospitalization, (a small percentage don't engraft and it is very serious), this mysterious peace I mentioned kept me at rest. I felt miserable but I was resting comfortably in God's hands. I did not want any transfusions but required three during the middle week. Again I saw God's hand helping me to surrender to what is, not what I would like it to be. I had entered the hospital weighing 134. One day I looked in the mirror and noticed, girl I had hips. How could that be, I wasn't eating a thing and thought I may have lost 10 pounds. The nurses brought the scale and I weighed 164! Child please, what was going on? Dr. Pereira told me that the IV fluids they were giving me to protect my kidneys were causing the weight gain. In typical Pereria fashion we discussed it and since I was taking in a lot of liquids she discontinued the fluids and just monitored me. I left the hospital at 146 pounds and felt better.

When I started feeling better I resumed walking laps in the hall. I had the nurses in stitches when I appeared in my one piece tiger pajamas complete with a tail and hood pulling my pole chanting what was to become my mantra, "Room 406 on the move." The other comedic highlight of my stay occurred around day 12 at 5 AM. My husband and I were both up in the middle of the night. After days and days of feeling sick I had a brief window of feeling okay. In honor of this we played Eminem's Guess Who's Back? Guess Who's Back? No it wasn't Slim Shady it was

me. The first glimmer that I was coming back. We danced for 30 seconds and I fell into the bed exhausted.

Towards the end of my stay, the President of My Personal War on Amyloids came to see me, James Hoffman. It was a welcome face. I felt like years had gone by since the carefree easy days of outpatient office visits in Deerfield. I was so removed from that I no longer was hanging onto my vow to return to him, I was just hoping to get off the 4<sup>th</sup> floor and just make it back to the 3<sup>rd</sup> floor outpatient transplant center again. I would think about Deerfield later. One step at a time. Hoffman was shocked to see my eyes. I had reported to him purpura as a historical symptom but with the Vaseline on my eyes he had never witnessed it in actuality. Now due to a low platelet count from the melphalan and lots of retching from the dry heaves and vomiting, my eyes were black and blue from the eyebrow line until the top of my cheekbone. I looked like a horror story. Hoffman got excited to snap an anonymous picture as purpura is such a misunderstood but highly relevant diagnostic amyloid symptom. He wanted to use me to illustrate this symptom in his work with others. Well so glad I could be of help buddy. We visited for a short time, can't remember a damn thing that was said except his closing remark...Full remission in 2016. And for that he got a big whooping Amen from me.

Let me tell you how just how not vain this disease and its' treatment can make a girl. I almost forgot to write about losing my hair. Nine days before I was admitted I chopped off my collar bone length hair into a short punky Jamie Curtis type cut. They recommended doing this to avoid the depression associated with watching your hair come out in clumps after you drink the Kool-Aid. I didn't want to walk around bald any longer than I had to so this was my compromise. Twelve days into my stay in the hospital I had really not lost very much hair. My mind flew into denial... maybe it wasn't going to happen to me and I could keep my hair. Day 13 changed this short lived wish. My hair started falling out everywhere and within a week I was bald.

As soon as my counts started rising they started to discuss discharge. I took a few nupogen shots to assist my white blood cells in climbing. I was not really sure how that worked as the neupogen would artificially inflate the numbers only then to wear off and then just drop down. Why not just let them climb naturally? I never

asked about this believing that Pereira was a master at what she was doing.

**LESSON #23 While it is good to ask questions, Andie you don't have to question everything.**

Not that I wanted to remain in the hospital any longer than necessary but my weakness and ability to function outside of the hospital was an unknown. We had made a list of people who agreed to either babysit or shop for me if necessary but my husband wanted to be self-reliant as much as possible. I had entered the hospital on November 18<sup>th</sup> and now they were planning to remove the port on December 4<sup>th</sup> and tell me to go home. I negotiated to be discharged on the 5<sup>th</sup> because I believed with my diminished energy it would be too much to have the port removal procedure, pack up the insane amount of stuff I had, leave the hospital, and go home all on the same day. All that seemed in my mind more grueling than running a 26 mile marathon. In my post- transplant days I have been very careful about over extending myself, not quite sure if that is a tool or a weapon.

Please recall now my fears of being re-infected after transplant during the port removal. Pereira gave me a prophylactic dose of the specific antibiotic to combat the infection I had in November before the removal... just in case. Risk management had determined my blood had not been infected BUT we know my skin was. Anyway they did assume a lot of concern over my comfort in returning to the scene of the first infection. To that end the head of Risk Management a wonderful man named Arsenio oversaw the entire operation even accompanying me to the procedure. Talk about customer service. Thank you U of M. for taking my fears seriously.

Discharge Day. The great nursing staff had already educated me backwards and forwards. Warning signs of infection, when to call the doctor, low bacteria diet, (no fruits and vegetables... eating still was not my favorite activity), were all covered. I was ready to go, even though I was concerned about my vomiting. I couldn't stay there forever. Still not feeling great but trusting that they had accomplished what they set out to, discharge was the next step. I was pretty scared about all the stories I had heard about people early in their recovery from stem cell needing to be re-admitted to the hospital. I had no illusions about how fragile I was. I DID NOT WANT TO COME BACK TO THE HOSPITAL. Although I was

not energetic enough to demonstrate in a celebratory manner, I left having succeeded. I had survived, Epstein Barr Virus did not take over and my bowels did not shut down. True enough I had been sick to my stomach, but I had totally avoided the serious side effects. Now if I could just achieve full remission my life would be totally complete and perfect. The last 2 years had humbled me, made me grateful for the basic things in life and made my goals a lot more primary and simple. As they rolled me off the 4<sup>th</sup> floor in my wheelchair I issued a silent prayer, "Thank you guys for everything. Please God I never want to have to come back here." **LESSON #24 Life is a matter of perspective. I looked at the transplant floor as trying to kill me, my husband saw it as saving my life. I choose his glasses**



## CHAPTER 5 Homeward Bound... Let the Healing Begin

Phase 2, The Saga Continues or We're home Lucy. H.E. (Harold Eugene) my handsome husband had to do everything. Apart from sleeping 14 hours a night with two daytime naps, I was useless. I could actually feel my body repairing itself inside when I laid down to rest. Gradually, I was able to wash a load of clothes or empty the dishwasher. It took me two full weeks until I could sit up in bed and open the mail that was waiting. I had rapped all our savings to pay bills ahead so there would be no pressure when I returned home. I was always unsure just how debilitated I would be after my hospital stay and wanted to be prepared. My husband is not the best with business matters; he excels in many other areas. I wanted to make sure we kept the homestead functioning.

