

## **My Three F's**

It was fall of 2003, life was good. I was 47 years old with a family I love, my wife Sylvia, and our two sons Matthew and Seth. I was still physically active in sports and scouting. I had just got back from backpacking at Philmont Scout Ranch which is a high adventure trip. Life was good.

Then on November 19, my life changed, I was having severe abdominal pain. Sylvia called 911 and they rush me to the hospital for an emergency splenectomy.

The next morning the Surgeon told me my spleen was badly damaged that he had to remove it. He pumped four and a half liters of blood from my stomach. He also said he check my organs for cancer and noticed a little bit of hardness on my liver. He removed a sample of it to do a biopsy along with my spleen. The Surgeon said how fortunate I was to survive what I went through. When I got home and talked to people about how close to death I came, telling them that every morning I woke up was a good day.

Two weeks later I went to see the Surgeon. He said that he got the report back from my biopsy. That it tested positive for Primary Amyloidosis. I went home and told Sylvia what the Surgeon had said. She looked it up on the Internet and copied the information and gave it to me to read. The next day while everybody was gone, I pick it up and read it and it said: "There are three kinds of Amyloidosis: Primary, Secondary, and Hereditary. Primary Amyloidosis is rare, affecting about eight persons per million annually. Its cause is unknown. It can affect anyone, but the majority of people with Primary Amyloidosis are over the age of 40, with age 63 being the average age at diagnosis. Two-thirds of all patients are men. Definition: a disorder in which insoluble protein fibers are deposited in tissues and organs, impairing their function. The deposits infiltrate the affected organs, causing them to lose resilience and become stiff, which decreases their ability to function. Prognosis is usually a progressive disease which in the majority of patients leads to death from kidney or heart failure."

When I got done reading it I said, "Oh my God, I'm going to die." I started thinking that God has already decided my fate, and that I'm not going to see Seth graduate from High School, I'm not going to see both my sons get married and have children, and worst of all I'll be leaving Sylvia all alone. I was feeling sorry for myself and wishing I had some other disease that might be disabling or make me sick. Not that I'm afraid of dying, I just wanted to be there physically for my family longer. I never talked about it to anyone. I started checking out my life insurance and my retirement funds to see that my family will be taken care of. I would think about my funeral and finally I told myself to stop and wait to see what Doctors have to say.

Two weeks later Sylvia and I saw a Hematologist, He did a bone marrow biopsy and two days before Christmas we saw him again. He says the biopsy confirms that I have primary amyloidosis. There is no cure and I maybe have one to three years to live. A strange sensation went throughout my body. Immediately I thought, "God make me strong." Because I knew my family needed me too. We went home and sat down with

Matthew and Seth to tell them. They took it hard, after everything said and done our family really pulled together. We became very strong after that. Then Sylvia and I drove down to my parent's house. When I told them my Mom cried and my Dad got angry. Later Sylvia went to tell her parents and then the word got around to the rest of the family and friends. As the word got around I was amazed of the response. To this day I still don't know how many prayer chains I was on. I was on prayer chains all over the country, even Canada and Germany. Later that night when Sylvia had gone to bed, my boys and I were watching TV. Matthew asked me, "Dad are you going to fight this." Till that time nobody had asked me that. I thought about it and said, "Yes of course I am." You know sometimes teenagers don't think their parents are cool. But I got up to go to bed, Matthew walked up to me and hugged me and said, "Dad you're no joke, I love you." I looked at Seth and he walked over and the three of us hugged. They both cried and it took everything I had to whole back my tears, because I still wanted to keep that strong front.

Then came Christmas Eve at Mom and Dad's house, everybody was trying to have a good time. Before going to the Christmas Eve service that night, I approached my brother Tim. I asked him that after Christmas if I could come over his house to get on the Internet. Tim has roadrunner and he is a lot better than me searching the net. Christmas morning I sat between the boys with Sylvia on the camcorder recording while they opened their gifts. Afterwards Sylvia and I laid down and talked. I told her, "It would be so much easier if I were alone because of all the people it was hurting." I told her we need to back to Good Shepherd, because I need the people of Good Shepherd. Then I finally let go of my emotions.

