# Real-Life Stories

Yourself

# Joe Mansaray

It all started in the beginning of the summer of 2015. On June fifth of 2015, a Friday morning, I woke up finding it very difficult to breathe.  I woke up my dad and he decided to take me to Pinnacle Hospital where they began some tests. After a chest x-ray, the doctor came in with a very worried look on his face. He said that my heart was enlarged and that it was a very serious concern. He showed us the picture of the x-ray and I was able to see that my heart actually was enlarged and it was pretty terrifying. I've never been sick before so this was a huge shock. I wondered if they could fix this issue, if I was going to be ok, and I wondered if I would be I able to play soccer, which was starting soon. The doctor told us that they were unable to manage my heart issue and that we needed to go to Hershey Medical Center immediately by an ambulance.

Once we got to Hershey I ended up being admitted and staying there for about twelve days. They ran a bunch of tests on me and decided that they also were unable to fix my heart issue. At this point I was losing hope. From someone who ran track and played soccer my entire life, laying in a hospital bed every day, all day was horrible. I didn't feel like myself and I wasn't sure if I would ever get to be myself again. Hershey told me that CHOP in Philadelphia would be better to help me, so they were transferring me to CHOP by helicopter. Even though this was all very scary for me, the helicopter ride was pretty cool and it was the most exciting part of this whole process.

Once I got to CHOP, the doctors began to run even more tests on me. It felt never-ending.  Finally, after a few days, they told us that I was suffering from a heart condition called cardiomyopathy.  Not long before this my mom had actually also been diagnosed with this, while at CHOP we found out it was hereditary. When they found out how bad my heart was, they told us that they would have to put in an LVAD, to support my heart function, since it was no long able to do it on its own. Since I had no idea what an LVAD was, and because it was all happening so fast I felt like I wasn't able to process any of it. My dad and I asked a lot of questions. The doctors were very helpful and explained everything to me so I could understand which helped me feel calmer. The doctor's hopes were the LVAD would help improve my heart enough that eventually, it could be removed and I could go back to normal life. They installed the LVAD on July 24th, - at this point I had been living in hospitals for almost 2 months. It was mainly my dad and I this whole time, my mom remained home with my other siblings. Recovery from the surgery was difficult, but I did begin to feel better.  I was finally discharged from the hospital in September – after 3 months in the hospital! Because of my situation, I was unable to go back to school and unable to play soccer in my junior year of high school – which was really upsetting. The doctors and nurses suggested we stay at the Family House after my discharged for about a week to be close to the hospital – and they also felt like it was an amazing place, and it would be a very supportive environment for us. When we went home I finally began to feel normal again and really felt like I would get better.

Unfortunately, that was not the case, and around October everything began to fall apart and our lives were turned upside down.  I remember going back to CHOP for a checkup and being told that my heart was not healing and that I would need a heart transplant. I was very frustrated; I remember thinking that this can't be

# Joe Mansaray (continued)

happening to me. I honestly thought that my heart would heal because I was a healthy kid. I played soccer and ran track and never got sick. I was very scared and freaked out.

It all became even scarier because around this same time my mom became very sick. She was being evaluated for her own heart transplant at Penn and ended up being admitted. Because of how sick her heart was, she was very quickly listed for a heart and waited for her transplant in the ICU. Not long after being listed she received her new heart. This time we were not staying at the Family House because of my health, we were staying at the Family House to be closer to my mom.

Things continued to get worse. She had major complications and did not recover well from her heart transplant. It was constant ups and downs and it was so difficult for me to watch, knowing I could go through the same thing. On November 3rd, 2015 my mom passed away in the ICU at Penn with all of us at her side. Watching my mom's transplant and what happened to her afterwards was so hard for me. I was so sad that my mom had passed and also so scared that this was going to happen to me. I thought if I get a heart transplant and have to go through what she did, I might not make it either. The support from my doctors at Chop, who knew that my mom passed, helped quite a bit. They reassured me that I was young and healthy and I would do well with my surgery.