I had terrible stomach aches, difficulty eating, and swallowing pills when I returned. The melphalan had killed some good stuff too. We knew I would have some extra absorption problems which by the way is the core of my pre-existing bowel problems. Unfortunately the melphalan further damages the finger like villi that suck the water out of your gut, a weakness for all celiac people. The vomiting would continue another month at a progressively less frequency. But one thing that caught my attention was that although the vomiting remained as violent as it

was in the hospital, it no longer caused my eyelids to hemorrhage. Could the transplant have caused the amyloids to retreat at this early stage? Could I be in remission? I tried not to hope too hard, but it was pretty exciting. I wanted to be in remission with all of my heart and soul. But I knew that if I was not in remission I wanted to be able to cope and not fall apart.

Amyloidosis presented me with a whole entire new set of things to dream, pray and hope for. **LESSON #25 Hope for much. Expect nothing.** This lesson embraces a fine art of detached balance. My hope became the life blood of my heart and my being. I knew as Jeremiah told me that God had a plan for my life. First John says that He hears the requests that are in line with His will. Ah the caveat present at the end of that last sentence. Expecting nothing helped me to maintain humility and buffer any entitlement I might have that a good outcome was owed to me. So I was able to approach God with the hope in my heart that remission would be His will for my life. Philippians 2 verse 13 helped me to ask God to work in my heart in case it wasn't. As much as with every breath I took I wanted to be in remission, I also wanted to be okay if I wasn't.

**A medical illness detracts from our higher ordered needs and desires. I needed nor wanted gifts upon my return home except for my health to be reinstated. I did however receive one of the most meaningful gifts from two of my stem cell mentors, women I had mentioned earlier. The gift was from Kathy and Kim who had amyloidosis and had undergone a stem cell transplant and were able to resume their passions; one returned to long distance biking the other to running marathons. Positive transplant results like that are not commonplace amongst amyloidosis patients. Kim and Kathy's ability to return to their life with so much strength is inspirational. I like to think we bonded not just because we have the same disease in common. I like to tell myself it is because the three of us are athletes and I hope I am at least half as gutsy as they are. Anyway before my hospitalization they joked that I was trying to join their club or their sorority. They told me the transplant would be my initiation. I was told I was going to go through hell week like the college kids. When my transplant was over I said I wanted extra credit because hell week lasted 18 days! Anyway a package arrived from these two women at my home. In it was a shirt that said Kappa Lambda Free Light Chain Sorority... Membership is costly but the people are great. I had officially become a survivor.**

**We hired a maid to come in and clean my little condo to take the pressure off of my husband. With a low immune system you must be very, very careful and very clean. I was on heightened alert, I like to say I was appropriately paranoid to minimize my risks. One night I started to run a fever and it went to 99.5. Over 100 degrees means you go back to the hospital. That didn't happen but I will say that had it happened I would have lied. I did not want to go back to the hospital. That is really the only close call or complication I had the first 100 days. And it was still a pretty tough road to go through.**

Being at home again, people start to ask how are you are doing. Though a simple question on the surface, with amyloidosis that requires a loaded response. Let me see if I can break it down for you. The first aspect is recovery from the treatment itself. The stem cell transplant is an aggressive and drastic procedure. Rest, isolation, how I was actually feeling and regular stable blood counts from Pereira were the indicators that said I was doing well in this area. I was slowly regaining strength, had improved appetite, less stomach distress etc. The complicated part comes in knowing that your body can possibly be healing from the stem cell but may or may not have gone into remission from the disease. Did the transplant shut down the clonal light chain factory that was producing the demon amyloids? The degree of remission you achieve determines if your organs recover from the onslaught of damaging amyloids. In my case organ recovery meant a decrease of leaking protein in my urine coming from my kidneys and a cessation of the purpura in my eyelids. How much remission the transplant yields has an impact on your predicted survival so it is pretty serious stuff. The measure that determines if I was in remission is the lab test that started this whole mess, the kappa/lambda free light chain and ratio test. And that test was not scheduled until 100 days from transplant. So although I was very glad to be getting better from the treatment in the hospital, I was not able to really jump for joy yet, as the success of the mission, obtaining remission still remained cloaked in mystery. I was trying to be patient but I was becoming more than eager to know what the hell was going on inside my body!

Before I proceed I must let you know all my life I have struggled to learn how normal people cope. I watched and studied healthy people to observe their patterns. This stems from a very dysfunctional upbringing; an emotionally unavailable dad and a histrionic mother. I never knew whether it was more

appropriate to get into a frenzy or not give a flying F--- in response to life's difficulties. This inner conflict was translated to my relationship with God taking the form of not knowing whether we are supposed to just accept our circumstances or fight back. With age comes a little wisdom. I have realized I can do two things at once. Coping does not require an all or nothing at all mentality. With this little backstory in mind I approached Pereira to ask for an early Kappa light chain tests. Whatever the results I had to believe God who had gotten me this far, would give me grace and guidance to cope (accept) and press forward (fight).