The next day Matthew approached me and said, "Dad my friends and I were talking. That if you pray for a miracle and believe God can do it, you will be healed." I thought about it and said, "Matthew, theirs nothing wrong thinking that. So I started wondering about that mustard seed inside me if I needed to grow more branches. I pick up my Bible started reading it and then prayed for more spiritual growth. I read Matthew 26: 39, "Going a little farther, he fell with his face to the ground and prayed, 'My Father, if it is possible, may this cup be taken from me. Yet not as I will, but as you will.'" If Jesus had his moment when he wanted his life spared, then why couldn't I, God been waiting on me to ask for his help. Daniel Taylor, author wrote, "Does it really do any good to ask? Isn't he going to do whatever he wants anyway? The short answer is, we don't know-or at least I don't. God didn't tell us how these things work. But he has told us one very important thing-we are supposed to pray. He says it does matter. He says, "Tell me what you want, how you feel. I want to know. I want to hear it from you. It does matter to me." Also in Matthew 7: 7-8, "Ask and it will be given to you; seek and you will find; knock and the door will be opened to you. For everyone who asks receives; he who seeks find; and to him who knocks, the door will be opened." So now I'm ready to fight for my life.

On Saturday, I went to Tim's house. We got on the Internet and were looking at all the information we can about amyloidosis. And then we came across Stem Cell Transplant. It was saying it was not a cure, but it would put the disease in remission. A

lot of people who had the treatment were calling it a cure. We were reading some of the case history of these people, how excited they were with the results. Then I said, "Well Matthew theirs that miracle you were talking about." When the news got around about Stem Cell Transplant everybody was excited. I called the Hematologist, he checked around and recommend the Mayo Clinic. Finally there was hope. In Romans 5: 3-5, "Not only so, But we also rejoice in our suffering, 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, whom he has given us." Hope does not disappoint us. That became my battle cry; I would read those verses everyday. There is a song called Hope written and performed by a group named Klaatu. Some of the lyrics are:

*"Hope is like a lighthouse keeper's beam.  
Hope, the guardian angle from above.  
And hope is the heart in Mothers love.  
No ships could fare the seas for there would be no courage were it not for hope.  
So let us feel hope and feel the sunrise in our minds.  
To give hope is to enlighten all mankind.  
But lose hope and life seems black as blind.  
When faith gives way to fear.  
When motivation disappears all is lost if one abandons hope."*

I would spend a lot of time on the Internet (mainly Amyloidosis Support Network). Because I wanted to know everything I could about my enemy. I even enjoyed talking to people about it. Author Philip Williams wrote: "I struggle, but I don't give up. Somehow I feel that in my very struggle with this I am choosing to say that there is meaning and purpose. Giving up may mean the quiet desperation of despair. There is wisdom in the search and struggle."

Another thing I learned is sometimes insurance companies doesn't want to cover Stem Cell Transplant. So I checked with my insurance company to make sure I will be covered. They finally told me that it will be covered under the Bone Marrow Transplant Policy, but it will not cover anything that is considered experimental.

On February 2, my Dad and I left to go to Rochester, Minnesota to see Dr. Gertz, to look at my medical records. We talked about the disease and he said that I was eligible for a Stem Cell Transplant. So we scheduled late March for the transplant.

One week before going to Mayo Clinic, I received in the mail from the insurance company a rejection of coverage. I called them and they said it was experimental. I called the Mayo Clinic and they said that happens all the time. That after their test results are in, the wording will be different. That stem cell transplant is not experimental to them, because they do this everyday. So I felt better thinking everything was going to be alright.

In Matthew 21:21-22 which Jesus says, "I tell you the truth, if you have faith and do not doubt, not only can you do what was done to the fig tree, but also you can say to this mountain, 'Go, throw yourself into the sea,' and it will be done. If you believe, you will receive whatever you ask for in prayer." After reading it I thought I can never have that much faith. A couple days later I read it again and realized that it's not me moving the mountain, it's God. I'm not going to beat the disease by myself; God is going to defeat it. God is going to take care of me. After that I lost all fear of the disease, knowing God on my side I have already won.

March 22 was my first of three days of tests at the Mayo Clinic with my other brother Doug as my caregiver. On the third day, I saw Dr. Gertz in the afternoon to go over the test results. My insurance company still denied me coverage. I called my benefit administrator and he said don't give up, that he going to fight the insurance company on this. The next day was my first of four days of growth hormones shots and the second day, I had my Catheter (called a Hickman) installed in my chest. My benefit administrator called that afternoon to tell me everything is alright, that the insurance company will cover. I thought thank God that's over with, now I can concentrate on my battle.

Sunday, Mom took over as my caregiver. The next day was the start of stem cell collecting; they needed 5,000,000 cells and got it in two days. To know what is going on; the growth hormone shots would over produce the stem cells in my bone marrow, which will over flow into my bloodstream. Then they hook IVs in each arm to a machine which would separate my stem cells from my blood.