So we buried my mom and went home to wait for my transplant. On February 24th at around two a.m. they called us saying they had a heart for me. I remember being excited to get a transplant and have a normal life again, but I was also extremely scared. I went into the ICU and all the nurses and doctors were so excited for me. I remember going into the OR and saying bye to my dad, brother and sister, and still being unsure if I would wake up again. Obviously, I woke up. I was back in the ICU and my dad was there smiling. The first thing I said was, do I still have the LVAD? And my dad said no you have a brand new heart.

My recovery went so well and in only a couple of days I was out of bed working on getting back in shape. It was very hard work because I would get tired very easily but I kept working at it. My dad and siblings were able to stay at the Family House during this time and after only about 10 days I was discharged to the Family House. CHOP still wanted to keep an eye on me so we stayed at the family house for another few weeks. It was great because the entire staff was so welcoming and supportive – and had been through our entire transplant journey. The House made life easier for me and my family during this time and I am very grateful for that.

A couple of weeks later I was cleared to go home and be a normal teenager again. I was able to play soccer again in my senior year in high school. I am hoping to play soccer in college - hopefully Temple University, where my oldest brother goes, but also to remain close to the hospitals.

I am very grateful to my donor and their family, and I hope to express my gratitude towards them someday. My family and I are also extremely grateful to my mother's donor and their family since they gave her a second chance and gave us a bit of extra time with her. I am very thankful for everybody at CHOP, the doctors and nurses are amazing and without them I might not be here today.

# ROGER WEAVER

## WHY NOT?

Why?

Around two years old this question begins to surface and never fades. We are constantly asking why. It seems we want to understand, we want our world to make sense, but often the answer eludes us or at least is unsatisfactory. Now I realize this is a bit philosophical for a bio, however, I am afraid that in my attempts to answer the why to my donation it may not make sense because I am not sure I totally understand it myself.

Nearly a year prior to my donation I felt what I can best describe as a nudge. There were a few things that took place that led me to consider the possibility of being a living donor. Sure, I have been donating blood for many years, but this was… let's just say a little more involved. So, I looked up the number and again it's difficult to define but I had a real sense of calm with stepping out in faith and calling them. I was not donating to a specific person or on behalf of someone to help them move up the chain. I was what they call an altruistic donor. That word is not often used and seeing it written out it looks like some type of medical condition; it simply means my kidney had no designated recipient.

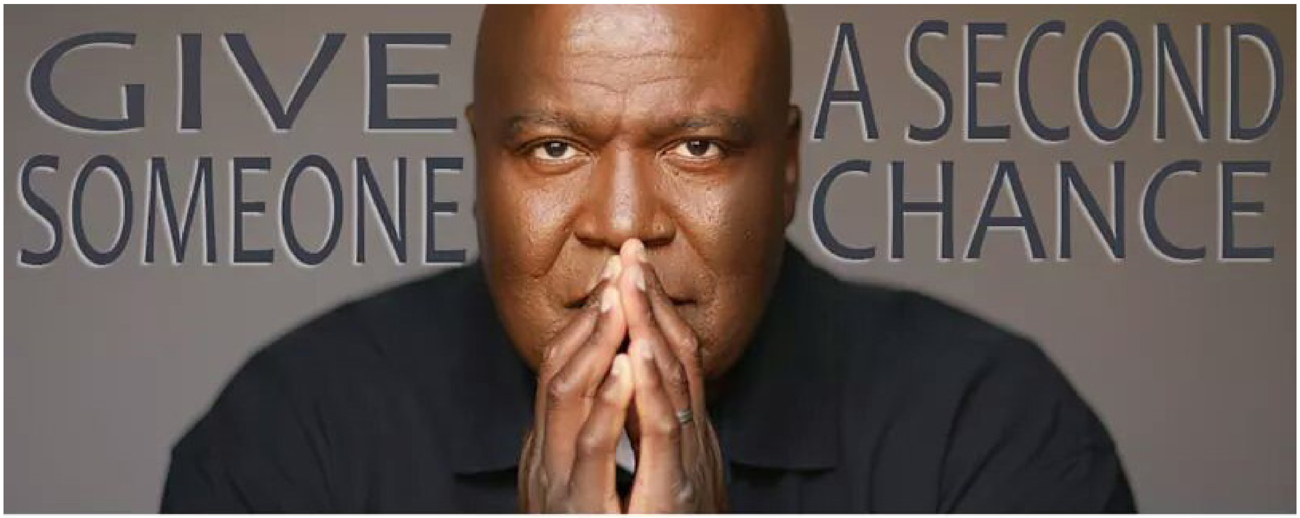
My journey began after that initial call; everything starting lining up – a supportive family, a job that was flexible and a boss that was generous. Of course, like all journeys there were some hiccups along the way; lots of additional tests and then four days before the surgery they noticed something in my lungs from the chest x-ray; this postponed it for a month until I was cleared. In the end I kept feeling a peace about simply taking the next step and these steps eventually led to my kidney being successfully transferred into someone who desperately needed it.

