

Thank you, Chairwoman DeLauro and Ranking Member Cole for holding today's hearing.

The United States is a global leader in advancing research on life-altering diseases; however, much remains to be done.

LYME

I currently serve as co-chair of the House Lyme Disease Caucus together with our colleague Collin Peterson. The Caucus—with its 17 members—works to advance initiatives to help the more than 300,000 Americans who are diagnosed with Lyme disease each year, and all of those already suffering from the disease.

Specifically, I request that you provide a significant increase in funding for the Center for Disease Control's (CDC) Lyme disease program, to allow the agency to intensify its efforts on developing improved diagnostics, critical surveillance and prevention of Lyme disease.

In its inaugural report to Congress late last year, the Tick-Borne Disease Working Group—created by our 21st Century Cures Act—found that “increased Federal funding, prioritization, and leadership are needed to reverse the alarming trends associated with tick-borne diseases.” They added: “Federal funding for tick-borne diseases is less per new surveillance case than that of other diseases.”

Lyme is the most prevalent vector-borne disease in the U.S. today. If not diagnosed and treated early, Lyme can lead to disseminated infection and can affect every system in the body, including the central nervous system. Later symptoms of Lyme include neurological problems such as facial paralysis, memory loss and heart symptoms such as heart block and inflammation

of the heart muscle. Lyme has been reported in every state in the U.S. and incidences are rapidly increasing across the nation.

Lyme is a burgeoning epidemic and we can no longer ignore or short change our federal responsibility.

AUTISM

In addition to the House Lyme Disease Caucus, I also co-chair the Congressional Coalition on Autism Research and Education, together with our colleague Mike Doyle.

According to the latest data, the CDC estimates that 1 in 59 children have been identified with autism. The estimated total cost per year for children with autism in the United States is between \$11.5 billion and \$60.9 billion.

At a minimum, the 2020 funding level for autism needs to match and—I would urge—exceed the 2019 levels of \$23.1 million for CDC for surveillance and research activities, \$50.6 million for the Health Resources and Services Administration (HRSA) for early detection and intervention programs, and \$260 million for the National Institutes of Health (NIH) and the Interagency Coordinating Committee.

DUCHENNE

Last year, I requested that this Subcommittee prioritize research for Duchenne Muscular Dystrophy by inserting language into the final Committee Report to urge the NIH to allocate more research dollars to Duchenne. Report language was added, but no new monies have been allocated just yet.

As you know, Duchenne is considered a rare disease with approximately 300,000 young boys affected worldwide and fewer than 600 new diagnoses in the United States each year. It causes a loss of both muscle function and independence, with a 100 percent fatality rate,

occurring normally in the late teens or early 20s. Most research dollars for potential therapies and treatments are raised by private organizations like JAR of Hope and Ryan's Quest in New Jersey.

I hosted a meeting with NIH experts in my office last month, who stated that they believe a breakthrough for DMD is in reach. Thus, I ask that you again prioritize Duchenne so that NIH—which believes we are on the cusp of a breakthrough—spends the money to help make it happen for these boys and their families.

DYSTONIA

Dystonia is a neurological movement disorder that causes muscles to contract and spasm involuntarily. Currently, dystonia research at NIH is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the National Eye Institute (NEI). **If we are to continue the progress these institutes have made in determining the causes and mechanisms of the disease, Congress must and—I urge the Committee to—encourage further research advancements and emerging opportunities in dystonia at these institutes.**

CORD BLOOD STEM CELL RESEARCH

I also ask that the Committee fully fund the C.W. Bill Young Cell Transplantation Program at \$30 million and the National Cord Blood Inventory (NCBI) at \$23 million for FY 2020. These cell sources are used to cure more than 70 diseases and conditions, and give hope to patients who would otherwise have none.

The dollars that Congress appropriates to the Program and the National Cord Blood Inventory go toward not only increasing the number of potential donors and cord blood units on the national registry but improving the outcomes of patients who receive a transplant. Increasing

funding to authorized levels for FY 2020 would also allow the Program to advance new and innovative methods of providing the best possible transplant to every patient in need, regardless of socioeconomic status, age, ethnic ancestry, or any other individually defining characteristic.

HYDE AMENDMENT & OTHER ABORTION NEUTRAL PROTECTIONS

Finally, I urge you retain all the bipartisan protections for life that have long existed within the Labor-HHS Appropriations bill. Over forty years ago, Congress enacted the Hyde Amendment — a law that continues to this day to protect taxpayer dollars from being used to pay for abortions. According to more than 20 peer-reviewed studies, over 2 million people are alive today because of the Hyde Amendment. A new Marist Poll released in January found that the majority of Americans—54 percent—oppose taxpayer funding for abortion.

I urge you to also retain conscience protection for health care providers who refuse to provide, pay for, or refer for abortion, and I urge you to continue to prevent federal funds to be used to pay for research that harms human embryos. As you know, President Trump has made it absolutely clear that he will veto any legislation that undermines or nullifies any existing pro-life policy.

I thank the Chairwoman and Ranking Member for their time and urge consideration of my requests.