My Life as a Hemophiliac

I was born in the spring of 1953 in the suburbs of Pittsburgh, PA, the first born for my parents. After my birth when I arrived home from the hospital my mother made the frightening discovery that my diaper was full of blood. I was immediately rushed back to the hospital at which time my diagnosis was confirmed Hemophilia Type A-moderate, although through the years I would present as severe. Hemophilia wasn't completely foreign to my mother as she had grown up with a brother, my uncle, who was a hemophiliac. It is unknown though whether the family knew enough about the genetics of hemophilia to know that there was a chance I could be a hemophiliac. Also, this was during a time when she wouldn't have known if I was even going to be a boy or girl until birth.

After my diagnosis my parents likely realized that they would now have many more concerns than just being new parents. This was when my grandmother, having raised my hemophiliac uncle, stepped in to help raise me. I was fortunate enough to live down the street from her and so it was a great option for me to be able to have more attentive care. My dad, having married into this, was less familiar with the disorder but was always very concerned about the risks of bleeding and strived to make sure I always had the most safe items available. Everyone was very attentive and this is why I spent most of my early years in a playpen with the hope that I would be more safe from the bumps and bruises that come with being a toddler.

During my childhood years I was seen at the Children's Hospital of Pittsburgh. Growing up in the 50's and 60's hemophilia was still somewhat of a mystery so my treatments were often more harmful than helpful. For example, they would treat my joint pain from the bleed with aspirin and they would put me in a cast and traction for leg bleeds. Every time I had a bleed my parents would have to take me to Pittsburgh to the Children's Hospital. We would first have to drive into the city, then at the hospital we would wait long hours to be seen. Then, once seen, they would finally confirm what I already knew which was that I had a bleed. After that they would order the frozen plasma, wait to thaw it, and then administer it intravenously over hours. Sometimes I could then go home but if the bleed was bad enough I would then have to be hospitalized. If the bleed was in my leg, often my knee, they would also cast the leg and use traction for therapy for the bleed. This pain was absolutely horrendous.

As you can imagine this process was often a challenge. Driving into a big city like Pittsburgh was stressful, my dad worked long hours trying to provide for my needs, and my mom didn't drive yet. Plus, I hated the process so much that at times I would ignore a bleed and not tell my parents. Then there were some situations when I'd have a bleed and our insurance wouldn't cover my treatment. This was when my father would search through his friends and co-workers to find people who would be willing to donate blood to give me a transfusion. Because of these reasons sometimes we didn't go to the hospital or going was delayed. Unfortunately, this would only make the bleed worse and I would then be at home in agony. Some of my worst memories are being at home with a bleed at night time when everyone would go to bed. I remember hating that time of day because the night would be so long and I would be lying there all alone in excruciating pain, unable to sleep.

Hospitalizations were a big part of my childhood since going to the hospital was the only way I could receive products for my bleeds. Most of the memories from being in the hospital at

this time are sad. But, I do remember this one time when I was in the hospital over Christmas with a bleed. I had a surprise visit from Lynn Hieber and Joseph Potocnik who were baseball players and they also gave me a signed baseball. This was so exciting to me and it brought me great joy during a sad and painful time.

The Children's Hospital of Pittsburgh was a teaching hospital. Dr. Jessica Lewis worked there and was an expert on blood disorders and hemophilia. She would often have students come into my room and ask me questions about my health. I was instructed by her to only answer their questions with a yes or no and it was their job to figure out my diagnosis.

Then during one hospitalization in 1965 when I was admitted to have surgery to remove an impacted 12 year molar I was given plasma every day for 2 weeks for a total of 24 pints. And because they weren't screening blood products for hepatitis C I, unfortunately contracted it. I remember being scared as they put me into isolation where everyone had to enter wearing gowns. I would have no idea of the negative impact years later that hepatitis C would have on my body.

