Introduction

Good morning, members of the committee. My name is Jaime Brown, and I stand before you today as both a constituent and a patient living with lupus nephritis, a serious and often misunderstood autoimmune kidney disease. I am here to advocate for the designation of May as Lupus Nephritis Awareness Month in our state.

The Reality of Lupus Nephritis

Lupus nephritis occurs when systemic lupus erythematosus, or lupus, causes inflammation in the kidneys. This can lead to kidney damage and, in severe cases, kidney failure. Despite affecting thousands of individuals in Ohio and across the nation, lupus nephritis remains underrecognized. Its complexities often result in delayed diagnoses, inadequate support, and significant personal and medical challenges for those living with the condition.

My Personal Journey

My lupus nephritis journey started when I was a teenager. In the beginning, I was experiencing joint pain mostly, I had to start pulling out of sports like gymnastics, softball, and track because my body just didn't feel right, and I was in a significant amount of pain. As my symptoms worsened, they became more unusual and harder to explain. I started having lots of pain while urinating and my urine would be foamy and a very dark yellow/brown no matter how much water I was intaking, I couldn't go out in the sun without getting rashes, I had frequent infections and illnesses, and had overwhelming fatigue.

I eventually ended up in the ER because of the pain and they noticed I had AKI (acute kidney injury) and that my eGFR was below 90. eGFR stands for estimated glomerular filtration rate, which is a blood test that measures how well your kidneys are functioning. eGFR estimates how much blood your kidneys filter per minute and is calculated from a blood test that measures creatinine levels, along with your age, sex, and body type. A low eGFR means your kidneys may not be working properly. A normal eGFR usually means you probably don't have kidney disease, while a very low eGFR may indicate kidney failure.

So the fact that mine was below 90 was no big deal because I was young and sometimes your kidneys can bounce back from AKI. Fast forward a month later and I am back in the ER with pain. This time I had a kidney stone, which I will add is not a typical issue amongst lupus nephritis patients and they still don't know why I was prone to them in the beginning of my journey, but they also discovered my GFR had gone down again.

From here I was diagnosed with stage 2 kidney disease since my GFR did not recover from AKI and I was seeing a kidney doctor regularly and while my GFR remained stable during this time, none of my other symptoms were going away. Unfortunately, I received a lot of pushback in my doctors appointments, especially when I brought up my chronic pain and fatigue, I was written off as a moody teenager going through puberty and I was told that the symptoms I was experiencing were "normal" and apart of growing up, this response made me more moody than any doctor ever thought possible… as you can imagine and this is when I finally decided it was time for me to push for a new doctor.

This new doctor soft diagnosed me with lupus in my very first visit and was able to get confirmation from an ANA, complement testing, DSDNA, which are all blood tests and other testing such as x-rays which revealed arthritis in 16 different areas of my body and eventually a kidney biopsy which further confirmed lupus nephritis.

My lupus nephritis diagnosis was relieving yet devastating. There is no treatment for my condition, just managing symptoms and as a young woman, it was very hard realizing I would have to continue the next 60 years of my life in chronic pain and managing my lupus. Because of the feelings I had from my diagnosis I received therapy and also joined online support groups, which ultimately shifted my entire perspective on my chronic illness.

The Importance of Awareness

My experience with lupus nephritis is not unique. Many lupus nephritis patients endure similar struggles with delayed diagnoses and inadequate awareness, both in the medical community and the public. This is why community, education, and advocacy are critical.

Designating May as Lupus Nephritis Awareness Month in Ohio would provide an opportunity to:

1. **Educate the Public:** Increase understanding of lupus nephritis and its symptoms, leading to earlier detection and better outcomes.
2. **Support Patients and Families:** Foster a sense of community for those coping with an often invisible and isolating disease.
3. **Encourage Research and Resources:** Highlight the need for continued advancements in lupus nephritis treatment and care.

Conclusion

As someone who lives with this condition every day, I know the transformative power of awareness and support. Recognizing May as Lupus Nephritis Awareness Month will make a meaningful difference in the lives of patients and their families across Ohio.

Thank you for your time, attention, and consideration of this important initiative. I am happy to answer any questions you may have.