



YOUR VOICE, YOUR HEALTH: A KIDNEY COMMUNITY NEWSLETTER

BROUGHT TO YOU BY THE KIDNEY PATIENT ADVISORY COUNCIL OF THE FORUM OF ESRD NETWORKS

A LEGACY OF LOVE: ONE MOTHER'S JOURNEY THROUGH LOSS, KIDNEY DISEASE, AND ADVOCACY

By Precious McCowan, PhD

Born at just 27 weeks and weighing only 1 pound, 12 ounces, my son William came into the world tiny but incredibly strong. He spent five months in the NICU, surrounded by machines, alarms, and the steady hands of caring nurses and doctors. Despite the odds, he overcame the many complications common in premature infants and grew into a joyful, curious, and active little boy. His resilience was nothing short of remarkable.

At the age of two, William passed away unexpectedly from an illness his doctors believed he would quickly



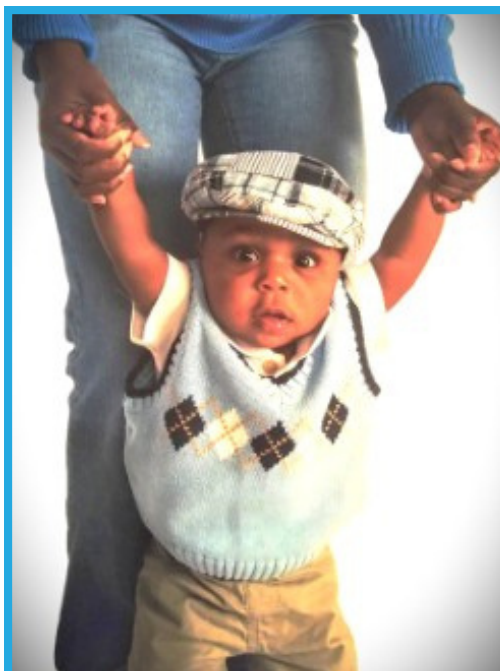
Precious and her son William

recover from. In our devastation, my husband and I were asked a question no parent is ever prepared for: Would we consider organ donation? At the time, I was seven months into recovering from my first kidney and pancreas transplant. Grieving while being asked to give so profoundly was one of the most challenging moments of my life.

Two coordinators from our local OPO met with us with deep compassion. They gently explained the process and gave us the time and space we needed. In the end, we chose to say yes. Though our hearts were broken, we knew William's life could bring hope to others.

After the donation, we learned that he had saved multiple lives, including that of a young man who later wrote us a letter of gratitude for the gift of a kidney. That letter still brings me comfort. Saying yes didn't erase our grief, but it gave meaning to our loss. William's love lives on in those he helped save.

I live with kidney disease myself. Over the past 13 years, I've been on and off dialysis and have received three kidney transplants. I understand both the pain of loss and the long wait for a second chance. My personal experience has shaped my advocacy work. Serving on the UNOS Organ Procurement and Transplantation Network (OPTN) Kidney and Multi-Organ Transplant Committees, as well as other advocacy efforts, is deeply personal to me. This isn't just policy--it's William's legacy. It's about fairness, compassion, and



William

honoring every donor and recipient in this system.

Every time I speak my son's name, I honor the life he lived and the lives he saved. As we continue improving transplant and ESRD care, may we never forget the people behind every statistic—the patients, the donors, and the families who give and receive the gift of life.

National Impact of Deceased Kidney Donation

In 2023, more than **17,000 kidney transplants** were made possible by **deceased donors** in the United States, accounting for **over 70% of all kidney transplants** performed that year. Each deceased donor has the potential to save **up to eight lives** and improve **dozens more** through organ and tissue donation. Nearly **13,500 deceased individuals** gave this gift in 2023 alone.

From UNOS & Organ Procurement and Transplantation Network (OPTN) Data