When I was in 6th grade I was fitted for leg braces to help with stability since I was having so many knee and ankle bleeds. Both of which were spontaneous and injury related. I had so many issues that year related to hemophilia that I missed an entire year of school. And because of that, the Catholic school I was attending wouldn't allow me to return and so I had to start going to the public school. At this point my mother didn't want me to use the braces any more since it didn't seem to be helping and they were such a challenge to wear. Without the braces my legs were able to move more freely and get stronger. The public school was hard and my mother was so afraid of me going to such a big school. She would make me leave my classes early so that I wasn't in the hall with the crowd of other children. Her hope was that this would decrease the risk of me getting hurt, which I think it did but it also made me stand out to the other children in a negative way. Since I wasn't in the hall with the other children I missed a lot of the socializing time and I was seen as different. This led to bullying and in fact one time a kid pushed me in the hall causing me to fall and have a bleed.

My parents had more children after me and actually ended up having 3 more boys, none of which had hemophilia. The effects of the bleeding disorder kept me from making friends at school so I relied on my siblings and many cousins who lived nearby for friendship and play time. Growing up I loved sports like baseball and football. When we would play I always knew that playing meant I would likely get a bleed, but that was a sacrifice I was willing to take. Fortunately, my siblings and cousins would often try to make accommodations for me when we played games. Sometimes they would have someone run for me after I hit the baseball or during football they would allow me to be the all time quarterback.

As the years went by, I would have many cousins born who were diagnosed with hemophilia. Which meant I would have other boys in my family that I could relate to, even if they were younger, but being older made me a sort of role model for them. I continued to spend most of my time growing up at my grandmother's house that was down the block from my house. I would enjoy the extra special attention she would give me which helped for all the pain and isolation I felt in the other areas of my life. I think my grandmother, having raised a hemophiliac, always felt she could take better care of me especially with my mother having 4 other children. I got very close with her and my fondest memories are when she would take me fishing. This was an activity that was very safe for me so I enjoyed it very much.

As I got older and reached the high school years my dad would insist that I further my education. He hoped doing so would give me a good paying job with insurance and also a job that would provide a less physically demanding work environment. In high school, I got interested in printing and after graduating in June of 1972 I decided to pursue a printing degree from Williamsport Community College (now Penn College). My parents were happy that I was continuing my education, but they were worried because Williamsport was so far away from Pittsburgh. I would be far away from my family, from my doctors, from the Children's Hospital, and from a community that was getting more knowledgeable with how to treat hemophilia. Plus, I was going to be on my own now. I remember one time during my first year in school when I had to fly back to Pittsburgh for an uncontrollable finger bleed. But, the good news was research and treatment were improving for hemophilia and in fact it was at Williamsport when I had my first dose of Factor VIII. Factor infusions were life changing. It meant that I didn't have to wait so long for a plasma infusion to infuse and since it was isolated to just Factor VIII that made it more effective.

It was also at Williamsport that I met my wife and had my first child. In 1975 after 2 ½ years in college, when I was in my 20s, I got my degree and moved with my wife and daughter to State College to start my first job at Josten's Printing Company. State College was a little closer to Pittsburgh and the job had insurance so that was a relief. While there I eventually started seeing Dr. Richard Dixon. Dr. Dixon was a blessing. He had trained under the infamous Dr. Mary Elaine Eyster, an expert in the field, and she was who he consulted from Hershey Medical Center for everything when treating me. I didn't do anything without his consultation and he didn't do anything without Dr. Eyster's consultation. It was a good working relationship that really helped me. I had a competent and caring doctor who was a direct link to Dr. Eyster, whom I had recently just started seeing. It was on July 25, 1974 that I started going to the new Hemophilia Treatment Center (HTC) at Hershey Medical Center (HMC) every 6 months. And it was Dr. Dixon who was the one that took the time to teach me how to self infuse blood factor. That was another life changing moment that positively affected my course of treatment. I no longer had to ignore bleeds because of the agonizing process or deal with the ER trip and long wait to get my treatment. Now I had the freedom to infuse the factor when I needed it in the comfort of my home without any delay.

Sometimes when treating one medical issue, the medications or treatment can cause another issue. That is what happened in the summer of 1982 when I was 29 years old. Due to my history of joint bleeds I developed arthritis that was causing severe pain. I started taking Indocin for the arthritic pain when I suddenly developed extreme fatigue and lightheadedness. During examination I presented as being pale with a low hemoglobin of 7.3 and a hematocrit of 21.7. It was discovered that I had been suffering with a bleeding stomach ulcer that required the transfusion of 4 units of packed red blood cells and transfusions of factor VIII. The Indocin was withheld and I was started on oral medications to treat the stomach ulcer. Moving forward I would have to be more aware and conservative about taking pain medications.