So on January 4, 2016, (45 days after the transplant), I took my nervous little self to Quest and had the tests performed. It takes a week to receive the results. Recall, if you will that I possess an advanced degree on waiting for test results. Though I wasn't extraordinarily crazy during this waiting period, the tension did become wearing. I was prayed up, I had done all I could. All the non- important results trickled in first. Finally one week later the kappa /lambda results came. The intensity never wanes when opening the envelope that contains such powerful news. My kappa level had fallen from 345 to 29, (normal being no higher than 19) and my ratio had gone from 23.0 to 1.90 (normal being no higher than 1.65). The Kool Aid had killed at least some of the clones! Gratitude and relief flooded my mind and body. The doctor commented that the levels could still go up or down, that nothing was definitive till we reached 100 days. But they were pretty sure the levels weren't going to do anything drastic till then. I was hoping for much but preparing to cope if not. I had and will continue to lean on Ephesians 3 verse 20 that God can do exceedingly and abundantly above all that we ask or imagine. And I knew that to be true, truly I did. But I also know that our will does not always match the Will of God. But it sure feels great when our prayers, longings and desires line up with His.

When I was released from the hospital I was put on a follow up outpatient schedule, starting twice a week. For the first three weeks that was my only social contact apart from my husband. I had no one to talk with in the first days at home. I believe I was driving my normally quiet husband crazy. He had already nicknamed me princess talks a lot! So even though it was a long trip for me, all the way to the U. of M., the chance to interact with others was inviting. I got off the elevator for my appointments with Pereira on the third floor outpatient

transplant floor, knowing one floor up was the inpatient transplant floor. A bit superstitious I would send my husband up to say hello; I just didn't want to go. My appointments consisted of having labs taken and seeing the doctor. I was so weak I had to use the wheelchair to get around the hospital in the early visits. There were a lot of sick people in the hospital and it seemed a very threatening field trip for an immunologically compromised patient. But I was too far in to question protocol at this point. After two weeks I was titrated down to weekly visits. And then because it was the Christmas holiday season, only one month after my release from the hospital, they let me go three weeks without a medical appointment. I didn't know if it was because everyone was taking holiday vacations or because I was looking medically stable but it was fine with me.

On my first hiatus from appointments at the U of M, I began to walk outside around the circle I lived on. It was the exercise that signaled my turning of a corner. I was still living basically in isolation but functioning well inside my little bubble of a home. I wasn't very sick anymore, but had poor stamina and the doctors were pretty much leaving me alone. I knew that would basically end when I passed the 100 day mark. Then the doctors would swoop in like vultures wanting to reassess me. Mid- January until February 29<sup>th</sup> was a continued respite from the world, but a respite also from the doctors who had invaded my life from every possible angle for the past year. I felt safe during this time with only an occasional thought about remission intruding. I was in a holding and healing mode. So my venture outside to walk became the structure I hung my hat on daily. At first it was a walk of half a block then one block, it took several weeks to make it the 7/10 of a mile, the full distance of the circle I lived on.

The next challenge would come on January 5<sup>th</sup>. I became ambitious and decided to try to ride my bike. In my former life I had been a distance runner capable of running 26.2 miles at a clip. I got on the bike, now picture this, with rubber gloves and a mask, (as protection from overly friendly neighbors who were coming too close to me). A mask is a great tactic to keep people at bay. I looked a mess on this bike with all my protective gear. I rode that first day 7/10 of a mile, and was forced to take 2 breaks just to make it around. My legs were in searing pain; I was totally winded and sweating when I finished. BUT I DID IT. It wasn't 26 miles but it felt like a marathon to me. I used my skills acquired from my running days to negotiate and confront this new activity. From then on my training gene kicked in

and I determined to make it 5 miles. It took me 5 weeks, but by about February 10<sup>th</sup> I rode that bike 5 miles without stopping and my legs weren't even screaming. Achieving these exercise goals elicited joy in me as strong as winning trophies for either running super-fast or extremely long distances from my old glory days. So even though a 26.2 mile marathon was no longer on my to do list, that same heart and spirit were fueling me now. I am just running a very different kind of race now.

By late January early February I can honestly say I was starting to lose my mind a little bit from being alone so much. I had definitely been overly conservative with the risks I took coming into contact with other people as my immune system has always been my weakest link. I did not want to risk secondary illness or infection. Since my transplant recovery occurred during the winter months, it appeared that everyone I knew was struggling with some type of cough, cold, virus or flu during January and February. Others were as scared as I was of harming me. One night feeling like I would lose it, I called my second family the Casteleiros. This is an extended Cuban family with 2 small grandchildren. Somebody was always sick in that household. Desperate to get out of the house we formulated a plan. I drove to their house, cracked the car window, sat with a mask and gloves on, and la familia surrounded the car and we talked and visited. It must have looked pretty silly but I left with a deep feeling of satisfaction.

About this time I started to reconsider my relationship with vitamins. I had been given the medical go ahead about one month post- transplant to resume my supplements. But I did not. I wanted to rethink what I was doing. I wanted to try to determine which supplements were necessary and helpful. I was doing better than I ever thought possible without any vitamins. Before I had the transplant, well-meaning friends had advised me to consider alternative treatments and go greener. I tried to explain to them what I realized. First of all my system was fairly clean. Secondly this disease did not occur because I was toxic. I had a genetic mutation. All the green drinks in the world could not undo that mutation. The balanced perspective I reached, was that the natural alternatives were important in strengthening my immune system for the fight. Perhaps my supplements were a force in me doing well in the stem cell transplant. The curcumin may have also been one of the reasons that my light chain numbers did not progress in the two

years I took this substance and had this disease. But in the end I knew I needed medicine.

I began to take on more challenges as well. At this point in time my appointments with Pereira were monthly. Although my faithful husband always accompanied me, I started to drive the 40 miles to the University of Miami on my own. I wanted to wean myself from dependence on my husband as through the months of his caretaking I had become reliant. I was not strong but I kept pressing forward slowly. One day I had to go IN the bank. The bank is a very dirty place. I gloved and masked up. I had a hat and sunglasses, one crazy looking character. All eyes turned to stare as I walked in. So I had to declare my intentions. I yelled out don't worry, I'm not here to rob you! The bank was more than accommodating cleaning the chair and the worker's desk. I made a lot of progress in February and began to plan that my recovery would continue to proceed onward and upward. I did not factor in room for setbacks. Setbacks, I was to learn are a part of the process. The February 29<sup>th</sup>, 100 day testing was also coming incrementally closer.

