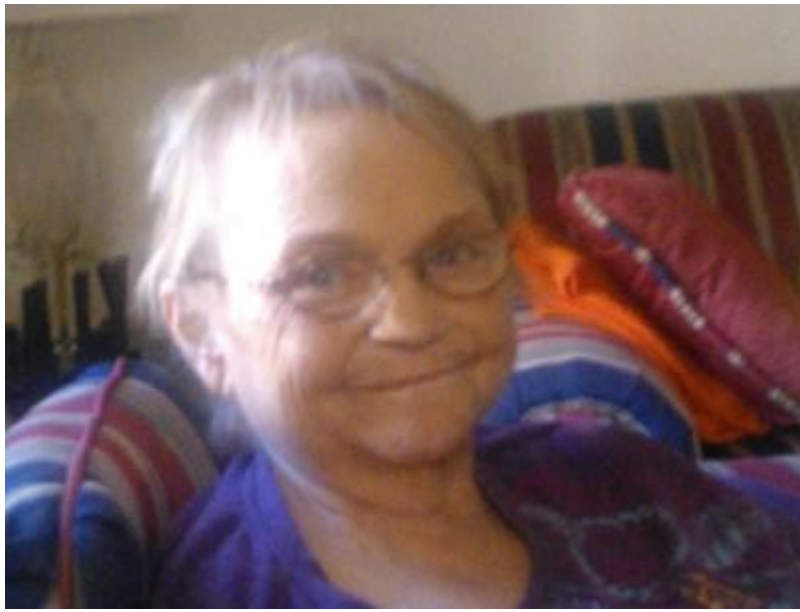


MY MOTIVATION FOR THE AAKP PEDIATRIC PALS NEWSLETTER

By Jim Myers, AAKP Ambassador and BOD member

I have been asked to write about my motivation for the AAKP Pediatric Kidney Pals Newsletter. It's a good question. I was not a pediatric patient, diagnosed at the age of 30, however I do love children and have an affinity with them. But that's not the answer either. I met someone when I first went on dialysis in 2012. She changed my life forever. This is her story.

A Kidney Pioneer and A Heroine



My first day of dialysis was August 3rd, 2012. I remember the date because that is my birthday. I was none too pleased to be in-center. I had gotten ill at work and home several times. I passed out at home and struggled to reach my phone to call for help. I live alone. When I was finally able to call for help, I was taken to the hospital. Two surgeries and a tsunami of information later, I was in no mood to have a catheter in my neck and start dialysis. Anger doesn't describe the

feeling; I felt rage. I felt I would die soon like my Dad did (he too had been diagnosed with kidney disease).

After a few weeks I made a new friend - short, vibrant grey-haired lady, with glasses, a moon face and a brilliant smile. I think she reached out to me, because I was such a miserable patient. She had been around. She had experience. She was kind and sweet, motherly to me. Little did I realize she was a piece of history. I didn't know this at first. I didn't know she was a hero. I didn't know that she was a pioneer. Maureen O'Brien was a piece of history. A mentor to a crabby old man.

Rarely do you run into a story of a person who was *first*; a person who was among the *first* more than once; a person whose kidney story spans decades and not just years, from childhood through adulthood and through middle age. It is even more rare to find that this same person has stared death in the face, and despite incredible odds, walked away from it. Maureen O'Brien is a dialysis pioneer in the State of Indiana. She is a transplant pioneer in my home state. She has had multiple transplants over the years. She has contracted what for most would have been fatal. Her story holds valuable lessons for all of us that assume we will be given dialysis, assume we will be put on a transplant list, listed at a transplant center, and given a fair shot at a transplant. Without Maureen and people like her, our experiences at dialysis and in transplantation would not be as simple or routine. Every one of us owes her. She is the one who taught me what it's like to be a dialysis patient as a child. She is the one who taught me what it means to face multiple surgeries in your life.

