

September 13, 2021

Women In Government
444 North Capitol Street, NW
Suite 40
Washington, DC 20001

Dear Legislators:

Before my Autosomal Dominant Polycystic Kidney Disease (“PKD”) journey even started, the odds were already stacked against me -- black people in America develop PKD at an earlier age than whites,¹ are associated with a higher rate of end-stage renal disease (“ESRD”) than whites,² initiate dialysis at a younger age compared to whites,³ and have 76 percent lower odds of obtaining a kidney from a living donor compared to whites.² Since being diagnosed with PKD six years ago in my mid-thirties, I have been exposed to some of the institutional, economic, social and cultural barriers that have a real detrimental impact on black PKD sufferers. As a black woman with PKD, I write this letter to urge you all to support initiatives that provide a path to better outcomes for black and brown people suffering from kidney disease.

The Diagnosis

Being diagnosed with PKD was extremely overwhelming. I vividly remember being in the nephrologist’s office, not quite comprehending how a mild reaction to an antibiotic, following a routine ENT visit, had led me there. Before this, I had never had any major health issues nor had any doctors signaled abnormalities with my blood pressure or organs. I do not smoke, rarely drink, eat healthily, have a normal BMI, and have no known history of PKD in my family, yet there I stood alone, confused and depleted, listening to a doctor tell me I have a chronic illness that could potentially lead to a transplant.

I was in denial for the good part of two years, attending hospital visits every few months without fully acknowledging this life changing event. I kept the diagnosis to myself for a long time and to-date I have only shared it with a few people, including two of my siblings. I have kept the news away from my elderly parents for fear that it would be too much to bear. In the black community, there is a lot of stigma associated with disease. Having a chronic disease has also worked against me in other aspects of life – a couple of years ago, my life insurance application was denied because of it. I am working on furthering my legal career and do not want to be discriminated against because of this chronic illness. For all these reasons, I write this letter anonymously.

Knowledge is Power

The development of my condition forced me out of denial into acceptance. In a bid to curb its progression, I have tried to learn as much as I can about the disease. Early on my doctor told me

¹ Murphy et al. *BMC Nephrology* (2019); 20:55

² *Id.*

³ Hall. et al. *Am J Kidney Dis.* (2012); 59(6):849-857.

about Tolvaptan (the only drug authorized in the U.S. to slow the decline of PKD), but without any forewarning my condition had advanced to a point where I was no longer eligible to take it. I have followed all my doctor's directions, but much to my frustration, my kidney function continues to deplete. I have no control and at times feel helpless.

I have a very attentive care team at the Rogosin Institute (New York), but my 45-minute consultations are never enough to answer all the less obvious questions – what does a 3.8 albumin level signify, is my heavy menstrual cycle tied to my kidney function, how are my minerals still being regulated despite the decline in kidney function, can I go on dialysis if I become pregnant, the list of questions go on and on, and every interaction with my nephrologist spurs a whole new set of them. I began to conduct my own independent research, attended events for people with PKD and online webinars targeting health practitioners, and was fortunate enough to be introduced to a black nephrology fellow at Mayo Clinic to help make sense of the disease and my numerous tests and examinations. The knowledge that I have acquired has allowed me to play an active role in my care.

Navigating the Healthcare System

As a lawyer, problem solving is an essential skill, but navigating the U.S. healthcare system has proven to be more complex than any legal issue that I have had to resolve. The process is mentally, emotionally, and financially taxing even though I have what is deemed to be “good” insurance. Exchanges with my medical insurance company are often a hair pulling experience, with multiple representatives giving conflicting guidance re: the same matter. I have had to jump multiple hoops just to secure a second opinion from Centers of Excellence such as Mayo Clinic. And trying to decipher what factors to take into consideration when deciding where to list for transplant is still a mind-boggling exercise.

Racial Disparities

As I continue through this journey, I have become very conscious of race and how it impacts the outcomes and resources available to PKD patients. I noticed that there were very few black and brown faces present at PKD events, which is baffling especially considering that black people are disproportionately affected. The PKD patients at these events were predominantly white and most of them were either on Tolvaptan or managed to secure a living donor.

These groups are very welcoming and eager to help, but because a lot of the members have experiences that are vastly different to mine, the disconnect is hard to ignore. People in these groups often talk casually about preemptive transplants and having family members or strangers that are willing living donors. Belonging to a community that has a higher burden of chronic health conditions, means potential donors are fearful and reluctant. I quickly learnt that although we all had the same disease, people of color and whites are operating in two different worlds when it comes to the disease hence the racial disparities in overall outcomes.

Hope for the Future

Being diagnosed with PKD has changed my life forever and, although dialysis seems inevitable unless I receive a transplant, I am determined to be hopeful. I have found a new purpose that involves raising awareness re: my experience as a black person with PKD. If I can make things easier for just one person that is going through this process, my journey has not been in vain. I am particularly passionate about equipping black people that lack the tools and education to navigate the healthcare system so that more of us can have access to quality care; increasing black participation in PKD/Kidney disease focused events and trials; ensuring that black patients are offered available treatments; and eliminating barriers that prevent black patients from accessing treatment at top tier institutions such as Mayo Clinic.