In the back of my mind I noted that it was now three months since the transplant and I had not suffered an Epstein Barr Virus episode. I dared not say it aloud so as to not jinx it. I am originally from Philadelphia where we are raised on an almost religious respect of the jinx. Even though I didn't do a thing to jeopardize myself, I eventually got an EBV episode at the end of February. I stopped all activity and retreated to my bed in respect to my fragile status. I was very impressed with my lack of resilience as even though the acute attack lasted only 5 or 6 days, I lost a lot of ground and would struggle through most of March with diminished energy and fatigue.

The setback would affect me mentally as I had no distractions apart from dwelling on the recovery of my health. Alone it becomes a lot easier to allow your thinking to go south, than to stay uplifted. My spiritual life helped me make some mid-course corrections. I also realized I had gotten ahead of myself in my mentally planned out upward trajectory of progress. I had not considered or factored in regression. Also in the midst of a fall backwards, it becomes difficult to realize you are not in freefall but have only gone a step or two backwards. That famous smart guy was right. Life is what happens while you're making other plans. **LESSON # 26**  
**Perspective doesn't always come in the middle of the storm but usually returns**

**after you have weathered through it. Recovery, as is life, is not a linear progression.** The Epstein Barr episode also was the event that convinced me it was time to start reconsidering some vitamins. And I did start back on supplements in a much more limited manner.

February 29<sup>th</sup>, 2016 Truth time arrives. The bubble of innocence that had engulfed and protected me while I rested at home, relatively unbothered by the medical community since my return home on December 5, 2016, would now start to erode. Tests would be taken, results would be given, opinions would be rendered and recommendations offered. Knowing this was coming helped to prepare me to shift gears and resume a more active mentality again, in order to confront the next phase of my recovery. Therefore, I proceeded back to Quest in the same soldier like obedience I had presented myself some 100 days prior to the University of Miami 4<sup>th</sup> floor. Having become a veteran at the blood draw and results game, I knew that, that week would only bring the secondary results. The light chain test results that would broadcast the success or failure of the mission would come a week later.

However 2 or 3 days later a big surprise came. I received the 24 hour urine results. I had been told by many sources that it takes a considerable amount of time for the amyloids to regress and hence could take about one to two years for a drop in protein to register. My peers in the support group bore witness to that fact. So as I was ready to open the urine results, I prepared myself to accept that the protein level would probably remain the same, around 1200 which was my pre-transplant level. I did not want to read into the protein results possibly staying at 1200 as implying I was not in remission. That prognostic responsibility belonged only to the light chain level. Good mental state helps acceptance.

As I opened the file on my computer my jaw dropped. The level of protein had dropped from 1200 to 270. That was only 100 points above normal. I was elated. The thoughts rushed in that if the protein was dropping and the light chains were creating the amyloids, and the amyloids were creating the protein in my urine, then a drop in protein must mean the light chains had been destroyed. You follow me here? Let me try and break it down this way. If A (the light chains), causes B (the amyloids) and B (the amyloids) causes C (the protein) then if C is going away it has to be because A went away. Right? I so needed to be right in



this hypothesis. I know this stuff gets complicated but I need you to get my reasoning. Down the road I would learn from two doctors that my reasoning was absolutely right. Sometimes I get weary of being immersed in all this medical knowledge and terminology. But it is my life now. And it is better to be informed than not to know what is going on, no matter how complicated. I just need to remember to factor in some fun in between all these damn tests. Please call me up and remind me as it is so easy to forget. That feels good to get that off my chest. But for a psychology and mental health person, I was starting to kick some serious butt in my new career as a jail house hematologist.

My girlfriends get happy from going shopping or taking vacations, I find true happiness from opening good lab results and boy was I happy. Whoa girl, slow down! I had already seen the consequences of getting ahead of myself. The only thing that could prove for certain that the clonal light chains had been eaten up by the Kool Aid would be the kappa free light chain test....and those results would not come until the following week. I tried to be reserved and hide my joy over my protein level decreasing, but I was beaming with hopefulness throughout my body. The rest of the week was a blur as I tried to busy myself with other activities. By Sunday night I was irritable, the tension of waiting wearing me down. How is it you can want something to come so badly but are scared of it at the same exact time? On Monday the results came. For the first time in the two and a half years I have been opening the results from kappa free light chain tests the results were not in orange they were in green. Could I actually be in the normal range?? Yes I was baby, in the green. The ceiling for the normal range goes up to 19.6 and my level had dropped from 340 to 18. Thank you God. The second remission determining test was the ratio between kappas and lambdas. Mine went from 23 to 1.70 with the normal cutoff range at 1.65. I missed it by .05. They couldn't keep me out of complete remission for 5/100 of a point could they? I was so happy I wanted to scream, instead I just fell into my husband's arms and cried.

So now it is March 7<sup>th</sup> and I have an appointment with Pereira on the 10<sup>th</sup>. I am sure they can't deprive me of the label IN COMPLETE REMISSION. Just in case something unforeseen happens I refrain and restrain myself from blasting my news all over Facebook and the rest of the civilized world. Pereira would have to crown me officially for me to wear that title. Thursday comes and we ride on

down to University of Miami happy and a little cocky that I will be inaugurated into the complete remission club. When the nurse enters the room she is businesslike unconcerned about my results. She informs me that if all goes well today I will be cut down to every 3 months and when I return in June they will expect me to start the revaccination program. I was a bit shocked as I thought that was not supposed to occur until one year out. My surprise was translated into this nurse advising the doctor I would brow beat her about the vaccinations.