Her Kidney Story Starts at the Age of 11

Maureen's story began when she was just 11 years old. Up to this point, she had a normal childhood, going to school at St. Mary's in Crown Point, Indiana, (a catholic school preparing you for high school), being a small pixie of a girl with pigtails, wearing the school uniform, acting as a cheerleader for her school, having friends and studying like children do. Before 1968, she had led a normal, idyllic childhood in sleepy Crown Point. After '68 it was anything but. She caught what appeared to her parents to be the flu. She had all of the normal symptoms, nausea,

lethargic, and sleepy. She had some that did not fit the pattern: her skin color was off, and her urine was discolored. She seemed unable to shake the virus.

When she failed to respond to medications, she was admitted to Gary Methodist Hospital and almost immediately transferred to Riley's Children Hospital in Indianapolis, Indiana. The news was jarring. Maureen's kidneys had failed. She would die without dialysis. Now, dialysis is taken for granted in kidney failures. The only question seems to be do you want to do dialysis in a clinic or would you rather do it at home? Hemo or peritoneal dialysis? Most of us receive our first dialysis treatments in this hospital before we are discharged. It is routine; old hat now. You have a quick surgery to insert a catheter in your chest and that is your dialysis connection. All in all, from surgery to my first session, it took 24 hours.

LITTLE MAUREEN HAD TO QUALIFY FOR DIALYSIS

Not for little Maureen. She and her parents would have to go before Methodist's medical board and argue that she was mature enough; that she had both the physical and mental ability to handle dialysis. They had to raise money and come up with \$40,000 before she would be seriously considered. Just imagine how brave this little 11-year-old girl and her folks had to be. Knowing the alternatives, they would have to argue that this little girl could handle the 1968 version of dialysis. Dialysis was new at this time. If they accepted Maureen, she would be one of the first children in Indiana to be placed on dialysis. The machine was not even called a dialysis machine at the time, but a contraption called an "artificial kidney device." It was complicated difficult to operate. It relied on a 3ft long by 1 ½ ft wide cellophane kidney with cellophane layers as the substitute kidney. This cellophane kidney would easily rip and tear, and basically failed frequently. It was very touchy. She and her mother would be expected to operate this device. This is a far cry from the smooth running, computer operated machines that practically run error-free that I used three times a week. She and her mom were expected to operate this device every day. At home. Alone. I took dialysis at a Fresenius Medical Center. Except for showing up and weighing myself before and after my run, I was really expected to do nothing except sit there. I was closely supervised by trained nurses and dialysis techs who respond to alarms from the machine indicating that the smallest thing is wrong. If my blood pressure is a little low, they'd come, answer the alarm and check it out. They knew what to do. I

was not alone with some machine I know next to nothing about. Back then, Maureen and her mom were expected to run the artificial kidney machine, at home, alone. No nurses. No trained medical personnel. No center.

My typical run on dialysis was four hours long. I was constantly checked on, given meds, my blood pressure is automatically taken. Except for the time, there really is no issue with pain and most of my runs were silky smooth. This young 11-year- girl and her mother faced daily runs of 9-12 hours. And they had to be trained to use it. This was not the go-to class for a 4-hour period and graduate with honors type of deal. If accepted into the program, Maureen and her mom would have to take an apartment in Indy and stay there for three months. Methodist had expressed to the family that they had their doubts about little 11-year-old Maureen. A “no” decision would have brought the little girl from Crown Point to the edge of life. Fortunately, the Board said “yes”.

LIFE FOR MAUREEN AFTER STARTING CHILDHOOD DIALYSIS

After 3 months of training, Maureen and her mother came home. The family set up a room in the basement designated as the dialysis room. They did not have a highly trained dialysis staff; they had a phone number. The incredible amount of time dialysis took meant Maureen could not go to school as often. She wasn't a cheerleader any more. She did not have a real classroom experience. She missed her friends. Her life now revolved around dialysis. And dialysis only. For a 2-year period she was on dialysis at home. She missed a great deal of school in both her Junior High and High School years.

Why did little Maureen's kidneys fail? Even this is not answered completely. There are two theories. Either it was congenital, or she lost her kidney function due to strep throat. As there was no evidence of a genetic disease, the doctors concluded that it must have been the strep throat she had with her flu. This is still an issue today, where many people suffer kidney failure due to some type of infection.



