Honorable Members of Congress,

Thank you for the opportunity to submit written testimony in support of House Bill 2457, which establishes a Rare Disease Advisory Council to address the significant gaps in care, knowledge, and support for those living with rare diseases, such as Huntington's.

Huntington's disease has been a part of my family for multiple generations. My great-grandmother had five siblings, and tragically, one in five of them succumbed to the disease. My great-grandmother, however, was the only one of her siblings who developed Huntington's, but she was mistakenly diagnosed with Alzheimer's disease in the early 1980s. Similarly, my grandfather's symptoms were misdiagnosed as "fatigue syndrome" by rural doctors, and he suffered for years without proper treatment or understanding of his condition.

By the time his health was properly diagnosed, my grandparents had already raised nine children—many of whom were in their childbearing years. The news that their children were at risk for inheriting Huntington's disease was devastating. My family was then subjected to a genetic counseling session that was woefully unprepared to address the full implications of the disease. My mother and her siblings were told they should not have children or should limit their family size, without a clear understanding of what Huntington's actually was or what they were truly facing. Those who had already had children were informed that their children had a 50% chance of inheriting this fatal, progressive, and neurodegenerative disease.

The truth about Huntington's disease began to emerge when my grandfather was properly diagnosed in the early 1980s. Sadly, the loss continued. Both of my great-grandmother's children, and six out of nine of my grandfather's children, died from Huntington's disease. Even my grandfather's brother's children were affected—two out of three of them inherited the disease.

Today, we are in the fourth generation of our family living with Huntington's disease. My great-grandmother, the source of this long-standing suffering, has left behind 60 descendants—descendants who have either suffered, died, inherited, are at risk for, or been fortunate enough to escape the disease. This is not just a personal issue; it is a generational tragedy that has affected my family on a profound level.

It is also important to recognize that the struggles of families like mine are not isolated, nor are they solely personal or familial issues. There is a long and painful history of societal discrimination and ignorance surrounding diseases like Huntington's. The eugenics movement, along with systemic biases against impoverished and minority communities, has compounded the suffering of families dealing with rare diseases.

Despite the discovery of the gene that causes Huntington's disease in 1993, many medical professionals still lack a full understanding of the disease. Doctors and genetic counselors often offer outdated, incorrect, or insufficient advice. For example, I've heard doctors describe Huntington's disease merely as a "movement disorder," failing to acknowledge its profound impacts on cognition, behavior, bodily functions, and brain structure. This lack of knowledge and empathy is deeply frustrating for families like mine, who struggle daily to find adequate care and support.

The medical system is broken. While Huntington's is recognized as a rare disease, it affects many families and carries enormous financial, emotional, and personal costs. The average cost of nursing

home care for someone in the later stages of Huntington's disease can exceed $60,000 per year. Given the progressive nature of the disease, families may face this burden for decades. But the financial burden is only part of the picture—families are also forced to endure the emotional and physical toll of caregiving, often for many years, in a healthcare system ill-equipped to provide the necessary support.

I have personally struggled with these issues. I have encountered numerous challenges in dealing with doctors, healthcare providers, and disability workers who lack sensitivity, understanding, and basic knowledge about Huntington's disease. It is disheartening to be dismissed, ignored, or misinformed when seeking help. This ignorance only adds to the suffering of families already enduring the overwhelming challenges of rare diseases. As children or young adults, we are often left ill-equipped to be caregivers for our parents who are suffering from debilitating disease, leaving us with little time to redefine our lives after caregiving, only to then become ill ourselves and require care.

As we look toward the future, it is imperative that we do not repeat the mistakes of the past—mistakes that marginalized and discriminated against individuals and families affected by rare diseases. My family has done nothing to deserve the burden of Huntington's disease, and we should not be ashamed of our genetic makeup. Yet, there remains a stigma and misunderstanding surrounding the disease that continues to affect us. In reality, every human is born with the Huntingtin protein; in our families, it repeats excessively, causing destruction until it results in loss of life.

While significant advances in science have been made over the past few decades, progress has been slow, and the burden on families persists. The Huntington's Disease Society of America (HDSA) and other non-profits are tirelessly working to raise awareness and push for a cure. But we need more—specifically, we need government involvement in research, funding, and treatment development.

That is why I am writing today: to urge Congress to support the creation of a Rare Disease Advisory Council. Such a council will help bring attention, resources, and leadership to rare diseases like Huntington's, ensuring that families like mine receive the care, support, and recognition they deserve.

Thank you for your time and attention to this critical issue. I stand here today not just for my family, but for all those affected by Huntington's disease and other rare diseases, and for future generations who deserve better than the history we have inherited.

There are many families like mine who cannot or will not write advocacy letters like this—either because their time is consumed by caregiving or due to the dark history of discrimination against our families. Nonetheless, if we can overcome fear and work together with our government and healthcare organizations, we can advance medical science, find treatments, and perhaps even cure Huntington's disease, as well as other conditions like Parkinson's and ALS.

Sincerely,
Rebecca Ambrose