**LESSON #27 Taking care of yourself can sometimes be misinterpreted by medical staff as rebellion. Take care of yourself anyway.**

When the doctor came in I made sure she knew that my issues about vaccination were born of legitimate concern. I informed her I had done extensive research. I wanted to have my titers run to make sure the vaccines were in fact necessary. I also wanted to have a lymphocyte panel done to make sure my immune system was high enough to wage an immune reaction in response to the vaccine. It is so nice to have a workable relationship with one's doctor. She agreed to my plan. Next when Pereira pulled out my results she told me she was thrilled. All the indicators were looking good. The kappa level was back in the normal range. The ratio was .05 over. Complete remission I asked shouting? No she said the .05 puts you out of range. My balloon was deflated. I had wanted to hear those words so badly. **LESSON #28 Don't lose sight of the big picture. It is about progress not perfection.** Who made up these numbers anyway? Only God really knew what was going on in my body. I refused to let my obsessive need for perfectionism rob me of this joy. I was feeling good, things were looking good, and I had a great response to a very big procedure. Get with the plan Andie. And I did. In the words of my very wise husband, "Just pull up baby". So I got back into the celebration with my transplant doctor and my husband. When I left that day, Pereira released me to go back to Hoffman in Deerfield and to come see her again in 3 months. Her parting instructions were it's time to start living again... very carefully but start living.

## CHAPTER 6 Life Rebooted...Reentering the Land of the Living

In the last six months or so they had scared the daylights out of me, they had treated the daylights out of me, and they had isolated the daylights out of me and now they wanted me to live again. Not so sure I know how to do that. They say

you never forget how to ride a bike, but I was not the same rider, the landscape of my life was blank and the restrictions and concerns had me confused as to how to proceed. Coupled with all of that, I had really failed to redefine myself and establish a meaningful post-retirement life as I had stumbled into retirement unplanned and unexpected. Being a therapist for 34 years had occupied a big chunk of my identity. I was floating in ambiguity before the amyloidosis reared its head; now that schism of who I am and what I am doing looms even a little larger.

**LESSON #29 *Who you were is not necessarily who you are now or who you will become. Redefining the self is a necessity of life no matter what fueled the need for the change.***

Dealing with other people's mental illness all my life I saw a lot of people go down the road of mental sickness due to a variety of losses that would not allow them to be the person they were. Inflexibility and inelasticity can cause tragic outcomes. Just because you can't be who you were doesn't mean you can't be someone new. And I know this to be true ... so if I could just figure out how to apply this to myself, as I am searching for a new gear to live in, I should be okay. But it is a very good thing I can drive a stick shift. Changing gears is not easy but it is necessary in life. As unsettling as coming to grips with possibly losing my life is, no one warned me I might struggle some, with what to do with that life when it was given back. The process of being diagnosed with an incurable disease, the treatment for it, and the isolation of recovery had shut my vital juices down, reduced my goals to very primary ones and rendered me to living in a survival mode. I think the doctors are trying to tell me I don't have to live that way so much now but I am still too uneasy to come out of the bomb shelter where I have been hiding.

Writing this book has been a big step back into the land of the living. My body is still fatigued and lacks stamina but my soul and spirit are hungry to be helpful and find meaningful activity. In my career I exerted very little effort in finding the jobs I had, but rather seemed to let God move me from place to place where I was needed most, never missing a day of work between jobs in 34 years. Perhaps this is just an expanded opportunity to use my trust and prayer skills and allow God to place me, and use me according to His purposes. It will be a welcome change of pace to pursue Him about something else besides those damn light chain levels.

One of the issues I ran into, in my reentry into everyday life and you may not believe or understand this, was coping with normal stressors. I had been withdrawn from regular concerns and before that had been facing life and death issues for some time. For several months I was in a protective bubble in my home with very little demands from the outside world. It became difficult to put regular problems in perspective and not overreact. I became easily overwhelmed when scheduling more than one task. At first it was because of stamina issues but then it became about a lack of confidence in my ability to function well. I had had so little on my plate for so long even a small amount seemed too much. This led to feeling like I was failing. My husband has always said that I juggle and handle huge problems with mastery, but get tripped up on the simple things in life. It was looking like he was right. How could someone hit a home run in courageously facing a stem cell transplant and foul out over a check that didn't clear or an unexpected request. I think the threatening aspect is that I am aware that everyone else is living spontaneously, but I am still tightly wrapped, preoccupied with being safe. How do I let go?

Another issue is the task of enjoying the remission you do have while the cloud of relapse hangs over your head capable of showing its' face on any given day, or not. Relapse can possibly come in a minute, in a day, in a month, in a year or in 20 years. My dad died of Lou Gehrig's, a disease that has no remission no second chances. I try to remember this when I feel down about my situation. God has used relapse to reduce me from obsessively living years in the future to living one day at a time. This is a gift because in and of myself without the terms my condition imposes, I was unable to accomplish living so strongly in the present. Every transplant patient knows this, but we must take the stand with ourselves as my mentor Kathy taught me, that any day in remission is a good day. She goes further to say, "Why ruin a good day in remission with thoughts of relapse"?

Eventually I stopped beating myself up and started to just understand this was another phase of my recovery from serious illness. I am quite sure when I master this level the next phase will present itself. I always taught my clients that you can't win today's ball game on yesterday's home runs. Sometimes I wish I had been a little less honest with them; it would make me feel like less of a hypocrite when I want to cut and run. Now I know it is time for me to hit some more home runs, but honestly starting out with a single or double will be more than just fine

with me. I gotta get back up to the bat people! I am two and a half years away from 10 hour workdays, going non-stop from one clinical arena to the next, rounded out by daily exercising and household chores. The load I carry in my life now is a fraction of that but feels so much more. Maybe the threat of active amyloidosis rents too much space. I guess I will just have to learn to bloom where I'm planted with what I'm given.

