***The Story of My Heart***

It was a pleasant winter morning in Texas. I had my 8:00 AM appointment with the doctor before heading out to a busy day at work. I like morning appointments, good to be done with it before starting the day. The doctors are not yet behind the schedule so the waiting time is small, not to mention the staff and the doctor seem fresh and friendly in the morning than later in a busy day.

The cardiologist who I was seeing for the first time, saw all the reports that I brought from my physician’s office and then ordered an ultrasound of the heart and a bubble test. I have been so used to ultrasounds of the tummy with the baby; it felt odd to get an ultra sound of the heart. The nurse injected bubbles into my vein on the arm and checked for them in various chambers of the heart.

I waited in the room while the test results were being studied by the doctor. He finally came and talked to me. He drew me a picture of the chambers of the heart and told me that my heart was enlarged and that I had ASD or Atrial Septal Defect. He explained to me that I probably had it all my life although surprisingly it went undetected. As it was not fixed as a child it led to the enlargement of the heart, of course the pregnancy and delivery put so much more stress on the heart that it got worse with the delivery and I started to see the symptoms now. He said there is a significantly increased risk of a heart stroke every day that I walked around without getting the problem fixed and that nothing can be done about the damage that has already been done with the enlargement of the heart, fixing the hole would prevent further damage though. He asked the nurse to schedule me for cardiac catheterization or angiogram, so that they can take a look at how big the defect was and the position in the heart. As I scheduled the angiogram, to be done at the Irving Medical Center, and walked out, the nurse handed me brochures on open heart surgery and about life after the surgery. That is when it struck me that this was a serious issue. They really think I need an open-heart surgery!

I walked out into the parking lot, got into the car and tried taking it all in. At once too many questions popped in my mind — my son is still a baby; he is just learning to walk. He has become the center of my world in the last few months. What does it mean to us now? Why now? And the biggest question of all, why me?

I called my husband who was already at his work and started to tell him what the doctor said and as I talked tears started flowing down my cheek. He asked me if I want him to come over but I told him I will be fine. There was not much to do right now anyway, not until after the angiogram. I went directly to work as I had planned earlier. I decided I was not going to worry too much about something that was not really in my control. I went to work and despite what I told myself, I just could not do anything right, I kept dropping my pen, and talking to colleagues about what they know about ASD, and tried to find out if anyone knew of adults dealing with ASD and how they fared in their life. I was acting like I had too much coffee all day.

After the first couple of days, filled with self-pity and trying to get a grasp on what suddenly changed my world in just a day, I went on the internet and read everything I could about ASD, congenital heart problems, enlarged hearts and heart surgeries. I needed to know everything there was to know.

On the day of my angiogram, they gave me general anesthesia and the last thing I remember was saying bye to my husband before they pushed my cart into the operating room. The next thing I know I was dozing in and out and could hear people talk, I was able to briefly open my eyes a few times and see the men in scrubs doing something and talking to each other, I think I actually heard them laugh as they talk. Looking back that was a freaky experience. I was not able to move any part of my body but could see and hear. The next time I woke up I am in the recovery room, there is a huge clamp on my thigh to stop the artery from bleeding and my husband was by my bed.

Nurse came in and checked the vital signs and told me that I am going to stay like that in bed with the huge clamp for several hours. Short while later the cardiologist arrived with another doctor who turns out to be a heart surgeon. He told me and my husband that the hole in the heart was of significant size and needs to be fixed as soon as possible. He introduced the surgeon to us and left. The surgeon sat with us for the next half hour or may be more and answered all our questions about the issue, surgery and the risks involved.

In the days after that, now that it is officially confirmed that I do not have a choice but to get my heart fixed, I spent a lot of late nights researching the issue. Going online and seeing posts from people who had similar problems and what they did about it, and how are they doing now. There were occasions when I would send messages to my brother about my concerns while I was online and researching, he being in the western time zone would reply back immediately with a nice message that would make me feel better.

