The Sisterhood of Hope and Wait

An Introduction written by Pastor Johnathan Trees
from Grace Church of the Nazarene

Diana stepped up to the Advent wreath and prepared to light the candle. It was the start of the Christmas season and the Sunday that we celebrate Hope through carols and scripture. The rest of the world was traveling back home after Thanksgiving break and busy with the shopping season of Christmas. Network news stations were running typical Black Friday reports. Everything seemed normal. Yet the myth of a normal world has other narratives of struggle and illness that often get ignored. So when Diana, who struggles with kidney disease, stepped up to light our Advent candle it was to remind us all that Hope was not just a feel good word but means that realities can change and healing can be found. We had prayed for and witnessed our community step up to be tested to see if they were a match for transplant.

Left to Right: Diane and Carl Higgins, Debra Hartman, Christa Lawson, Diana and Wayne Bentley
For months Diana had hoped that one of the donor results would be a match. There is another word that is the sister of the word hope - Wait. One of the toughest things to do is to sit and wait. Wait accompanies hope. The two cannot be separated. Hope causes the heart to sing while waiting teaches us to trust for something greater.

This year Thanksgiving was different for Diana. While families were rushing to their turkey and gravy dinner with friends and family, she discovered that there was a match after all. As she ignited the flame of the first purple candle on the advent wreath, we announced to our church that she will receive her new kidney on January 4! Hope has been realized and the awful word, wait, has evaporated into the advent of the coming year.

Be encouraged. Let your heart hope because the waiting will one day end. I’ve have seen that ordinary people will rise up and fill the gap where others only find illness. The gift of a transplant is a gospel of life. Wait. Hope. And sing in the meantime because illness does give way to wholeness. I’ve witnessed it first-hand.

Jonathan Trees - Pastor, Grace Church of the Nazarene, Nashville, TN
Kidney Transplant Could Fix What Diabetes Broke

Sergio Macias is a loving father and grandfather. He does what every good dad wants to do, provide for his family and fix things that are broken. Sadly, diabetes has deprived Sergio of his kidney function. While dialysis allows Sergio to live, it’s not the fulfilling life he’d envisioned for himself or his family. A kidney transplant is needed to restore Sergio’s ability to live the life he loves.

“For most of his life everything was normal, or so we thought,” claimed Nancy Macias, Sergio’s daughter. “Dad went to work. He took medication for his diabetes. We believed he was doing fine, that was until last March.”

Sergio has lived with diabetes for 26 years of his life. He managed it properly with regular doctor appointments and a steady medication routine. About six years ago, he was alerted to the fact that diabetes was impeding his kidney function. Sergio asked his doctor at his then quarterly appointments what he could do to save his kidneys. He followed the advice of eating a kidney friendly diet and taking his medicine, but in the end, his kidney function declined and dialysis was necessary. The thought of starting dialysis terrified him.

“I’ve heard from a lot of people that it was something horrible,” Sergio remarked.

Thinking about kidney disease and dialysis brought back memories of his brother who died from complications related to kidney disease just four years earlier. Living in Mexico, his brother did not have steady access to dialysis.

“One morning, he just died. He was on the way to dialysis and died in the street,” he said. The idea that this could happen to Sergio terrified him and his family.

“When mom and dad said that his kidney function wasn’t there, you just think I’ll give him my kidney. But it’s not that easy,” said Nancy. “My mom tried to give her kidney, but she’s pre-diabetic. I wanted to give my kidney but with two kids and diabetes in the family, dad didn’t think that was a good idea.”

Sergio began his in-center hemodialysis treatments in Murfreesboro, Tennessee. He quickly learned how to make his thrice-weekly dialysis appointments productive. He would make calls to clients in the morning and then take his cell phone, tablet, and notebook with him to his 3:30pm dialysis appointment. Once connected to the dialysis...
Sergio Macias sitting with his grandsons

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Sometimes it’s challenging to explain kidney disease and dialysis. Your friends and family, adults and children, may want to know more about what you are experiencing, but don’t know how to ask. Our DCI family has created two activity books, suited for all ages, that explain kidney disease. Take a look. Print a copy. Share it with those who want to learn more. Visit www.dciinc.org/educational-resources/
Diana Bentley has battled a chronic illness for the past 29 years. However, to meet her, you’d never know she was sick. That’s intentional. Diana, typically a private person, is a wife, a mother and an active member of her church. She has refused to let kidney disease steal her life’s purpose. Yet, her prolonged battle with chronic illness has been exhausting. There were days when no solution was in sight. On her toughest days disappointment overwhelmed her heart. She was tired of waiting. And then, there was hope for the holidays.