In the 1980's when I was in my 30's the HIV/AIDs epidemic hit the hemophilia community. The tragic story of Ryan White affected us all. My wife and I were scared to tell anyone I was a hemophiliac and at one point we even advised our kids to keep their dad's hemophilia diagnosis private. My blood was being checked yearly for HIV. In 1986, I received a dreadful letter that said I was HIV positive. We were obviously devastated. My wife and now 3

kids were also tested during that time. I remember when we all went to HMC to have their blood drawn. The staff was so upset and crying because all of their patients were testing positive and dying. Thankfully my wife and kid's tests all came back negative. My cousins weren't so lucky and all of them tested positive and one by one they started dying. An entire community was being wiped out at a time when advancements for the treatment of bleeds were improving the morbidity of hemophiliacs. This was such a scary time for me and my extended family. About a year later after receiving the letter that I was HIV positive I got another letter that the same blood was tested 3 more times and each time it was negative. The initial test was actually a false positive. Some time after that I remember talking to one of my AIDs positive cousins on his deathbed and he was saying how he can't believe they did this to us. I never had the heart to tell him my test was actually a false positive and that I didn't actually have HIV. It was such a devastating and emotional time. A community of patients, including myself and my cousins, did what we were advised by the medical community and that was to keep taking the blood products.

In 1997, when I was in my 40's, Dr. Dixon was by my side helping me during a time when I developed sepsis from a misdiagnosed strep throat and I was being seen in the Centre Community Hospital (now Mount Nittany Medical Center) ER. He had gotten word that I was in the ER and being the attentive doctor he was he rushed over to see me. Dr. Dixon was the one who burst into the room screaming for the tech to stop doing what she was doing. I was confused and out of it at the time the tech was drawing labs to figure out what was going on. The ER doctor had ordered ABG's to be drawn from the artery. Dr. Dixon stated "If you draw those we will have bigger problems than we do right now! STOP!". I was very sick at the time and spent many days in the critical care unit and a total of 10 days inpatient. I went home with a PICC line and home antibiotics. I ended up with a frozen right arm elbow joint from the infection that left me with only 10% movement. So, on top of my hemophilia joint issues I now could no longer reach my right dominant hand to my mouth to eat, drink, or even brush my teeth. I also had to re-learn how to write with my right hand.

I was so thankful for Dr. Dixon during this time. He had walked through this and so many health issues with me. Which is why it was so sad the day Dr. Dixon announced that he was retiring. I was Dr. Dixon's first patient when he started at State College and when he retired he made sure I was his last appointment (2006). We developed such a trusting relationship through the 30 plus years he treated me. As a hemophiliac it is always worrisome when a doctor you trust is no longer available. We have experienced so many moments in medical facilities where medically educated people don't know or understand hemophilia.

After working at Josten's for 37 years (58 years old) in 2012 my wife and I made the tough decision to relocate with the company to Tennessee. The State College plant was closing and moving would allow me to keep my job. While I was on a work trip to TN for training prior to the move I suffered a horrendous fall. The work meeting was being held in a tiered conference room. The flooring was black and white checkered and the steps didn't have warning strips to let you know a step was there. Due to my bifocals when I looked down I didn't realize that I needed to go down a step and I fell. I suffered a compound fracture of my right arm that required surgery to place hardware in my arm to put it back together. So, here I was in a big city states away, without my wife, or hematologists and having major surgery. I was thankful for my friend and longtime co-worker, Jim, who was by my side until my wife arrived. I was also

thankful that Vanderbilt was a knowledgeable hospital that had a Hemophilia Treatment Center (HTC). As a hemophiliac it is always comforting to live where there is a HTC.

While living in TN, outside of Nashville, I received good care at Vanderbilt Hospital and it was there that I started seeing a Lymphedema Specialist that implemented leg wraps and compression stockings to help with the swelling in my leg. The specialist was a man who was originally from Germany and he had great knowledge about lymphedema so he was a huge blessing to me. My left leg was suffering from recurrent cellulitis infections from the lymphedema that would require hospitalization to receive several days worth of IV antibiotics. The lymphedema started as a result of the portal hypertension, which was from the cirrhosis that I developed from the damage done to my liver after contracting hepatitis C.