After we left Pereira's office on March 10<sup>th</sup>, H.E. and I discussed the directive she gave to get out there and live again and how we could apply it to our lives. The past year we had been close to one another but to say that fun was missing from our lives would be a gross understatement. With that in mind we decided to do what we used to be very good at, planning fun activities. The first was an overnight trip to Naples to see cousin Abbe and Shelly and then visit with my friend of 49 years from middle school, Noodle. Next we booked an airline reservation for late May to Tallahassee to see two of my grandkids, Justice and Daijah graduate from high school. It has been almost a year since I've seen my 5 grandkids and boy I can't wait. One of the things we wanted to do was have a party to thank everyone for their support and celebrate my survival. We decided to time this with our 15<sup>th</sup> wedding anniversary in July and have a big luncheon. I am a little nervous about being around so many people in close proximity probably wanting to hug me. But this is a better problem to have than the side effects of melphalan, you think? Lastly, when the heat started to turn up last September we had to cancel our yearly vacation to New York. When we thought about going back there this summer, my immune system just didn't seem ready for being smashed with face to face New York subway contact. Instead we decided on Boulder Colorado in late August. We will see cousin Don and also possibly see a game at Mile High. My life will be complete if I make it to Mile High Stadium. H.E. says my first husband was John Elway and my son was Terrell Davis. I loved those guys so much. Being in the stadium where they played will be a peak experience for me. All these plans are a bit overwhelming like going from 0 to 60 in one shot. But if I pare my expectations down remembering I am not the same person I was last year I should be fine. I have also returned to church. A big shout out to Charles Stanley who was keeping me going on TV in the isolation days, but nothing like worshipping in person in my local community of believers.

Let me give you even further evidence of the vanity killing effects of my stem cell transplant. I forgot to even mention that my hair started to grow back in mid-February. The hair is a lot grayer than my pre-transplant hair, but hell I am in remission baby, so it is all good. Because I forgot to write about it, I had to add this piece about my hair that you are reading right now. It is an afterthought and I inserted it into the text at the time that editing began! No lie. How does a woman forget to say that her hair is growing back?

But seriously I understandably neglected my appearance for the past months. I wore baggy gym clothes every day donning my husband's extra-large men's sports jerseys on my women's size small body. I think my cuteness for that look had reached its expiration date. Even my husband who doesn't really care too much about how I wear my hair or if I gain or lose weight was starting to make some comments about my appearance. The comparisons he was making were let me just say not very nice. I tried to play the hurt card, but like everything else in this chapter it really was time for a change; a time to move forward. I started slow with jeans and tapered or fitted shirts. I bought new makeup... and wore it occasionally. Then I did a big breakout move and wore a dress to church! Strange and weird at first, but I did I feel and look better. I taught my clients this principle about change, you make the move forward when the pain of the change is less than the pain of remaining the same. There was definitely a big payoff, getting out of my comfort zone and shedding my hospital and home bound seclusion outfits.

On March 17<sup>th</sup>, 2016 I resumed my care with Dr. Hoffman in Deerfield. I felt a deep joy to return there, a sense I had successfully completed one leg of the journey, which in fact I had. Hoffman and I were glad to see each other like one army buddy returning from the front line ....alive and well. Before we could get down to the nitty gritty of my numbers, questions etc., Hoffman noticed both my husband and I were wearing shirts marketing the fight against amyloidosis, so we both made it into the doctor's twitter account that day. The hashtag read #motivatedamyloid patientandherhusband. I guess we are that, but so is he, truly caring about the advancement of the fight against the disease. Like Pereira he was very happy about my results, however his main concern was that my remission numbers stick. To that end I will see him monthly and be tested for three months.

If the light chain levels stay put, he said he would be delighted to crown me in full remission, if they do not we must consider medication.

So let me tell you a funny story before I reveal the outcome of the first of the 3 monthly labs Hoffman wanted to review. The week while I am, yes again waiting for the results to come in (my part time job), I received a letter in the mail thanking me for a \$50,000 contribution to my retirement account. I did not make any contribution, in fact I severed employment 16 years ago with this employer and am not permitted to make further contributions. I made some calls investigating the situation and I am told that the employer made the contributions and no one knows anything more. So in my mind I have done my part and I am mentally planning how the money will be spent. The point I am going to get to, is that remission is priceless to me. As the time came for me to open the light chain results I was waiting for, I humbled myself in prayer and told God, "You can take the \$50,000 just leave me in remission." In another space and time I would be praying to keep the \$50,000.

So the April tests are opened and the levels have not moved. Yayyy!! Another month in remission. Two months down and one to go to my possible coronation. And the next day the call comes, they found the mistake and the \$50,000 is now in the wind. But I am in remission and there is absolutely nothing else that matters more. Money can't buy good health and today I have some good health. I am in remission today; I am a very rich woman.

Hoffman was not pushing me at all about the vaccination protocol. I scheduled and went for a consult with an immunologist. He ran titers to see if I had coverage for all the proposed vaccinations. He also ran a new test called a lymphocyte subset panel to test my CD helper cells and NK killer cells to determine if they were high enough to even form a reaction in response to the vaccine. The results of all this lab work was very telling. My CD helper cells were as low as a full blown AIDS patient. Vaccination will have to wait. Though this is a hematology problem I learned that consulting with an immunologist was a very wise decision. Secondly the titers revealed I was still covered for all but 2 of the 8 vaccines they were trying to give me. I avoided a lot of unnecessary medication being injected in me for no reason. **LESSON # 30 Search things out. Research. Ask a lot of questions. Gather information.**



And now on April 20, 2016 as I discuss the tasks, trials and celebrations involved in my re-entry, I celebrate my 5 month post-transplant anniversary. And today is a special day for another reason. It was 5 months and 18 days ago that I had to say goodbye to my pool and my love of swimming along with it. But today in my best Adele voice I was able to sing hello to my pool again. I felt free in the water. I feel my muscles moving in the water. The sun feels good shining on my skin. I am alive again.

## IMPORTANT NOTICE

If you have been reading along thus far and are in fairly good health, you may have thoughts that I went through a lot. This disease is really a horrible one and the level of suffering and pain that I have gone through is not at all representative of what most amyloid patients go through. Most have multiple organ involvement, (heart, lungs, nervous system, kidneys, gastrointestinal, liver and or spleen). Every day I am hearing accounts of Amyloidosis patients having to have fluid drained, rampant diarrhea, heart and kidney failure, (some even require these organs to be transplanted), dramatic weight loss, inability to eat, screaming neuropathy pain, and blood pressure so low they cannot stand up. From the tone of my writing you can tell that I have not even come close to anything I have just described. I am only taking 2 medications due to the transplant and those meds are slated to be discontinued in another month. Most amyloid patients are taking tons of medication. I opened my book stating I had survivors' guilt. Can you understand why I might feel that way? If early diagnosis could affect others in the manner it has helped me, how can I not want to get out there and scream this message in some capacity? I want to find some way to get the early detection message out. I have witnessed many people just wandering around for years, getting sicker and sicker, while tossed from doctor to doctor failing to make the diagnosis. Many die before they receive the right diagnosis, others get diagnosed when they are on deaths doorstep too late for successful treatment intervention.