I call myself a Christian and I want my faith not to be just words but action. If I believe that God loves and cares for others than I need to demonstrate that myself. However, I want you to understand this was not to show my kindness or generosity (In fact normally I am not a very kind person), no this was simply about being obedient. The cool thing about being obedient is a husband and father of three was given a second chance and I got a card from his son that said, "Thank you for saving my dad's life".

The funny thing in all of this I feel that I have received more than I gave! And it makes me wonder when and where the next 'nudge' may come. Maybe you are feeling it too? So, I will add one word to the first question and ask you…

Why not?

# Ron Gooden



Words cannot begin to express how grateful I am to receive this wonderful gift of life. My name is Ron Gooden and I am a heart transplant recipient. My family has a long history of heart disease. My father passed away at the early age of 63 due to heart failure and my sister currently has Dilated Cardiomyopathy and Lupus. When I was growing up, I was always involved in sports, primarily football. I was fortunate enough to play at all three levels without any problems. So, over the years, I was very active, playing tennis, golfing, hiking, and coaching high school.

In 2005, I started to notice I was having a hard time doing the things I had come to enjoy. I had shortness of breath and always seemed to be tired. I thought it was due to me just getting older and pushing myself too hard. I went to my primary doctor who in turn recommended me to a cardiologist. After many tests, I was diagnosed with Dilated Cardiomyopathy and I started a regimen of cardiac medication. In 2007, I was implanted with an ICD, Implanted Cardio Defibrillator, due to some arrhythmias. My symptoms kept getting worse over the years, with swelling starting in my ankles and abdomen, along with palpitations.

In January 2011, my cardiologist referred me to the Heart Failure Clinic at Allegheny General Hospital, saying there was nothing more he could do for me. My girlfriend and I met with the doctors at AGH to discuss what the next steps would be. At that time, they tweaked my medications and suggested that I may need a heart transplant in a couple of years. My health started to deteriorate rapidly after January 2011. I was having difficulty climbing stairs and just walking in general. Every so often I would have to stop just to catch my breath. In August 2011, I had a routine heart catheterization that indicated the pressures in my heart were very low and that some of the oral medications were not effective enough. We met with the doctors and it was determined that I should be evaluated for an immediate heart transplant. I began to receive my cardiac medication intravenously 24 hours with a pump. In late August, I started the process for the transplant evaluation. On September 7, 2011, I was placed on the transplant list and could be called at any time. Being a high school football coach, this time of the year is really busy for me. I have been coaching for the past 25 years and enjoying every minute of it. My heart problems made in increasingly difficult to coach.