I wanted a second opinion before scheduling the surgery, I wanted to be sure that I needed the surgery and wanted to know that I have exhausted all other options before going into surgery, I also wanted to hear that if I have the surgery that will indeed solve the problem. Luckily for me my sister-in-law’s uncle was a cardiologist in Florida. She introduced me to him over the phone. He was very willing to help, and asked me to send him a copy of all my related medical records. He called me back and told me the same thing that my doctor here told me, that the defect was significant and needs to be fixed, which I knew was the case but was just hoping to hear something different. He also told me the story of one of his colleague’s wife, who went through a similar situation. He told me that his colleague, who is also a cardiologist, researched every possible means and finally took her to a Children’s hospital in Houston where they were able to fix the defect with-out the open-heart surgery.

I learned more about the clamshell and similar methods to fix the ASD without surgery. In simple words — they send in a device that is inserted into the hole in the heart by a similar process as angiogram and then they pop it, it opens on both sides of the hole and clamps to the skin around the hole thus causing a barrier. Eventually with the natural healing process of the body heart muscle will develop on and around it. Of course, the device stays in the heart forever; it becomes part of the heart. This was under research at that time and done on select few. I learnt that the procedures have been FDA approved a few years later. I am happy to know that quite a few folks will be able to get this problem fixed without open heart surgery.

The consulting cardiologist talked to the hospital in Houston and told me to make an appointment to go see the cardio surgeon there. My husband and I drove down to Houston the day before the process was scheduled. I did not want to go stay in a hotel, so we stayed at a friend’s sister’s place. We went to the hospital in the morning, the same process repeats, which I got used to by now, with all the IVs and Anesthesia. They also prepared for a surgery as they were doing an endoscopy and if they determine that I am the right candidate they will do the procedure to insert the clamshell and if anything goes wrong while doing so they informed that they may have to perform an open-heart surgery. So, I went in not knowing if it will be just the endoscopy, or will it be the clam procedure or will I come out with a surgery by the end of the day.

It did not take long, just a few hours later I woke up with a really sore and painful throat, the endoscope is inserted through the throat into the chest, and learned that the position and size of the defect was such that they could not insert the clam shell. Yet again it was confirmed that I needed open heart surgery. By now I think I exhausted all possible known options for non-surgical process. I had to face the facts and prepare for it.

Now the subject of my research changed to finding the right surgeon and hospital. I found out more about the surgeon I met in the hospital during cardiac catheterization, who was planning on doing my surgery. He is a good surgeon but I could not find any information on how many of the kind of surgery I needed, did he do. I called his office to find out, it turns out that he does quite a few open-heart surgeries in a year but very few of the kind I need as this is something that is normally fixed in childhood and so most of the time handled by a pediatric surgeon. I wanted to find a surgeon who was more experienced in handling these issues in adult hearts. I started looking up information on all the good heart surgeons in Dallas area. Meanwhile one of my husband’s classmates at his MBA program heard about what I was going through and gave a health magazine that she borrowed from her boyfriend. Her boyfriend was in the medical field and when she had mentioned my case to him, he remembered seeing this article about a heart surgeon in a magazine and so it makes its way into my hands. I was really impressed with the information on the very experienced surgeon, Dr. Steve Ring, who operates both on pediatric and adult hearts, is into research, and has done heart and lung transplants. The next question was, with his busy schedule, would he accept me for a simple heart surgery. I had to give it a try, somehow felt like I found the surgeon I was looking for and was convinced that I need to get him to accept my case. I found out his phone number and called up his office directly. I talked to his very friendly assistant and explained my case. She said she will talk to the doctor and get back to me. That was a positive sign! She got back to me the next day and let me know that the doctor wants to see me. I went in with all my reports. This famous surgeon was very friendly and easy to talk to. He was really interested in my case. He wanted to know everything there was to know, did I ever experience any symptoms as I grew up? Did I play sports? Did I get tired easily? Did doctors make any comments about heart murmur when they listened to my heart at checkups? How about during pregnancy? Did the doctor notice anything wrong with my heart beats? Did I have complications during pregnancy and delivery? What were the symptoms that led to all the tests? How was it that, the problem was discovered now when it went un-detected all my life? That is a story in itself.

