The Importance of Advocacy Work
Curtis Warfield’s story - in his own words

How did you get involved in kidney advocacy?
When I received a diagnosis of this disease, I felt alone. I really didn’t know anything about CKD, except negative thinking such as you go on dialysis, then you die—unless the dice roll in your favor, you “luck-up”, and get a transplant.

My first meeting with [other] people with CKD was very negative. Everyone in that room was angry. So, I wanted to help people by mentoring and through education. I’m also interested in legislative activities that can improve the quality of life for kidney patients through new laws that will enable more research, ease financial burdens and [provide] better care. Secondly, I am so

The importance of advocacy work helps bring more awareness to kidney disease to 1) prevent the disease in those who have a chance not to develop it; 2) educate—bring a battle mentality to those who don’t see any hope; 3) increase awareness of organ donation, especially living donation, to the general public; 4) celebrate those living donor heroes as much as those who have given posthumously and 5) help break down myths about CKD, especially in the African-American community and other communities of color.

I would like to bring kidney health and awareness more to the forefront and not have CKD treated as a secondary disease. [Instead of just saying] if you have high blood pressures or diabetes then you can get kidney disease, our kidneys should be viewed/valued as important as any other organ.

What current kidney advocacy are you working on now?
Presently I am advocating for legislation for:

- Living Donor Protection Act - Senate Bill S.554/House Bill H.R.12224 which protects discrimination against a living donor. Recently Indiana State Legislation introduced a similar state bill – Senate Bill 264.
- Immunosuppressive Drug Coverage Act – U.S. H.R. 5534 which will lift the three-year limit on Medicare coverage of anti-rejection drugs for people who have kidney transplants.
- CKD Improvement in Research and Treatment Act (S.1676/H.R. 3912) which will increase awareness of kidney disease, expand preventative services and increase nephrologists care in underserved areas.

A different advocacy approach, for me, will be launching a blog page soon called “My Kidney Watch”. It features personal stories from me on living with CKD and special guests on subject matters to encourage, motivate and be relative to patients, caregivers, donors and families covering multiple areas that kidney patients and other chronic diseases patients have to address in their “normal lifestyle”.

Curtis Warfield is a Senior Quality Analyst who received a living kidney donation from his daughter’s severity sister in 2006. Curtis is very passionate in advocating and educating about CKD, dialysis, organ donation and living donors. He is a volunteer for the local Indiana affiliate of the National Kidney Foundation as well as an advocate for the National Kidney Foundation in New York and DC. Curtis has been married for 54 years and has 4 adult children and one grandson.