I had another heart catheterization on September 23, 2011, and as a result, I was admitted to the hospital. It was a Friday, and I begged to be able to coach the game and come back on Saturday, but to no avail. The doctors said I would not be on the sidelines for a while. I was placed at the top of the transplant list due to my low heart pressures. Due to my condition, the doctors recommended that I receive a LVAD, Left Ventricular Assist Device, while I waited for a transplant. They did not feel that my heart would hold out long enough for a new one without some assistance. On October 3, 2011, I received a LVAD and I remained in the hospital until October 19, 2011. Life with my LVAD was not easy for me, but I knew it was helping to keep me alive and live the best life I could have, given my circumstances. My girlfriend and I had been together for 8 years and I decided to propose to her on November 11, 2011. She said yes and we decided to have a small family wedding on November 26, 2011, the Saturday after Thanksgiving. But fate had charted a different course for us.

On November 22, 2011, at 5:45am, I received the call from my heart transplant coordinator. THEY HAD FOUND A HEART! With this new heart, I am able to live my life to the fullest extent possible. I am able to walk, jog, and coach again. I look at life with a whole new appreciation. I was able to make my girlfriend my wife, see both of my kids graduate college, walk my daughter down the aisle at her wedding, and witness my son's wedding. I was appointed by the governor to sit on the Organ Donation Advisory Committee. The committee is responsible for advising the Secretary of Health on matters relating to the administration to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.

Every day I thank God and my donor family for the wonderful life I have been given, because without them and their decision I would not be here today. I plan to be the best steward possible to my gift of life. I hope that by reading my story, others will choose to support organ and tissue donation, so that those on the waiting lists can receive their gift of life.

# MATTHEW BYRNE

I've been called many things in the past 42 years but never in my wildest dreams did I ever think I would be called a 2 time transplant survivor. I had a normal childhood, typical colds and the occasional sprained ankle from my skateboarding days. It wasn't until my late teens, early twenties that I started to get repeated sinus infections. While on vacation for my 22nd birthday, I became very ill. Thinking it was the flu, I rested and took the week off from work. Five days after initially getting sick I had a fever of 104.5 and my fiancé, at the time, took me to the hospital emergency room. My blood levels were critically low and I was ordered to receive blood transfusions and strong antibiotics for the next five days as doctors scrambled to figure out what was wrong with my immune system. Two bone marrow aspirations later, the oncologist believed I had MDS, a type of bone marrow cancer that usually happens to older women. We tested my siblings to see if their immune system could be a match for me. Two of my siblings were a perfect match and we set the transplant date for a few weeks later.

I kept getting a lung infection that would delay the date of my transplant. After months of treating lung infections and getting better, the pulmonary doctors ordered a lung biopsy. The result was a common viral infection that most healthy people's immune system could keep in check. But since mine was compromised I didn't have that ability.

About a year after first getting "sick" I went to Sloan Kettering in NYC for a second opinion. They reviewed the bone marrow slides from University of Pennsylvania and could not confirm the diagnosis without getting their own bone marrow slides. I was so traumatized from the the first two rounds of bone marrow aspirations that I declined. I was young, 24, and at this early stage tired of constantly having to consent to painful procedures.

Years passed with infections, antibiotics and hospitalizations. With the urging of my sister I went to Johns Hopkins in Baltimore. They determined that I didn't have bone marrow cancer but an immune system defect. My doctor worked with a doctor who recently moved to the NIH ( National Institute of Health) . The NIH is a government run research hospital that helps people with rare diseases. They had me there for a few days of testing and said I had a immune system defect. They have seen other people who had a similar health background and wanted me to participate in a case study. That single decision changed the course of my health care for the better.

October 2008 I stopped working and was placed on oxygen 24/7 due to my pulse oxygen levels being too low. A wheelchair was soon to follow. I was in and out of the hospital monthly.

In May 2009, after 10 years of fighting my failing immune system, I conceded to do a Stem Cell Transplant. NIH wrote a specific protocol for the transplant for my disease. I was patient "0", the first to receive a BMT for this disease. The disease is now called Gatta2 referring to the defective gene that superseded my immune system. I spent 28 days in the hospital after my transplant. I slowly got better and a year later decided to take a 10-week cross country trip with my dog to see the USA.

