The Ohio Rare Disease Council Act

Jan 14th, 2020

Chairman Lipps, Vice-Chair Manning, Ranking Member Boyd, and Members of the House Health Committee,

Thank you for allowing me to testify today. My name is Kathryn Poe and I am an undergraduate student at Capital University. I am also a rare disease patient and a non-related donor bone marrow transplant survivor. I am here on behalf of other patients like myself as a strong supporter of the creation of an Ohio Rare Disease Council.

Growing up as a young person with a rare disease comes with its own set of challenges. By my Junior year of high school, I had lost the ability to hold a pencil, walk for long periods of time, and use my hands. I was covered in a rash, had lost 30 pounds, could not eat, and spent months bed-bound with no explanation. The years of extreme, unexplained pain and physical disability coupled with no diagnosis complicated everything in my life, from getting denied proper disability accommodation in the classroom to being accused of faking my illness by my peers.

Then, when I wasn’t dealing with my unknown disease, I was being pulled out of classes to have hour-long arguments with insurance companies and trying to figure out how to give myself shots of 30,000 dollar biologic medications-- many of which didn’t work. By the end, it took doctors nearly 4 years to properly diagnose my full condition. But with a mortality rate of nearly 50% for each relapse and after 6 relapses, I truly shouldn’t be standing here today.

Yet, here I am standing before you, a year and a half post bone marrow transplant, alive today because of the medical invocations and amazing doctors that were willing to take a chance on me, making me the first bone marrow transplant conducted on a Rheumatology patient at Nationwide Children’s Hospital.

Most people don’t realize the importance of Ohio in stem cell research. Hospitals like Nationwide Children’s, Cincinnati Children’s, and the Cleveland Clinic are globally renounced centers of research for rare diseases like mine through cellular therapy. My own bone marrow transplant doctor, Dr. Rolla, is currently conducting cutting edge clinical trials to help patients like me at Nationwide Children’s. Not only are improvements constantly being made in diagnosis, but new treatment options are being developed all the time. We need to support these efforts.

But I’d also like to remind you that it’s not all about finding solutions. It’s also about finding innovative ways to maintain long term care for patients like me.

Not only do rare disease patients face unique obstacles in access to medication, medical professionals, and the burden of having a preexisting condition for the rest of our lives, but we also struggle with survivorship and adjusting after long term trauma. We are often dealing with treatments that are brand new and rarely get to meet others who share our experiences. In fact, in my entire life, I have only ever met one person who also has my disease and none that have had a bone marrow transplant for it.

The truth is that survivorship and life with a rare disease is a bittersweet experience. People like myself, who get these diseases when they’re young, are thankful for new treatments, but also must deal with the ramifications of the disease for the rest of their lives. There are no rare disease days off or getting a break when you live in a body like mine. Even now, as I speak, I am currently getting an IV Infusion of antibiotics and had to wear a mask in order to come to speak today.

We must think deeply about ways to put people and their lives at the center of our long term treatments, and the ethical implications and actual realities of patient life. We must always seek to include patient opinions in the conversation and focus on patient centered care. We must remember the purpose of medicine: not only to heal, but to also provide a good quality of life.

It is for all of these reasons, I encourage this committee to improve the lives of Ohioans like myself and say yes to creating an Ohio Rare disease council Act.

I will now take any questions.