Genetic Testing Is Beneficial to the Entire Family

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Upon reading a recent CJASN article titled “Preimplantation Genetic Testing for Monogenic Kidney Disease” (1), I felt as if I had gained some insight into the future and knowledge that could help my future unborn child. As I was reading, I envisioned a wedding that was in the near future, with thoughts of how kidney failure has affected my life, both past and present, and how it would play a role in my husband-to-be’s and child’s life.

What makes me think two steps ahead is my kidney disease that is characterized by local inflammation that, over time, can hamper your kidney’s ability to filter waste from your blood. The cause? Unknown. However, we know, in medicine, that it means that somewhere in my ancestral DNA, a gene existed and presented itself when I was 18 years old, just missing the pediatric mark.

Having a normal life one day, and then being put onto dialysis and dealing with nutritional and diet changes and a dramatically altered social life take a toll on a young woman’s body. At that age, one is supposed to be venturing out into the world, yet I was learning to live cautiously. Regular checkups required blood draws and other various tests that needed to be done regularly to monitor kidney functions. These tests were preventative to help me maintain a healthy lifestyle.

Living with two kidneys is a myth; you can live with only one. I had a living donor hear my plea of wanting to live and then understand what it meant to donate an organ. The donor understood the risks and benefits of donating an organ, even if the individual did not understand the technicalities of how the genetics behind the kidney problem affected me. I want to keep my organ healthy as long as possible. I want it to give me a good life, which can include having a family, even a small one of three.

If I did not know about genetic testing, I would have had children and perhaps unknowingly passed on the gene that could diminish their quality of life. Genetic testing is so important because it is not just my child’s life that is involved, but also anyone involved in caring for a child with diagnosed kidney disease. CKD actually affects an entire nation because taxpayer dollars are allocated to the care, maintenance, and treatment of this issue.

When it comes to having a baby, the burden of worry doubles. I have kidney disease, and that will not go away just because I have a child. That disease will stay with me for life and will progressively deteriorate my body, mind, and soul. However, I still have to find a job with benefits, care for my family, and hope that my life will be fruitful.

The pro versus con list of genetic testing is very short for me, as I see mostly positive outcomes. However, one aspect that I would consider in getting a genetic test done is the cost. Some tests can range from $100 to >$2000, depending upon the nature and complexity of the test. If there is a reason to continue testing, the cost will increase if multiple people need to be tested for an unborn child to attain a meaningful result. Luckily, some states will cover these costs, but for the ones that do not, the cost can go up to $100 per baby.

Another issue with testing is the time to results, given that many patients have time limits. Some patients may have a few years to produce a family, or, in severe cases, a few months. Thankfully, prenatal results will be analyzed the fastest due to a pregnancy being only a limited number of months.

I have never been opposed to the benefit of genetic testing, especially because I have an underlying condition. I am always supportive of how far science and technology have come in the year 2020 to help better the future of human beings.

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