Then, after spending 4 years in TN, the company unexpectedly eliminated my position, just 3 years shy of my retirement. This was so stressful because I wouldn't be able to receive Medicare benefits for another 3 years (at 65). Which was a major concern for how I would pay for my treatment and expensive blood factor. We then decided to move back to PA to be near one of my daughters which was also near Hershey Medical Center and their HTC.

Despite my chronic pain, damaged joints, and health issues related to hepatitis C I persevered and worked 40 years (62 yrs old) at Josten's as a Supervisor and dedicated employee until, against my wishes, they let me go. It was then that my family finally talked me into applying for disability, something that was encouraged years prior by Dr. Dixon. Since my current physical limitations had an affect on my standing and walking abilities, finding a job that would accommodate that was proving difficult. The process was grueling and after initially getting denied I spent countless hours working on my appeal. As instructed, I was going into the Social Security office on a regular, often weekly basis and even reached out to my local State Representative for help. It took 18 long months of waiting before I was finally approved for disability. At least now I would be sure to have insurance again, which was my only goal.

At this point, I started having even more effects of the damage hepatitis C has done to my body. The portal hypertension had caused my spleen to be so full of blood that I had a procedure done in 2016 to put 34 coils in the main artery of my spleen. This was done to block off the blood supply to my enlarged spleen which "killed it " but also would keep me from bleeding from the spleen in the case of an abdominal injury. And the lymphedema continued to exacerbate the cellulitis infections which are now getting worse. I started having them more frequently and this was when Dr. Link (my primary care dr) and Dr. Whitener (my infectious disease dr) decided to put me on a daily antibiotic dose to help manage the infections.

Then in June of 2019 at the age of 66 I took my first dose of a brand new prophylactic drug called Hemlibra. This drug was a major advancement in the treatment of hemophilia and life changing for the hemophilia community. Hemlibra is a subcutaneous injection that I administer to myself at home every other week. It works by bridging the activated coagulation of factor IX and factor X which is normally the function of factor VIII, the factor missing in hemophiliacs. With this new drug my need for blood factor infusions has decreased which has been amazing.

A month later in July of 2019 while visiting a family member at a hospital in upper PA at the NY border I developed a sudden fever. This fever came on fast and without warning. To find relief for the uncomfortable feeling of the fever I went to my car to lie down. This was the first time that I got confused with a fever. It was in that confusion that I attempted to drive.

Luckily my car bumped the handicap pole at the front of the parking space preventing me from driving. Moments later when my wife came to check on me and saw my current state of confusion she immediately got me to the ER with the help of hospital staff. I would now find myself in a foreign hospital in Sayre, PA without a hemophilia treatment center and my team of specialists.

There are books and books of medical records on my extensive health history. With all of my diagnoses my body is very complicated to treat. If you attempt to correct one issue you have to be mindful of all the other issues and it's all about balance. The doctors treating me had very little knowledge of my history and complicated health. But, they were rightfully concerned about sepsis and so it was good that they pumped me full of IV fluids. But, when doing that they also completely took me off lasix. I take lasix on a routine basis for my edema. So, with the combination of overload on fluids and the lack of lasix my body was forced into congestive heart failure. At this point my lungs were filling up with so much fluid that I needed oxygen and had difficulty breathing. This gave me anxiety and scared me to the point where I was tearful, which rarely happens. My wife was continually updating our three children at which point they decided to drop everything to drive up north to be with me.

It gave my wife and I great comfort to have our three children (plus 2 granddaughters) by my side. My younger daughter is a nurse so she was able to help communicate my health issues with the staff and doctors which helped get me stabilized. She also contacted the Hershey HTC on call to discuss the issues and to possibly facilitate a transfer. Oftentimes we have to educate the medical staff about hemophilia and this time was no different. My daughter was so concerned about my current state that she spent the night by my side while the others (minus my son who returned home) stayed in a hotel. The doctor who was treating me was a nice lady. She was young but really listened to us and assured us we didn't need to do a transfer just yet. Soon after, with the risk of sepsis gone they were able to discontinue the IV fluids and start administering the lasix. At this point the CHF started to resolve, the oxygen needed was resolving, and the IV antibiotics were improving the breakthrough leg cellulitis infection as well. Soon after I was discharged.