## Matthew Byrne (continued)

In 2012, my breathing became worse and was placed back on oxygen. Now hospitalizations lasted months instead of weeks. I was told we had exhausted all options and I should consider a double lung transplant. I interviewed at INOVA a transplant hospital in Virginia. I was accepted for the transplant and placed on the list. I spent five months hospitalized, waiting for the gift of life.

September 23, 2013, we received the call that I had a matching donor. A joyful day for me and a sad and heart breaking decision for someone else. Recovery took four months. It was hard living on a ventilator for weeks. Then a tracheotomy for a few more weeks . Learning to sit up, move my hands and legs, and swallow were all things I had to teach my body to do again. I was out for seven days and my body started to break down. Each day I tried more than the last.

Sometimes failing but not giving up. My family was by my side the whole time; they were strong when I couldn’t be.

It took a long time to regain my ability to function physically but more mentally. I still suffer from PTSD and trauma from years of pain and months spent in physical isolation from staff and especially other patients. My donor was a 17 year old young man from Clinton, South Carolina named Eugene Kinard. He was the victim of a single gun shot wound to the head. His mother, in her darkest hour decided his senseless death was not going to be the end of his story. As long as I speak his name he lives on. In me.

In April 2015, I had a heart attack. Not a big deal considering my past. Then a few months later, I met Jenna, my fiancé. I was told I would probably not be able to have children due to chemo and radiation I received during stem cell transplant. Now we have a son named Noah and he’s going to be 3 in June. Don’t believe everything your told.

My sister would always say during my seemingly endless hours attached to a breathing machine, “Don’t give up before the miracle happens.“

# ZACHARY SWEITZER

## By Missy Sweitzer, mother

On October 19, 1988, our lives were changed forever. We were blessed with the first of our three children, Zachary Daniel Sweitzer. He was an energetic and passionate boy who grew up to be a compassionate young man with a great desire to help others. He was a talented athlete, a dedicated volunteer firefighter, and an amazing son and friend.

Our lives were changed forever once again on November 27, 2008, Thanksgiving morning. We received a phone call that our son was involved in an accident. We didn't know what to expect when we got to the hospital, but nothing could have prepared us for what we were about to see. He was admitted to the trauma ICU at York Hospital with closed head trauma. He had been ejected when an underage, DUI driver hit his truck. He was on his way home to celebrate Thanksgiving with our family.

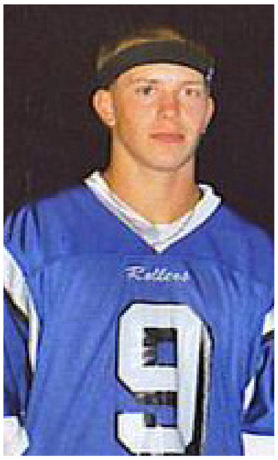
The surgeon explained they were going to attempt to alleviate the pressure that was building in his brain. Zac survived the surgery but he would never regain consciousness. Never again would we see his beautiful brown eyes. Never again would we hear him say "I love you." We never gave up hope or stopped praying for a miracle but there came a time when we knew that our boy was gone. There's something that a parent experiences when their child dies…something that really can't be explained or described…but a part of you is gone…forever…and you feel it in your deepest being.

Zac made the decision to be an organ donor when he got his driver's license, a decision for which later we would always be grateful. We informed the nursing staff that if we were faced with a decision, Zac was a donor and would want to help as many people as he could. We met our transplant coordinator, who explained the transplant process to us. Never once did we feel pressured or that the decision was not ours to make. But after hearing the story of a mom who got to hear her son's heart beating in another man's chest, we knew that Zac's decision was right. We never really thought about organ donation, other than deciding to be one, and now we found ourselves as a donor family. Even though we have never met or heard from any of his recipients, we feel as though his six recipients have become a part of our family. We think about them and pray for them all the time.

