



AAKP Ambassador Mary Baliker shares her story with AAKP Pediatric Kidney Pals readers....

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At age nine, Mary was diagnosed with chronic kidney disease and doctors told her parents that she only had six months to live. This was in the early 1970s in Wisconsin when children did not receive dialysis; dialysis was a daylong treatment. At this time, children did not receive kidney transplants either. The best they could do is keep her comfortable and hope for a miracle.

The first signs that something was wrong with Mary were at school. The teachers complained to Mary's parents about her falling asleep in class and not wanting to play outside at recess. The teachers thought she was just bored, but her parents knew that did not sound like Mary. She loved school. So, they took her to the doctor, and she was immediately admitted to the local community hospital. Mary began to retain fluid, she could hardly walk and became deathly ill. She was transferred to the University of Wisconsin's Children's Hospital in Madison where more tests were done including a kidney biopsy, and after many lab tests it was discovered that her kidneys were failing. The hospital suggested some experimental medicine, but that was all that could be done.

Mary remembers that her parents gave her the best birthday ever when she turned ten years old. A day filled with family, friends, birthday cake and of course many birthday gifts. It was at that point when she thought she might be dying. But with every doctor's visit Mary had, she slowly progressed. The medical staff were so excited that she actually grew! The kidney disease was not progressing as fast as they had predicted.

When Mary was 17 years old and a senior in high school, she started dialysis. During that time her brother, Doug, was being tested to be her kidney donor. It turned out he was a perfect match. Doug donated his kidney later that year, which was her first transplant. The kidney disease was not genetic - it was unknown what caused her kidneys to fail. Because of her brother Doug, her "hero", she was able to go on to college, fulfilling one of her life goals. Unfortunately, her brother's kidney failed after four years due to reoccurrence of the kidney disease. Mary has had three more kidney transplants and has been back on hemodialysis in between. Her most recent kidney transplant is still going strong after almost 20 years. Mary says life has been "like a rollercoaster ride, lots of highs and lows"; however it hasn't stopped her from following her dreams. As a Healthcare Consultant and someone growing up with kidney disease she cherishes her life and this has given her a strong interest in improving the quality of healthcare.

Advice for Parents and Children

Mary's advice to parents and children is to focus on what you can do instead of what you can't do. Mary says that growing up, she was not able to participate in gym class or sports; she was tired all the time and slept often. She also was on a very strict diet and always took a hand full pills. She remembers this being her life and not really knowing any different. Her mom was her constant, always by her side, always focusing on her diet and her health. As she looks back, Mary says it is especially important for the parents or caregivers of sick children to take breaks and do something they enjoy doing for a few minutes each day. Additionally, she encourages children to not give up hope and to focus on things they can do even though they are sick and may have limitations. Mary has written a children's book called, **"Maria Never Gives Up, Are You Like Me?"** She says the book was written to help other children and their families in their struggle with chronic illness. To purchase a **copy of the book go to amazon.com (20 % of the sales will go to AAKP)**.

Mary's motto is "Live Every Day, Laugh Often and Love Beyond Words." Today, she is happy and living a healthy normal life. She enjoys hiking, biking, Pilates, yoga and traveling, as well as her volunteer work.

AAKP thanks Mary to sharing her story and giving advice to parents and children of kidney disease.