Then in September 2019, at the age of 66 yrs old I made the tough decision to have surgery to fuse my left ankle with the hope to alleviate some of the chronic pain I was having. The post op road was predicted to be long with a projected 18 month recovery. I had the surgery and was admitted post op. The surgery went well and my bleeding was under control. Since I was now taking Hemlibra, my Factor dosing was less predictable. But the team and Dr. Eyster figured that part out. With my history of damaged joints my gait and balance are unstable at baseline. So, after this surgery I was not prepared for the restrictions I would be under. I wasn't allowed to put weight on my left foot. Which for most that wouldn't be an issue and they'd be fine with crutches. But for me that simply wasn't an option.

So it was decided that I would need to go into rehab after discharge. But, due to my need for blood factor and the high cost of that, Medicare wouldn't cover rehab. They would pay for the blood factor at home and they would pay for rehab. But they wouldn't pay for blood factor at rehab since this combination would go over the daily allotment they allow. So, we had to come up with a plan for home care. My wife and daughter learned how to use the walker and wheelchair to navigate the 2 steps to get me into my house. And I received home physical and

occupational therapy. Recovery was hard work for my family and I, but I pushed through and made a full recovery until after 15 months when I suffered a setback.

I developed another cellulitis infection on December 31, 2020. Since this was peak covid time it took 3 trips to the ER, 3 negative COVID tests, and persistence until the hospital would admit me for the needed IV antibiotics. WIth my treatment delayed my leg looked awful and a few days after discharge my foot began to swell with intense pain. This continued for a few weeks until Dr. Juliano suspected it was due to infected hardware. So, on January 27, 2021 I had surgery to remove parts of the hardware but after this surgery I didn't recover well.

The pain was so debilitating that I was bed bound for 8 weeks. After complaining for that long I was finally seen by the orthopedic surgeon on March 4, 2021 who was scratching his head. He didn't understand what was going on and he told me I may have to have the leg amputated, which was shocking and devastating to say the least. My nurse daughter who was with me in the dr office was in tears upon hearing this news. It was at this point, he said we could try three things first. We could add Vitamin D to my meds, he could give me a steroid injection, and I go back to another lymphedema specialist. So, of course I wanted to do all 3 of those options. As advised, I added Vit D to my medications and I received the steroid injection. After this I was able to get out of bed and start moving around with a walker. I also had some relief from the pain.

Then on March 15, 2021 I went to the lymphedema specialist. This was my first time being seen at this lymphedema office. I arrived using a walker but my foot was still so swollen that I couldn't get my shoe on. I was desperate for relief after being bed bound for so long with intense pain. The specialist assessed my leg and reviewed my history. She then provided clarity and peace by reassuring us that my entire lymphatic system was out of whack. And so, that's when we came to the conclusion that what likely happened was the mistreated cellulitis infection and then the surgery created the fluid imbalance. She felt confident that we could get the fluid back under control. She developed a plan which included restarting the leg wrapping technique I had done in the past and getting a home leg pump. We arrived desperate that day but then left the office with hope.

Two weeks later at my next appointment I arrived with my shoe on and able to walk with a cane, the wrapping was working. At this appointment I met a Medi representative (stocking brand) whom the specialist invited. This office wasn't part of this rep's territory but she since lived nearby and she was willing to help advise me. This was a blessing. Come to find out this lady knows the German man I was seeing in TN. This gave me peace that I was where I needed to be to get help. She and the specialist discussed the plan and she fitted me for new stockings. Soon after this appointment I was able to get back to my baseline gait, something I didn't think was possible.

Through the last few years, I had never stopped wearing the stockings since first starting them in TN. And, the specialist noted that I was her most compliant patient. She said the reason I was able to get back to baseline is because of my hard work and compliance. We were so appreciative of her help to get my life back again.