*The medical community must ask itself why doctors are failing to make the amyloidosis diagnosis in the face of gross symptomology. The medical community*

must look at one woman who was able to obtain an amyloidosis diagnosis with a paucity of serious symptoms but a great physician noticing some subtle ridging, (a telltale amyloid sign), along the edge of her tongue. In order to find amyloids you must consider and think about amyloids. You can't find what you refuse to think about or look for. My motto is got light chains... think amyloids! This book will have accomplished its' mission, if it can have a role in at least one person achieving an early diagnosis.

## CHAPTER 7 Growth and Change in the Darkness...Spiritual Reflections

During my career as a therapist I would sometime ask a client the following question. "Do you think you are attracted to me or feel close to me because of my many years of schooling, training and degrees? Or do you think the bond we have is more about you being drawn to all that I have suffered and learned from in life?" The answer was always the later. Struggling as a young girl to understand the terms of this life and also to learn how to cope with it, it became obvious that difficulties are universal regardless of age sex, gender, color, religion etc. After my initial conversion to Christianity as a young woman of 23, my strong attraction to my faith has been and continues to be a strong promise that I can grow in the midst of darkness, problems and adversity. I loved the idea that if we had to suffer in this life, that suffering could be purposeful or meaningful if we brought God into the mix of our circumstances. These past few years have provided a very strong opportunity to test this hypothesis again and I do believe it remains true. I have grown in spirit and character through this very difficult time.

I would be honored if you would continue to stay with me as I share some of the Scriptures that have impacted my struggle to cope with my disease, and my plight to spiritually evolve in spite of that disease. Initially, I hung onto Hebrews 12 verses 1-2, Therefore, since we have so great a cloud of witnesses, let us throw off everything that hinders and the sin that so easily entangles and let us run with perseverance the race marked out for us. Let us fix our eyes on Jesus the author and perfecter of our faith who for the joy set before him endured the cross. This appealed to me not just for the running analogy! At first I focused on the great cloud of witnesses and took to broadcasting my need for prayer wherever and whenever I could collecting supporters. While support feels great I came to learn it is no substitute for personal responsibility in facing your problems head on, or in developing your own relationship with God. I gained a lot of strength when I stopped riding the spiritual coat tails of others. Facing God on my own anchored me in a way that standing on the prayers of others could not. Let me explain myself this way; my relationship with God is the cake and the supportive prayers of others is the frosting. The great irony of life is we do not flourish when we live in a vacuum. We need others to reach our full potential. However, only we can run the race and confront the hurdles on our path; no one else can take our place. I went on my own to face my transplant with the cheers, prayers and applause of a stadium of supporters tucked away in my heart. I am still continuing to face my God one on one but do welcome the prayers of anyone offering!

Since I was a very young Christian struggling with life drug free, healing from being raised in dysfunction, low self-esteem and image issues, I was drawn to Romans 5 verses 3-5. It says, But we also rejoice in our sufferings, because we know that suffering produces perseverance; perseverance, character; and character, hope. And hope does not disappoint us because God has poured out His love into our hearts by the Holy Spirit. Wow this is heavy stuff! I was coming from a background where maternally I was taught that a grass stain on your clothes, or eating after 5pm when the dishwasher went on was a Greek tragedy. She was someone who couldn't let go of anything. The paternal side modeled that things like losing your job or the house were only opportunities to do some more

serious gambling. He was someone who would let go of everything. Not great role models for handling or putting life's problems in perspective. These verses were profound to me in that they suggest while we may not be able to change the nature of the issue on our doorstep, we can apply attitudes such as rejoicing, hanging tough and enduring, and hence be rewarded with improved character and hope. Outside problems and stress when handled scripturally can result in inside growth. That is a bargain you can't buy in Macys. These scriptures formed the foundation of a motto I've employed throughout my life: Don't run from the problem, run to the problem and make friends with it. I have applied these principles in my life. No they didn't always take away the problems I was facing, but they certainly took me through them and helped me to grow a bit. And this present darkness of the past several years was no exception.

In Isaiah 61 verse 3 we read: He gave them a crown of beauty for ashes, the oil of gladness instead of mourning, and a garment of praise instead of a spirit of despair. They will be called oaks of righteousness, a planting of the Lord. So this tells me God is a God of tradeoffs. Release your garbage to God and He will replace it with much better stuff, is the Barshay Williams translation of Isaiah 61. As I locked myself in my prayer closet petitioning God for my physical healing, a strange thing began to happen. The more time I spent with God the more aware I became of things within me needing change. Spending more time with a Holy God cast a light that captured my ego run riot, entitlement, anger, gossip, criticalness, fear and jealousy. The Bible calls this sin, my training looks at it as character defects. I knew my physical disease was ugly but I became aware of negative behaviors, attitudes and patterns that have always been undercover, not exactly blatantly obvious, but were now rising to the surface from the stress of the situation. I wanted nothing within me to prevent my blessing.

I became convicted that I could not entreat a holy God to help me in one domain, (the physical part of me), without presenting Him full access to my whole person. Perhaps God had authored all of this to have me focus on my inner person. John 15 says I am the true vine, and my Father is the gardener. He cuts off every

branch in me that bears no fruit. While every branch that does bear fruit He prunes so that it will be even more fruitful. Well okay now, I need to have some spiritual landscaping I thought. And I believe looking back that is exactly what happened to me. In 2 Corinthians 4 it says that outwardly we are wasting away but inwardly we are being renewed day by day. My age and my diagnosis were all factors witnessing the start of this outward decline. It is quite a task to age and confront illness render you not being what you once were. I have to remind myself that things go better for me when I accept the terms of life as they are. Life on life's terms not on my terms, is I believe the correct equation. I am learning to love my life in the physical/natural realm on one hand while progressively placing more value on the eternal and spiritual aspect of my being. Not easy stuff but very little of what I have written about in this book is. But Aha, now I find a promise in Isaiah that in the midst of this process, I can still grow in the spirit.