In the spring of 1989, after one year of marriage, Diana noticed she was putting on weight and had unusual swelling in her ankles. A trip to her doctor’s office in Longwood, Florida, revealed that she was spilling protein in her urine. In October of 1989, her kidney biopsy indicated Nephrotic Syndrome. She was given high doses of Prednisone. In 1991, Diana’s diagnosis was changed to FSGS (Focal segmental glomerulosclerosis). Again, she was placed on a high dose of steroids and a medicine cocktail. The prescription combination led to hair loss and steroid induced cataracts. The potassium pills, as large as horse pills, eventually caused ulcers in her esophagus. Despite her medical complications, Diana chose to live life.

“I was four years into my kidney disease journey when I was visiting my nephrologist’s office, ” said Bentley. “I noticed that many of the people in the office looked like they were at death’s door. I decided then and there that wasn’t going to be my life. That was not the kind of life I wanted to live.”

Diana refused to allow kidney disease to become her label. She served as the piano player in her Florida church for 24 years. She was the worship leader four years. She raised a daughter, Emily, and enjoyed being Wayne’s wife. She didn’t share her struggle with kidney disease.

“I didn’t tell people about my health issues because I didn’t want to be viewed as that lady with kidney disease. Instead, every day I made a choice to get out of bed,” explained Bentley. “My daughter understood that with kidney disease I don’t have the energy of normal moms, but I do what I can, and that’s okay.”
For a brief period of time, Diana’s disease went into remission. Then, after taking cold medicine, her disease was back with a vengeance. Diana tried a holistic approach to her health. She also drastically changed her diet. Those measures allowed her to maintain her kidney function and hold back kidney failure.

Then, her journey took a turn. In June 2016, Diana moved with her family from Florida to Mt. Juliet, Tennessee. She became a member of Grace Church of the Nazarene. And, her kidney function began to plummet.

“I met with a nephrologist who said it was time to start dialysis. I looked at her and said I don’t want to start dialysis,” explained Bentley. “She said no one wants to start dialysis. I told her, no, you don’t understand. I don’t want to start dialysis.”

It took the doctor some time to review Diana’s entire medical history. Upon review, she agreed to help Diana go straight to transplant, hopefully avoiding dialysis.

In January 2017 Diana and Wayne were eating lunch with Pastor Jonathan Trees and his wife Kara. They understood that Diana was facing dialysis unless she received a transplant. The Trees explained to Diana that they wanted to discuss organ donation with their church congregation. Diana hesitated. She’d only been a member of the church for six months. She was a private person. Then, Kara reminded her that another parishioner, Carl Higgins, was also in need of a kidney. Allowing Pastor Trees to share each person’s story and talk about living kidney donation could help both parishioners. Understanding that it might help Carl, Diana agreed to make her need public.

“Asking for someone to give you a kidney is hard. At one point I thought I could never ask. But, when you’re faced with kidney failure, you find it in you to ask,” said Bentley.

Diana’s husband was tested and wasn’t a match. Several members of Diana’s family were tested, but they either weren’t a match or health problems prevented them from donating. Diana’s sister created a Facebook post that explained Diana’s need for a kidney. Then, Diana followed up with her own post. But, it was when Pastor Trees led a sermon that incorporated living kidney donation with REACH Kidney Care present, that Diana’s hope soared. 21 people came forward that day at church to be tested to see if they would be a match for Carl or Diana.

The testing process revealed a match for Carl. There was a match for Diana, but
it fell through. Several other people were tested for Diana. Each time a “match” was identified, Diana began to hope. Each time the match failed, her hopes sank. It became a long, grueling process. The wait was agonizing.

“My husband and I have been through a lot, but this was the hardest year of our life. We heard stories of other people getting a transplant, but it wasn’t working out for me. When we would hear that someone was a match for me, we’d temper our excitement. To say the least, we’d become cautiously optimistic,” stated Bentley.