In life, Zac's mission was helping others…and in his death, that legacy continues. And we're still praying that someday we get to hear Zac's heart of gold beating in another man's chest.

# RYAN LEE MOHN

### By Alison Mohn, mother



This is the story about my 16 year old son Ryan Lee Mohn. In 2004 Ryan was a junior in high school. He led his team to a district football championship earlier that fall as the team's quarterback, and he was also one of the starting pitchers on the school baseball team. He was in the middle of basketball season as a reserve guard. On January 31, 2004, Ryan was on his way to the local mall with two of his best friends when the car he was riding in went out of control and hit a tree. The impact of the accident was all on Ryan's side. In addition to other less-serious injuries, Ryan suffered massive head trauma and was flown to a local trauma hospital by helicopter transport. His situation was very grave because of the massive head trauma he suffered from the accident. After a week in the hospital on artificial breathing support and various brain stem activity testing, Ryan passed away.

One month before his accident when he got his driver's license, Ryan signed up to be an organ donor. Because of that decision, six people received life-saving transplants and over 100 others' lives were enhanced through his tissue donations. My life and my family's life were forever changed that day by what happened to Ryan. As a way to help us deal with our grief and continue Ryan's legacy, the Ryan Lee Mohn Memorial Foundation was created. This foundation provides scholarships to graduating seniors from his high school, promotes organ and tissue donation awareness, and makes donations to other organizations in Ryan's memory. My family has also had the honor of meeting four of Ryan's transplant recipients and we have developed beautiful friendships with them. Losing a loved one, especially at such a young age, is really hard and my faith plays a major role in dealing with Ryan's loss.

Knowing that Ryan saved and enhanced so many lives also helps with our grief. Organ donation works. We never know if we could one day be on the other end of needing a life-saving transplant, and I believe if that would happen, we all hope that even in an extreme time of grief, others would say yes to organ and tissue donation.

# EILEEN KLINE

Eileen Kline was born and raised in Meadville, PA, a small town an hour and a half north of Pittsburgh, PA. Growing up, she volunteered at Spencer hospital where she developed a passion to care for patients. After graduating high school, she attended St. Francis School of Nursing, graduated in 1981 and then returned to her hometown to work as an ICU nurse at Spencer Hospital. During her first year of nursing, she realized how much she loved critical care nursing, validating her decision to pursue it as her career. Following her ambitions and desire to learn and experience more, Eileen moved to Pittsburgh, PA, a larger city with more critical care units and cutting-edge treatments and research.

In the early 1980's, the pioneer of liver transplantation, Dr. Thomas Starzyl started a liver transplantation program at Presbyterian Hospital (now known as UPMC). As Eileen reviewed nursing positions available in Pittsburgh, she jumped at the opportunity to work at Presbyterian Hospital, one of only a few hospitals in the world performing liver, heart, heart-lung and kidney transplants. At Presbyterian Hospital, Eileen went on to not only care for Dr. Starzyl's patients, but also patients of other renown physicians pursuing successful transplantation techniques and treatments. While working in the ICU, Eileen cared for patients waiting for life-saving surgeries, as well as those who received transplants. Eileen remembers how difficult it was to care for patients who died waiting for organs. She also recalls the excitement of witnessing miraculous recoveries and seeing a patient receive a second chance at life. She knew that with time, the sciences and procedures at Presbyterian Hospital would advance medicine and science for the future.

Eileen's time at Presbyterian Hospital was incredibly rewarding. She worked alongside the sharpest minds in medicine, met lifelong friends and formed life shaping bonds with her patients. For example, during this time, she cared for Father Michael, a Priest from Montana who received a liver transplant (the most complicated organ at that time to transplant). She cared for him for several months because of complications following his surgery, providing him faith and encouragement that he would recover and be able to return to Montana to resume his prior responsibilities to the Church. Eileen maintained a close relationship with Father Michael after his recovery and return to Montana. When it was time for Eileen to become married, Father Michael was there to officiate the wedding.