And I took this and ran with it. I confessed and worked on everything I noted above, and asked God to replace those characteristics with peace, humility, courage, acceptance, contentment and kindness. Next I set my will to stop practicing what negative behaviors and attitudes I could, and asked God in the spirit of Isaiah 61 to make me a spiritually prettier person. It is still a work in progress and sometimes a struggle, but well worth the struggle and I want to keep trying. The grace of God and sheltering myself in His refuge restores me and gives me the rest I need to continue on in my journey. And that folks is the story of how I grew and changed while negotiating the darkest period in the history of Andrea Barshay Williams.

Next let's take a look at 1 Peter 5 verse 10. And the God of all grace, who called you to His eternal glory in Christ, after you have suffered a little while will Himself restore you and make you strong, firm and steadfast. When I was young and mixed up, I had unrealistic expectations about this life. Some of those expectations were shed and unfortunately replaced with newer redesigned distorted beliefs. There was actually a point in time where I thought that nothing really bad would touch me because of the noble work I did with disempowered

populations. Like God couldn't get the work done without me, note to self a little overestimation of self-importance here, ya think? Before that delusion, I had formulated another crazy belief that I was physically invincible or superior, (sounds kind of crazy to hear myself say that out loud but I must share the truth), because I could run in excess of 26 miles. I saw that belief evaporate in 1995 when I was unable to walk or sit in a chair for almost 2 years. How did I get so lost and off track in my own mental process? I don't know if you have some offbeat ideas renting space in your head too, but I do know if you do it will certainly lead you, like me astray, if left unchecked. I also was in a bit of denial about death and facing it on a personal basis. Amyloidosis broke through that denial quick and hard.

And, so what I love about this scripture in Peter is, it grounds me in reality and good expectations for this life; there will be suffering in this life. No need to freak, its coming baby. But God is sovereign and in His time and in His way there will be an end to the trauma you are facing, a positive end to it. It may be in this life or it may not. I also like the fact that it is God who does the restoring, which takes a big weight off of the believer's shoulders. This gave me a lot of hope and comfort while I was in the dog days of pre and post- transplant. But it has become a help to me in everyday living. Things get clearer when you are fighting for your life, and you are in survival mode. It gets a little tricky to maintain that humility and all that you learned in the pit when the dust clears and you are restored to some degree of normalcy. Doing addiction treatment, I used to teach that the desperate get sweetly willing. The task is maintaining that willingness when the desperation evaporates. I am hoping and praying to keep the spiritual ground I have gained and not slip backwards. Believe that!

I believe in miracles. In fact I was the recipient of one in 1978. This happened when I, a then young 25 year old woman, was running alone in the early morning hours. A man ran up on me, knocked me to the ground and started dragging me into the woods to rape me. In desperation I called out to the Lord. My prayerful plea sounded like this, "Okay Jesus I've been hanging out with you for 2 years

now, if you're really real I could use some help now." At that moment something changed. My fear left and a peace came over me. Immediately I felt my would be rapist lose his power over the situation. In retrospect this was some divine intervention! I turned and faced my attacker and said, "Whatever happens here today we will go through it together." He then let go of his physical hold on me and we walked together to a bench where I shared my faith with him for 2 hours. The early morning nightmare turned miracle ended as we walked to my friend's house and then we drove this guy to work. It was the most unreal, surreal event of my life.

Several days later in church, Psalm 91 was prayed over me to heal my battered psyche from the trauma of the attack. Now fast forward 37 years to my present saga/ordeal, and I will inform you that the same Psalm 91 was the instrumental vessel in anchoring my boat. Daily I hid myself in the shelter of the Almighty finding refuge there; daily I claimed protection for my soul with His wings, faithfulness and feathers covering me; daily I believed that because I did all this and loved the Lord no harm would come near my tent as promised; daily I envisioned His angels guarding me; daily I placed my faith and hope in God's promise to rescue me because I loved Him. And this has sustained and healed me thus far. Just the same as in 1978. God's word... the same yesterday, today and tomorrow.

It's hard to know how to end this book as my story continues. So let me take a writer's privilege and call this a pause rather than an end. Should I ever again become pregnant with ideas, experience, information and advice, and reflections and insights, I will express it all by giving birth to another book. And I will invite you once again to come along. Thank you for allowing me to share my travels with you. I will leave you with the gift of Psalm 91. FINAL LESSON. What is impossible with men is possible with God. Luke 18 verse 27. God Bless.

Psalm 91 God's protection in the midst of danger

He who lives in the shelter of the Most High will rest in the shadow of the Almighty. I will say of the Lord, "He is my refuge and my fortress, my God in



whom I trust". Surely He will save you from the fowler's snare and from the deadly pestilence. He will cover you with His feathers, and under His wings you will find refuge; His faithfulness will be your shield and rampart. You will not fear the terror of night, nor the arrow that flies by day, nor the pestilence that stalks in the darkness, nor the plague that destroys at midday. A thousand may fall at your side, ten thousand at your right hand, but it will not come near you. You will only observe with your eyes and see the punishment of the wicked.

If you make the Most High your dwelling—even the Lord, who is my refuge—then no harm will befall you, no disaster will come near your tent. For He will command His angels concerning you to guard you in all your ways; they will lift you up in their hands, so you will not strike your foot against a stone. You will tread against the lion and the cobra; you will trample the great lion and the serpent.

"Because he loves me," says the Lord, I will rescue him; I will protect him, for he acknowledges my name. He will call upon me, and I will answer him; I will be with him in trouble, I will deliver him and honor him. With long life I will satisfy him and show him my salvation.