CAN A JUNIOR HIGH STUDENT GET A KIDNEY TRANSPLANT

Maureen now faced a second hurdle where she was once again a pioneer. In 1972, at the age of 15, she was considered for a transplant. She was still in Junior High School at Taft Jr High. The same issues were present. Was she mature enough? Would she be able to handle the potential of rejection? The average life expectancy of a patient on dialysis now in the 21st Century is between 3-5 years. Some people tolerate it much longer, but that is the average. Maureen had spent her 3-5. To protect her life, her mother was willing to donate a kidney. Would the now young junior high school student be given a chance? What we commonly call now a second chance at life? Once again, presentations had to be made. Once again, she would be blazing a trail. Once again, the young woman from Crown Point would be at or near the front of the line.

The verdict was in her favor. She would now become one of the youngest kidney transplants in Indiana. One of the very first for her age. The first transplant took place in 1972 at Methodist Hospital in Indianapolis. Maureen was 15 at the time; just a freshman in the 9th grade. She was now not only one of the youngest to start dialysis in Indiana, but also one of the youngest to be transplanted. One complication that occurred with the transplant, was the after-transplant meds. Anti-rejection medication was not in use then. Steroids were given to prevent rejection. This lasted for almost 30 years. They had a side effect of causing Maureen to balloon up in both weight & appearance from her normal small frame of 4' 9" & 80 lbs. Children & some adults teased the ex-cheerleader. This left some emotional scars that would last the rest of her life. I heard it in her voice when she tells you it was "hurtful."

On the plus-side, the change after the first transplant was remarkable. She had much more energy and freedom.



**Maureen When She Graduates From High School, Already Stating She
Wishes To Be A Nurse**

MAUREEN THE HEALER

In 1975, she went back to school at Gateway Community College in Phoenix. She completed work on her LPN at St. Anthony's Ivy Tech in Michigan City in 1977. She also worked in a Phoenix Hospital until 1989.

Unfortunately, her transplanted kidney was rejected by 1983, after 11 years. To gain some support, she moved back to Crown Point to be closer to her mother. Between 1983 and 1986, she was again on dialysis. She was back on the transplant list in 1986, and she received a new kidney for her second transplant within six months at Good Samaritan Hospital in Phoenix. This kidney came from a cadaver, a 15-year-old boy who died from self-inflicted gunshot wounds. This second transplant was complicated by the fact that she was pregnant three months after the transplant. She came through the procedure without a hitch. In that same year, 1986, she gave birth to her first child, Matthew. She married and her second child, Lisa was born on Thanksgiving Day in 1989. She moved back to Arizona and worked at Scottsdale Health Care from 1990 to 1999. She was divorced in 1993. At this same time, she completed work on her Associate's Degree and worked as a float nurse and as an RN in cardiac, critical care nursing.

A SECOND REJECTION

By 1998, her second kidney went through rejection. It was her 25th year as a nurse. She then sold her home in Mesa and moved back to Crown Point. She purchased a house there with her brother. This was particularly tough because she went back on dialysis with two little kids.

HER THIRD TRANSPLANT

Subsequently, her sister was tested and found to be a perfect match. In 2006, a third transplant was performed at Northwestern Hospital in Chicago. Unfortunately, she rejected her third kidney within four months. They placed her on chemotherapy due to the rejection. They were unable to save the kidney and it was a very fine line to save her life. While she was hospitalized in Northwestern for five days, she slipped into a coma. At that time, they felt she

would pass and sent her to hospice. Maureen miraculously, woke up from the coma hearing her daughter talking and she laughed at her daughter's joke. She went home, was very independent and happy. Every day before I took dialysis, we'd speak. I often visited her at her home. She taught me more than I can express. I took a vow when I learned she had passed. Pediatric Kidney Patients need advocates, too.



LEGEND

She was an invaluable friend and reference. I lost my friend after I was transplanted in 2016. She will always be my hero. Kidney Advocate and pioneer, Maureen O'Brien is the reason I am passionate about representing children with kidney disease and my motivation to work with the AAKP on the Pediatric Kidney Pals Newsletter. To the oldest, largest and most patient-oriented kidney group in America, I thank you!