HB412 Testimony
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My seven year journey with rare disease began in 2014 when I developed a series of mysterious, gradually escalating symptoms. I started unexpectedly passing out in school and was suddenly unable to eat. I got a bright red, splotchy rash and uncontrollable swelling in all of my joints. Soon, I was unable to go outside or stand for long periods of time. I missed three months of school and found myself spending weeks at a time completely stuck in bed. At times, my hands were so swollen I was unable to open the door to get out of my room, and I was unable to go up and down steps and walk more than a couple of feet. I became a shell of the teenager I was before. While other 16 year olds were learning to drive for their 16th birthday and had their first kiss, I received my first dose of chemotherapy and found myself losing the ability to walk. Then, at the beginning of my Senior year of high school, the high fevers started. Every single night around 5pm, from September 2015 through April 2016, I had a fever of above 101. Eventually, the fevers rose to 105, and on multiple occasions I had to be admitted to the ICU. Still, no one knew what was going on. My doctors told my parents and I that unless something was discovered soon, I wasn't going to make it past my 18th birthday.

In the spring of 2016, I finally received a diagnosis after another dangerously high fever landed me in the ICU just a month before high school graduation. I was diagnosed with Celiac disease, Systemic Juvenile Idiopathic Arthritis (SJIA), and Macrophage Activation Syndrome (MAS/HLH). While Celiac and SJIA are not dangerous on their own, my immune system had been left in an uncontrollable state of panic for years without treatment, causing a disease called MAS/HLH. And while in almost all cases MAS/HLH is a one time reaction to over inflammation, for me it had become a chronic condition that would likely eventually end my life.

Fortunately, treatment did work for me in 2016, allowing me to go to college and move to Columbus. But by my Sophomore year of college, my MAS/HLH had returned, and this time it did not respond to treatment. I was then offered a new, much more dangerous treatment option as my last resort: a non-related donor bone marrow transplant. While bone marrow transplants (BMTs) are traditionally used on blood cancers, they can also treat upwards of 70 diseases, including mine in very rare cases. Doctors in Nationwide Children's Rheumatology department had never transplanted a patient with my disease before, but I was willing to be the first. I received my bone marrow transplant in July of 2018, and although my recovery has been difficult (especially as a college student) I am now truly healthy for the first time since I was a teenager. I am set to graduate college this upcoming December; a milestone I never believed I would actually make it to.

Looking back at my young adult life is bittersweet for me. I feel a sense of extraordinary loss and confusion, and I find myself mourning the girl that I could have been. But the most traumatic part of my experience isn't the illness; it's the system that surrounds it. I spent my young adult life learning to navigate pharmacies and insurance companies, crying on the phone trying to get medication, worrying that my family was going to go bankrupt because of my life, and being constantly retraumatized and dehumanized by a medical system that was supposed to protect me.

Being a rare disease patient is existing in a constant state of uncertainty; navigating a world that not only doesn't understand your needs, but also cannot give a name to your suffering. It is difficult to describe the doors that a simple diagnosis can open and the legitimacy that it gives the searching patient. Without a diagnosis, IEPs and 504 plans can be denied to students, work exemptions can be thrown out, disability claims can be denied, and social legitimacy is ultimately stifled. What is not often spoken about is the sometimes 10 year waiting period between when symptoms begin and diagnosis-- a period of uncertainty, denied treatments from insurance companies, and thousands of blood draws, hospital admissions, and appointments. And once a diagnosis is found, there is often only a hand-full of doctors that are familiar with your case, and getting access to one of those doctors and the treatment needed can deplete an entire family's savings.

Rare disease is at the intersection of a number of ethical issues: high priced pharmaceutical drugs, unethical exploitation of patients, insurance companies denial of treatment options, restrictions to accessible living, ADA violations, and direct harm by physicians to patients when dealing with the complexities of often invasive treatment options. You cannot live in Ohio as a patient with a rare disease without an understanding of the interconnectedness and complexity of this issue. Rare disease is a topic that requires multiple perspectives and interdisciplinary ideas including doctors, patients, care givers, insurance companies, and lawmakers. Creating a Rare Disease Council is important because it connects all these complex issues in one place. Simply, rare disease treatments and progress cannot be solved by a single entity, it must truly be a group effort. For all of these reasons, I support the passage of HB412.