Then the next week was the two days of chemotherapy and with Sylvia being my caregiver for the remaining time I'm there. Then on the third day, April 8th (which is referred to as Day 0) they did the Stem Cell Infusion. They also call it your re-birthday, what they do is use big syringes inserted in my Hickman to inject my stem cells back in me. Now these stem cells were kept frozen in bags with preservatives which cause my body to give off an odor like cream corn and Sylvia does not like cream corn. So my body is going through this transformation where the chemo is making me weak and wiping out my bone marrow and immune system. While the stem cells that was injected back in me is rebuilding a new bone marrow and immune system. I found it ironic that this was happening at Easter time that the infusion was on the third day. Because Easter was a new beginning for mankind, and this is a new beginning for my life. After a few days I started to feel lousy and they told me that my white blood cell will eventually bottom out. When that happens then it will go back up and when it gets to a certain number and sustain it, you will get to go home.

Because the way I felt from the chemo, I lost interest in reading the Bible or anything. I would sit around stare off into space or watch TV. But what kept me going was cards and E-mail from family and friends. I would get a lot of strength from reading them. And at the end of each day I would say a little prayer, "Thank you God for a great day."

I was within a couple days of going home when I got a staph infection called MRSA, which lives harmlessly on the skin but causes havoc when it enters the body. They say patients who do survive MRSA often spend months in the hospital and endure several operations to cut out infected tissue. But God was looking after me with one operation to remove three of my lymphoid for culture tests. After nine days I was fine and released from the hospital.

So when I got to go home at the end of April, I walked into the house, it was decorated with welcome home signs that were made by my sister Kristi, sons Zach and Jacob. What a nice welcome home, and then seeing Matthew and Seth and also seeing that the house survived while we were gone. It was also nice to see family and a few friends later on.

On May 7, was the cookout fund-raiser at my Union Hall. It was great the support I got there. The next night at our church, was the spaghetti dinner at Good Shepherd Lutheran. I was overwhelmed by the turnout of members and friends. I will always be grateful for my relatives and friends, especially my family. My brothers and sister for their support, Mom and Dad for always being there when I needed them; Sylvia's Mom and Dad for their care and encouragement. Seth for being my friend, Matthew for making me look at my Faith. Sylvia, not only is she my wife, she's my best friend. I love her so much that I could never do too much for her. Even when I was at my worst when she had to tend to all my needs, I told her I'm sorry to put her through this she said, "For better, for worse."

In August, Dad went with me to the Mayo Clinic for tests and see Dr. Gertz. The Doctor told me the test results were great that I could back to having a normal life again; he said I'm in remission. And also the first of February, Sylvia and I saw Dr. Gertz again and he told me my test results were even better and in May, blood work showed my liver was almost back to normal.

I look back on what I went through and think, "My God is an awesome God." I still get choked up when I sing that song. In Romans 9:21 says "Does not the Potter have the right to make out of the same lump of clay some pottery for noble purposes and some for common use?" H. Beecher Hicks makes reference about the Potter's House in the book of Jeremiah. "The potter has re-creative power. That sometimes the pot is marred in the potter's hand. Sometimes the pot does not do what it was designed to do. But the potter just takes it and breaks it and molds it and makes it what he would have it to be. I'm glad to know that when I'm marred and broken, the Lord is not through with me yet. I want him to re-create me." In my prayers I felt that God wanted me to do this. To testify my faith in God, that nothing is impossible thru him. And also to inform people about Amyloidosis, and what they can do. A poem I read by Edgar Guest called "When Things Go Wrong." The last two lines go, "So, stick to the fight when you are hardest hit, It's when things seem worst, that you must not quit."

I leave you with this:

- 1) Listen to your body, it will tell you when something is wrong. And don't assume Doctors always know. Get a second opinion.
- 2) Some of you will say I don't want to bother anybody with my illness, I say **Bother Them!** You will not realize how much support and strength you can get from them. When ever I read your cards and e-mail or spoke to you and you would say you are praying for me and telling me I will be cured; I ate it up like it was candy. It was like a shot of adrenalin.
- 3) Love your family, because they love you. They will do anything for you.
- 4) Most importantly have faith in God. And remember your greatest adversity will lead to your greatest opportunity.

Some people say I was lucky----- no I was blessed. I'm not a survivor----- I'm an over comer. I'm not a victim---- I'm a victor. One of the tests at the clinic was a psychological test. The Psychiatrist said they never had anybody score this low before. He said you really must have it together. I told him, "No, don't give me the credit. I got my 3 F's, my faith, my family, and my friends.

Praise be to the God and Father of our Lord Jesus Christ! In his great mercy he has given us new birth into a living hope through the resurrection of Jesus Christ from the dead.

Amen.