In the days after my delivery after my first child, I felt too tired to wake up in the morning. I told the doctor at the two weeks postpartum that I am always tired and just feel too low on energy. Well, that is how most new mothers feel when they are recovering postpartum and the sleepless nights with the new born make it worse, is what I was told by her and lot of other well-wishers around me. They told me it will get better over time. It did get better in some ways but I could feel that something else was not right, I would have this strange sensation in my chest as if my heart skipped a beat or that something was turning over in my neck. I would sometimes feel my heart racing and felt like it was going out of control and I would feel really tired when that happened. I just had to lie down for some time and I did not care about the world around me at that point, I just had to lie down until it felt better, which it usually did in a few minutes.

I saw my primary care physician about it, who told me to wait it out until the baby was a bit older and told me I will feel better. After six months I felt like it was not getting any better, in a way it was getting worse, the frequency of the palpitations increased, I started to get light headed some times, and the skipping of heart beats sensation started to happen more often too. I went back to the doctor and this time she thought I had the symptoms of thyroid problem. She sent for a blood test and sure enough I was hypothyroid and the numbers were high. So, she prescribed a high dose of thyroid medication, within a few days I noticed that I had more energy and felt much better, I was pleasantly surprised at how I felt as I had forgotten what it feels like to be normal and energetic. But my palpitations continued and suddenly got worse. I went back to the doctor and she said it was normal for it to happen when the body is adjusting to the thyroid medication. I insisted that something was not right and so she had blood work done to test Thyroid level again. The numbers were really off but on the other side this time so she reduced the dosage and assured me that that will take care of my symptoms. I was not so sure; I had this nagging feeling that we were totally missing something else and that there was something about my heart that is waiting to be discovered. I did feel a bit better after the change in the dosage though. I got more involved with my projects at work and it started to get a bit stressful with the baby and work and my symptoms started to return again. This time I was fully convinced that there was an issue with my heart. I went back to the doctor and told her what I thought; she believed that I will be alright and asked me to give it some time. I insisted that in my heart I knew something was wrong, yes, I know she is the doctor not me, but I know my body better than anyone else. With pregnancy I think you get used to listening to your body better. Anyways after some discussion and me telling her that I am going to see a cardiologist whether she refers me to one or not, she regretfully sent me to a cardiologist. That is how I ended up in that cardiologist’s office that fateful morning.

Now that I found my surgeon, I needed to plan the dates and all the events. I did my research and learned that I could donate my own blood and save it for the day of the surgery. So, every week I went and donated my blood as much as they could get, which was not much but by the time it was the date for my surgery I had enough to cover for the surgery. My husband went with me to donate blood too, not for me but just to show support for me. I needed time to collect enough blood and I knew I needed full support from my husband to get through this. He was working full time and was doing MBA on the side, he barely had time for anything else, and so I planned my surgery during his semester break. I had my parents over and my brother and sister-in-law over for the surgery. I planned it for a Thursday so that my brother could stay through the weekend and go back on Monday. My mom was to take care of my then one-year old son and my dad and mom were there to support each other. My brother and sister-in-law were there to support my husband and all of them especially my husband was there to support me.

I had everything planned. Decided there was risk involved but I will be okay and if I am not, it would still be alright. I have made my peace with whatever was in store for me. At the same time, I did buy some special things for myself to be used after the surgery, I had to find ways to cling on to the assumption that everything will be fine and life will get back to normal soon.

On the day of the surgery I woke up and scrubbed with the surgical soap scrub that the hospital provided, dressed in nice clean clothes, kissed my son and said bye to my parents and drove with my husband to Zale Lipshy Medical Center in Dallas. We did not talk much in the car. Whatever little we talked was very generic nothing about the surgery. I was ready for the surgery, both mentally and physically. Once we arrived there I was prepped for the surgery, IV, ventilator, briefing from the anesthesiologist on what he will do and from the surgeon on what he will do and how long it will take. He would take a layer from outer surface of the heart and use it as a patch to stitch the hole up. It will be about a four-hour procedure and the heart will be stopped, and I will be put on a heart lung machine for about 45 minutes during that process. My biggest fear about the surgery had been — what if I gain consciousness in the middle of the procedure when they have my heart open. I guess this was the result of spending too much time on the web. The fact that I gained consciousness briefly during my cardiac catheterization did not help with my fears either. Luckily by the day I was having the surgery I had talked so much to myself about risks and what ifs, and made peace with all the possible answers so I felt nothing on the day, I was actually glad that the day had finally come and soon I will be able to move on.

