

**Opening Statement of The Honorable Brett Guthrie**  
**Subcommittee on Health Hearing**  
**“The Path Forward: Advancing Treatments and Cures for**  
**Neurodegenerative Diseases”**  
**July 29, 2021**  
*As Prepared for Delivery*

Thank you, Chair Eshoo, for holding this important hearing about advancing treatments and cures for neurodegenerative diseases.

I want to recognize and thank **Kala Booth**, who is here today to testify on her experience with Huntington’s disease. Kala is a constituent of mine from Cecilia, Kentucky. While not advocating for patients with Huntington’s disease and their families, she can often be found face painting at community events. Kala, is the fourth known suspected generation of HD in her family and is a strong advocate and voice for the Huntington’s disease community.

We are here today to examine how we can further advance treatments and hopefully soon, find cures for patients suffering from the more than 600 known neurological diseases.

We have made progress to create an environment in the United States that encourages innovation for new treatments. Thanks to Rep. Upton, Rep. DeGette,

and this committee, 21<sup>st</sup> Century Cures modernized our health care innovation infrastructure and included more flexibility to capitalize on this exciting time in science and enable private sector innovation. This committee has also worked on reauthorizing the National Institutes of Health's and ensuring its budget is adequate to help foster research for new treatments and cures.

Congress has provided FDA the resources and tools to expeditiously review drugs for serious, unmet needs and rare diseases. We have continued to examine the expanded access pathway to drugs outside of clinical trials, and added a flexible "right to try" pathway for patients seeking access to experimental drugs. While we have come far, we still have a long road ahead to help patients and their families.

**One neurodegenerative disease that I have focused on ever since coming to Congress is Alzheimer's.**

**Alzheimer's** is the sixth leading cause of death in the United States. In 2021, an estimated 6.2 million Americans age 65 and older are living with Alzheimer's. By 2060, that number is expected to reach 13.8 million barring the development of medical breakthroughs to prevent, slow, or cure the disease.

My bill, the BOLD Infrastructure for Alzheimer's Act, was signed into law in 2018, which created a public health infrastructure across the country to support prevention, treatment, and care for patients with Alzheimer's and related neurological diseases.

I have continued my commitment to this issue by introducing the Comprehensive Care for Alzheimer's Act this Congress. This bill would reduce medical complications for these patients by creating a new way to fund dementia care through Medicare.

It's not just Alzheimer's disease, but also other neurological diseases that are devastating for the person who suffers with the disease and their family, friends, and loved ones.

**Huntington's disease (HD)** is a progressive brain disorder caused by an inherited gene and can appear as early as age 2 or as late as 80 years old. More than 200,000 Americans are at-risk of inheriting the gene from a parent with HD.

**Parkinson's disease** is another type of progressive brain disorder that affects approximately 60,000 Americans each year. An estimated 50-80% of individuals with Parkinson's disease may experience dementia in their lifetime.

**ALS, often referred to as Lou Gehrig's disease**, is a progressive nervous system disease that affects vital nerve cells in the brain and spinal cord. For people with ALS, the average survival time is three years and reports suggest 15,000 Americans have ALS.

While I think we can **all** agree we want to advance treatment and cures for all neurodegenerative diseases, H.R. 3, Speaker Pelosi's drug pricing bill is **NOT** the path forward.

If this partisan bill becomes law, I believe innovation for therapies to treat neurological diseases will come to a full stop. We've seen estimates that 15 drugs over 10 years or as many as 100 life-saving drugs would not come to market due to H.R. 3 because it disincentivizes research and development.

H.R. 3 would **directly** hurt the patients before us today. I support the bipartisan alternative, the Lower Costs, More Cures Act, to reduce drug prices and also protect innovation for cures.

I'm glad we have Kala, Brian Wallach, and Yvonne Larry here with us today to share how Congress can keep hope alive and promote innovation for life-saving cures. I look forward to working on solutions for American patients and their families

I yield back.