Then, when Diana felt like she was out of options, and she was scheduled to start peritoneal dialysis, her brother-in-law, David Bentley, called and revealed that he was a match. He passed the first round of testing. His results showed he was a 4 out of 6 point match. The transplant team was very pleased with the quality of the match. The date for the transplant is set for January 4.

“When my husband and I spoke to David over the phone and he confirmed the date for the transplant, we both sobbed. We felt like we’ve been holding our breath for years. We can finally exhale and breathe again,” said Bentley. “My daughter has never known me without this disease. My husband and I only had one year of good health before the next 29 years of complications. I’m so excited to get a second chance at a more normal life!”

Diana’s kidney function has declined to the point where dialysis is necessary. She is on peritoneal dialysis while she waits for her kidney. It’s just one more hurdle to clear on her journey toward a transplant. She’s faced tougher challenges. Yet, this is a little easier to bear knowing there is hope for restored health this holiday.
A KIDNEY FOR CHRISTMAS, FROM MOM WITH LOVE

You can’t fool a mother. Stephanie Landrum, 51 year-old mother of nine, has watched her children grow and experience the wonders and sorrows of life. Like most moms, she’s in tune with her children’s needs. When something isn’t right, she knows and she looks for ways to help.

In November of 2014, Jasmine Nance learned she had high blood pressure. She was given hypertension medication which she took until she felt better. Then, she skipped her follow up appointment six months later.

“Looking back, I can say that I didn’t make time to take care of myself,” explained Jasmine who had been working full-time as a pharmacy technician. “But you’ve got to understand as a young African American, I was afraid to hear what I needed to do to take care of my body. Every time you go to the doctor, you wonder what problem will be found and what you’ll be expected to do.”

Stephanie, Jasmine’s mother, worked at Dialysis Clinic, Inc. (DCI) as a patient care technician from 2003-2012. After a brief time away from DCI, she returned to work in the DCI Kansas City business office, filling in occasionally on the treatment floor.

“When I came back to dialysis I noticed that the patients were getting younger,” stated Stephanie.

Jasmine, living at home with her family, recounts that her mother was concerned about the progression of kidney disease into kidney failure. She cautioned her daughter to take care of her health. “Mom would tell me about dialysis. But, I didn’t really pay attention because it’s what she does. It’s her job.”

On January 16, 2016, Jasmine had difficulty breathing. She had significant chest pain and had lost her ability to talk. Jasmine’s doctor explained she needed to start dialysis right away. She spent the next eight days in the hospital receiving dialysis treatments and learning all she could about how to get off of dialysis.

Jodi Oglesby, Care Coordinator for REACH Kidney Care of Kansas City, immediately went to see Jasmine in the hospital. “Jodi visited me almost every day. She talked to me about my diet. She provided me with a real guide on what to expect. We talked about how to get off of dialysis and I set a goal to be off within two years,” stated Jasmine.

Stephanie was shocked to learn about Jasmine’s kidney failure. “I never thought one of mine would be on dialysis. It was a blow to me,” declared Stephanie. Once Stephanie came to terms with her daughter being on dialysis, she said, “I felt like the Holy Spirit was leading me to get worked up to give her a kidney. When I told my husband, he encouraged me to do it.”
A KIDNEY FOR CHRISTMAS, CONTINUED

Stephanie began following up on her doctor’s appointments in January of 2017. Little by little, she prepared for a transplant work up but she didn’t mention her plans to her daughter in case something didn’t work out. In April 2017 she learned that she was a good match. She hid the results until her birthday party that Jasmine was throwing for her. Jasmine was both shocked and very excited to learn that her mom was going to be her kidney donor.

The transplant surgery took place at the Research Medical Center in Kansas City on December 13th. Both mom and daughter are doing well. Jasmine expects to return to her receptionist position on January 23rd.

28-year-old Jasmine has learned a great deal since kidney failure became a part of her life. “On dialysis I learned to be more aware of my health. Now, I stay in touch with my doctor. I ask questions.” She also encourages others to avoid the path she’s taken. “I was not very aware of the consequences of ignoring my health. I’m accountable for everything. I want others to understand that. Be aware. If not detected, you’ll be affected.”

“Be aware. If not detected, you’ll be affected.”

Jasmine was fortunate that her mother gave her a kidney for Christmas. No longer will Jasmine take her good health for granted. Both mother and daughter plan to retreat within their home and enjoy a laid back, low-key, transplant recovery this Christmas.