Currently, my newest life-modifying issue is that when I have my breakthrough cellulitis infections (despite the daily oral antibiotics and use of compression stockings) the sudden fever causes me to be confused. My leg doesn't show any warning signs of an infection until after the fever breaks. So, I am unable to predict when the fever will start. There have been many nights

that the fever suddenly starts and despite taking tylenol right away I still get confused which creates a fall/safety/bleeding issue. During those times, I have been fortunate to have my wife at home and my daughter down the road. And thankfully once the fever reducing medication starts lowering my temperature the confusion does resolve. But, as a family we have decided that I can no longer spend a night at home alone for fear that I will have a fever with confusion and fall.

During my last cellulitis episode it was accompanied with fever and confusion as usual. But, this time I also vomited and my Dexcom blood sugar numbers started to skyrocket. My nurse daughter, who monitors my blood sugar numbers on her phone, saw the numbers trending up. She was concerned that they were going to go dangerously high. And because of my current state of confusion she was unable to communicate with me about any other factors that may be causing them to rise like what I recently ate or if my site was or wasn't working. But, thankfully in the early morning hours the blood sugar numbers started to plateau and then drop back to my normal range and the fever resolved which meant the confusion resolved. These episodes are always scary.

As usual, the next day I went to my dr to be seen and it was decided that I needed to go to the ER for treatment. I still continue to dread this process so much and still procrastinate a bit about going. Through the years one thing that has not changed is the amount of time it takes for someone to be seen in the ER. To help reduce the time in the ER sometimes my infectious disease dr will call ahead and alert them about me. Thankfully this is what happened this time so it did help get my treatment started more quickly. But, also while going through the procedures in the ER I was approached by the hospital staff about a new home hospital program at HMC called home recovery care. They explained that they felt I was a good candidate for it and informed us about the program. We communicated this to our children to help make the decision. Honestly, on paper it sounded too good to be true. But, sure enough after a few more hours everything was arranged to transport me home with home recovery care.

I was amazed at the new program, because it was a perfect fit for me and my situation. I was able to return to my home, to my bed, and to my own yummy food. Plus, I was able to have my children more easily visit me all while still receiving hospital care and attention. And if my health situation would have declined I could have been transferred easily to an actual admission. Home recovery care was perfect because I just needed some extra monitoring and meds. I couldn't believe that they were even able to do my x-ray at home. I was excited that I was able to avoid another hospital stay.

Overall, I have so many health issues with each and every one of my body systems from numerous Mohs Surgeries for Basal Cell Carcinoma, to diabetes (at 40 yrs old) that requires me to use an insulin pump and a Dexcom, to cirrhosis, to lymphedema, to cataracts (which required bilateral eye lens replacement), to early stages of macular degeneration, to portal hypertension, to a frozen right arm joint, to damaged knee joints and ankle joints, to chronic cellulitis infections, to needing iron infusions…the list goes on. And, it's hard to not think about the fact that if the blood I received as a teenager would have been screened for hepatitis C what issues I wouldn't have right now. But through the ailments I continue to push forward. I push past the chronic pain that hemophiliacs are accustomed to living with. I strive to be compliant with my medications, treatments, tests, and many appointments.

I have walked through and witnessed the evolution of hemophilia treatments. From receiving whole blood or plasma to Factor VIII to now Hemlibra. Hemlibra has been amazing. Taking a simple small subcutaneous injection every 2 weeks has decreased the amount of factor that I have had to take. I have watched a generation of hemophiliacs suffer/die from lack of blood products to getting HIV/AIDS. But, I have hope for the future generation of hemophiliacs. The amount of knowledge we have now about the treatment of hemophilia and the new medications has changed the lives of the current generation of hemophiliacs. I am so thankful for the advancements that have been made with hemophilia. Treatment is now easier and less cumbersome and more effective. I am also so thankful to the community that has been ongoing in advocating for funding for the costly hemophilia treatments. And I am so thankful for my HTC that is so thorough in addressing all of my needs. They are so caring, educated, and are always just a phone call away. All of this is comforting to know that my hemophiliac grandson and affected carrier granddaughter won't likely have to live with the negative effects on their body that I have. I have hope that someday treatment and care will be even easier for future hemophiliacs.