When Eileen and her husband started a family, she left Presbyterian Hospital. During this time, they raised 4 children. Eileen was an active volunteer in their schools and loved working with children. Ten years after leaving nursing Eileen decided to return to school to earn her certification in school nursing. After receiving her school nurse certification, Eileen was hired by the Baldwin-Whitehall School District as the school nurse for Paynter Elementary and McAnnulty Elementary School. Eileen worked as the school nurse for 10 years.

In October 2009, Eileen woke up on a weekend morning with a sore throat. She went to Med Express where she tested negative for Strep throat and was informed that it was just virus. Eileen's sore throat continued for approximately 2 weeks. She recalls that this sore throat was different than any other sore throat that she had experienced.

## Eileen Kline (continued)

One month later Eileen felt her heart beating fast and went to see a cardiologist. She was diagnosed with atrial fibrillation with a rapid heart rate. Medication was ordered to convert her heart rhythm to a normal sinus rhythm. Over the next couple of months, Eileen began to feel better, continuing to work full-time, despite her heart rate at times going in and out of atrial fibrillation. Her medication was adjusted multiple times with continued followed–up testing. With each adjustment, Eileen’s medication would initially control her heart rhythm, but it would later return to atrial fibrillation. Other treatments, including cardioversion were attempted, but ultimately her heart would return to its abnormal rhythm.

At 6AM on January 20, 2010, when Eileen would normally get up to prepare for work, she did not wake up. When her youngest child, James, woke up for high school, he found her not breathing in her bedroom. James, along with her husband, called 911 and immediately initiated CPR. Eileen was rushed to a nearby hospital and was life-flighted from there to Allegheny General Hospital in Pittsburgh, PA. She had suffered a cardiac arrest and remained in the hospital for 2 weeks. During that stay, a Pacemaker and Implantable Cardioverter Defibrillator (ICD) was implanted into Eileen’s chest to stabilize her heart. Multiple tests were completed so that doctors could diagnose the cause of the cardiac arrest. Eileen was diagnosed with ”viral cardiomyopathy,” a virus that caused her heart to enlarge and not properly function. The doctors believe that the virus from her sore throat a few months earlier traveled to her heart and ultimately caused her cardiac arrest.

Doctors informed Eileen and her family that her condition would continue to worsen, and that she would eventually require a heart transplant. Eileen and her family were shocked, as Eileen had always been positive, healthy and energetic. For Eileen in particular, this was difficult to process, as only 25 years earlier she had cared for patients requiring heart transplants. This time she herself was the patient waiting for a second chance at life.

Eileen was closely followed by her cardiologist, which required multiple tests, increased hospitalizations and further adjustments to medication. Every test result showed that her heart functionality was declining and eventually it stopped responding to treatment. Later that same year (early December 2010), Eileen was placed on the heart transplant list. On December 20, 2010, Eileen’s heart function further worsened and she was now too weak to breath on her own. She was admitted to the ICU and placed on a ventilator and heart-lung machine (Extracorpeal membrane oxygenation) to allow the heart to rest.

On the morning of December 23, 2010, 3 days after being placed on life support, Eileen’s family received news that a donor’s heart became available and that Eileen would undergo a heart transplant, providing Eileen a second chance of life and her family hope that she would be able to return to her previous level of activity.

Eileen will forever be grateful to the donor who provided her with the greatest gift she will ever receive. Because of the amazing care of the doctors and nurses, and the support and prayers from her loved ones, Eileen has been able to return to her previous lifestyle. She lives every day to the fullest and cherishes the memories she makes with her friends and family. Eight months following her surgery, she returned to work full-time as a school nurse and has been working ever since. She plays an active role in providing education to High School students on Organ and Tissue Donation to increase awareness. Not a day that goes by that Eileen does not thank God for her donor and her second chance at life.