They were going to do what was then a not so popular procedure, open heart through thoracic surgery, they will make a horizontal incision on the chest and move the ribs apart on the right side and reach into the left side to the heart. It was a bit more involved than the sternum process where they make a vertical incision in the middle of the chest, but my surgeon convinced me that I will thank him in the years to come for not having to wear high neck tops all the time to hide the scar in the middle of the chest. I did not care much about the scar at that point all I wanted was the safest procedure, but years after it is done, I am thankful that he talked me into it and he cared enough to convince me to go for it.

Again, the last thing I remember before the surgery was saying bye to my husband and looking at the big doors open as they pushed my cart through them. When I woke up, I was not able to open my eyes but heard voices and then saw some folks. Later realized that I was probably hallucinating, with all the drugs that were going down my IV… I kept going in and out of consciousnesses. I had all these tubes attached, IV, tube through a hole in the neck, chest tube what not, definitely not comfortable. I saw my husband, brother and sister-in-law and talked to them briefly. My husband said something about my colleagues wanting to visit but he told them that I was in ICU and probably it is not a good idea for them to come over that day. I was kept in reclining position almost like sitting up but a bit slanted. Since I was in the ICU nobody from my family was allowed to stay with me that night, I wish they had allowed somebody to stay by my side. Every time I gained consciousness I was in a weird mental state, felt some kind of fear but at the same time felt so detached from my body. My body was going through so much but my mind felt like somebody standing beside me and watching all this. The nurse who was on duty that night probably understood my state well, he spent hours (at least that is what it felt like) standing by me and talking to me. It was about nothing important, I do not even remember what we talked about, but I remember how good it felt to have him stand there and talk to me, unfortunately I did not see him again during the rest of my stay there. I wish I had found out who it was and thanked him for his support.

I was glad when they moved me into a room the next day. My parents came and visited me and I was so glad to see my son. I thought he will be scared of all the wires and the tubes but they did not seem to bother him, he was just happy to see me. Slowly my friends started pouring in to visit me. Flowers came in from various people. I was in a lot of pain but when I had all these folks around me, I did not have the time to focus on the pain. On the fourth day they sent me home. I held my right hand as if it was in a sling as the incision and the ribs hurt if I moved my arm. I was happy to be home.

In the days after the surgery, I stay laying down in the bed at nights until somebody gave me the support to get up. I could not turn or get up by myself. I think thoracic surgery had to do with it. More than the incision itself it was the hole that was created when the chest tube was pulled out that was more painful. The spot where the ribs meet in the back hurt really bad. I would be laying in the sofa most of the day while my parents waited on me. That was the first time in years that I talked to my parents for hours at stretch. I enjoyed reconnecting with them at a new level. Before or after the surgery my parents did not show any signs of unhappiness or worry. They were always strong and standing by to support me in every way they could.

My son realized pretty soon that his mom will not hold him up or that he can’t climb on to mom. He was happy to just be around me to play and talk to me. He was at such a fun age! I always wanted to have two kids, but the doctors advised me that it may be too risky to have another pregnancy. I was happy that I at least had my son.

In the first few days, my legs would feel numb from not being able to move all night, but I was not able to roll or get up, so I would be laying in the bed awake for hours reflecting on my life so far, and how some things that felt so very important until a few days ago do not seem to matter much anymore. I realized that it is important to constantly remind ourselves to look at the big picture. I understood then what support from family and friends means and how it can make some of the most difficult times in our lives into manageable and may be even pleasant. When I look back what I remember the most is the love and support from my family and friends and the helping hands and kind words extended by everyone that I came in touch with during those days. This April (2020), it has been 20 years since my surgery.

I am by no means saying that I am happy that I had the problem and had to go through all of it, but given that I had the problem, I am glad that it was detected before more damage was done and that everything worked out the way it did. The whole experience taught me how important it is to listen to your body and to take control of taking care of your physical and mental health. It also helped me with the outlook on life. When I get stressed out by some mundane daily issues, thinking back and reflecting on my state of my mind during the days before and after the surgery helps put things back in perspective for me.

I returned to work six weeks after the surgery. Three years later, in 2003, under care from my obstetrician and cardiologist my second child, a beautiful girl was born.