But, through my walk as a hemophiliac I reflect on what living with a chronic bleeding condition has done to shape the way I live my life. As I have shown living with hemophilia has meant: living with chronic pain, having physical limitations, giving myself home IV factor infusions, taking a large medication regime, having a multitude of doctor specialists, going to countless appointments, and numerous hospitalizations. But despite all of that, I have always accepted that this is my life journey. I can't simply ignore the fact that my blood struggles to clot. So, I have made it my life goal to make the most of my time here on earth and find joy in MY life. I don't focus on what I can't do but instead on what I can do and find happiness in that.

In my teen years, as I was struggling with bullying and social isolation I decided to get involved in a church youth group called Young Life. It's at that group where I was able to find people who loved and accepted me. And where I was able to truly learn about the love of God. For this reason, I am thankful for my struggles. For it's because of those struggles I found this group that shaped my life in a positive way moving forward.

When I first met my wife, I told her of my diagnosis and warned her about all that comes with being a hemophiliac. She always accepted me and has always been by my side helping me with whatever challenge I was facing. We have had to walk through many tough moments together and I feel that has made us a stronger couple. I appreciate her for being willing to pick up the slack that my physical limitations have created. She has had to do more of the heavy lifting, no pun intended, than most wives. Since I often felt helpless about my limitations I decided I would always work hard at my job by being a dedicated and hard working employee so we would have a stable financial situation.

My wife and I always knew that my condition could shorten my life. This has made us appreciate the time we have together and the moments shared. We made a decision early on to always put family time first. And we do so by prioritizing family. Whether that is holiday traditions, beach vacation traditions, flying across the ocean, housing adult children and even one with a family, being present for children and grandchildren birthdays, or by just simply making sacrifices to be there for special occasions. We have always strived to be there.

Through it all I have found that it's about trying to find joy in the little things in life and by being present. I enjoy fishing, eating good food, cooking, watching movies, and listening to

good music. But of all of those things what I enjoy the most is doing those things with my wife and family. Of our many traditions, one of them is my homemade fudge. It's a family debate where the recipe actually came from, but I have made it my mission to master making it. The process is always tedious and sometimes it just doesn't work out. But, either way they love it. I think it's the fact that I have turned the entire operation of making the fudge into a special bonding time. A tradition that started with my 3 kids and has been passed down to my now 10 grandkids who love helping stir the fudge, anticipating a wood spoon filled with fudge from the pan, and fighting over the buttery corner pieces in the dish.

I also love sharing good recipes and food with my family. I value good food with good fresh ingredients. Maybe my obsession with good food comes from my times of having to eat not so pleasant hospital food. But, my family knows that when I have to be hospitalized, one thing they can do is bring me some yummy food when they visit. That act of love always makes my time there better. Another thing I love to do with my family is share with them a good song or movie that has a good life lesson. I feel that it is important in life to see what others are facing in order to truly understand them and have compassion for them.

As a husband, father, sibling, or grandfather my struggles have made me want to lead a good example and show how to persevere through adversity. I don't complain about my pain or about my treatments. I don't wish for the life of others who have it easier when it comes to their body. I have found it's just not productive to waste my thoughts or energy on such things. I hope what my family sees is when my calendar is full of appointments or when I need to be hospitalized time and time again that I do so with hope and a positive attitude. I also want them to see my compliance with the doctor's advice and treatments. That they watch me push forward after getting not so good news from the doctors or after another diagnosis is added to the list.

After my 1997 health incident I had an even deeper realization that life is more about moments than things. And through 70 years of ups and downs of my health I have learned to not take life for granted. The struggles have made me appreciate the good times even more and have forced me to be strong during the tough times. I have had to realize that there are so many things that life will throw at you. You can't control them but you can control how you react to them.

Even though my body is slow and fragile, I feel that I need to continue to work hard and do my part to give it the best chance possible to help me live life. I have learned that tomorrow isn't promised so make the best of today and to not take any treatments for granted. I strive daily to push forward and be present for my family and friends as much as I can. Even though my damaged body makes me walk really slow I still put one foot in front or the other. It may take me much longer than everyone else to get to the destination, but I continue to push forward at my own pace until I can no longer.