

**LHHS Member Day Testimony – Rep. Chris Smith (NJ-04)**

Thank you, Mr. Chairman, for holding this Member Day and giving me the opportunity to testify on critical requests before the Labor-HHS Subcommittee for Fiscal Year 2027. I look forward to continuing to work with you to advance key public health priorities.

I first want to encourage you to provide \$23 million for the National Cord Blood Inventory and \$35 million for the C.W. Bill Young Cell Transplantation Program. I originally developed the idea for a national cord blood program 25 years ago and authored the original law (The Stem Cell Therapeutic and Research Act of 2005), which created the NCBI and expanded the Transplantation Program.

Since the initial passage of my law, stem cells derived from cord blood and bone marrow have been used successfully to treat tens of thousands of patients. The NCBI, in particular, has been uniquely helpful in providing transplants for pediatric patients. The initial goals of the NCBI were to bank 150,000 high-quality cord blood units. To date, NCBI has banked over 122,500 units.

I ask that you continue to show strong support for these essential programs and provide hope for thousands of patients in need of a donor for a life-saving transplant.

I also ask that you provide \$2.5 million for the implementation of the “Grants to Assist in the Recognition of Trafficking,” as found in my law, the Victims of Trafficking and Violence Protection Act of 2000. This vital funding protects American children, supports child victims of trafficking and sexual abuse, and strengthens coordination with law enforcement. Since FY 2022, thanks to these grants, over 120,000 people have been trained in 2,500 schools and over 400

children have been identified as potential victims of human trafficking. I urge the subcommittee to support this critical grant funding and strengthen our federal response to human trafficking.

I appreciate the Committee's ongoing support for Lyme disease research and respectfully request that you continue to provide funding for a whole-of-government approach to tackle this pernicious and growing public health threat.

I first ask that the Kay Hagan Tick Act be fully funded to its authorization level of \$30 million. The Kay Hagan Tick Act funds vital research into treatment and prevention of tick bites and enables states to greater cooperate with the federal government to monitor the spread of Lyme. It provides \$20 million for states at high risk of Lyme to work with the federal government to prevent and mitigate outbreaks, as well as \$10 million for Regional Centers of Excellence, which train public health professionals to better track and treat tick bites and control the pathogens they spread.

I also again ask for \$5 million for the LymeX Innovation Accelerator. As you know, the LymeX Diagnostics Prize launched Phase 4 of its competition in March of last year. Phase 4 includes 7 teams working to submit new diagnostics for FDA approval, incentivized through prizes, which are generously made possible for by the Steven & Alexandra Cohen Foundation through a groundbreaking public-private partnership.

Last December, I joined Secretary Kennedy and Administrator Oz at a roundtable for Lyme patients, patient advocates and subject matter experts. At the roundtable, Secretary Kennedy announced the renewal of LymeX, cementing the federal government's long-term commitment to this program. Congress should follow HHS's lead and continue to back a program that has demonstrated longevity and the ability to produce innovative diagnostics.

As the federal government continues to shift its focus toward the 1 in 31 autistic children and 1 in 45 autistic adults across the country, I ask that you prioritize federal support for autism research. The Autism CARES Act of 2024, which I authored with substantive input from advocates in the community, reauthorized and enhanced critical federally funded activities that will drive further research breakthroughs in our understanding of autism, health interventions, and services to improve the health and wellbeing of children and adults with autism.

I respectfully ask that the Subcommittee to ensure that the NIH is following through on new requirements from the Autism CARES Act, including the requirement that the Director ensure that research reflects the entire population of individuals with autism spectrum disorders. I also ask that you provide \$61.344 million for HRSA's Autism and Developmental Disabilities program, which will support training programs, research, and systems with a focus on improving access, quality, and systems of care for children, adolescents, and young adults with autism or other developmental disabilities.

In addition, I ask that you provide the LEND program with at least \$40 million. The 60 LEND programs (located in 44 U.S. states with six additional states and three territories reached through program partnerships without additional federal or state aid) are an effective workforce program that operate within a university medical system and provide graduate-level, interdisciplinary training to the next generation of clinical, research, and community leaders. It is vitally important that we continue to support these programs, which help make a huge difference in the lives of the millions of Americans with autism.

I ask for your continued commitment to sustaining federal investments in biomedical research and public health initiatives focused on the treatment and cure of Fragile X and its related conditions. As you know, mutations of the Fragile X (FMR1) gene result in behavioral,

developmental, cognitive, reproductive, and potentially life-ending neurodegenerative conditions across generations and impact affected individuals from birth to death.

The Committee's previous support for the important work underway at the NIH and CDC is advancing research towards more effective treatments and a cure for Fragile X. For instance, the CDC funds the FORWARD project, a longitudinal database that now includes 12.5 years of historical data on individuals with Fragile X. Continued support for and expansion of this effort, particularly with regard to individuals over 23 who are beginning to age out of the study, is invaluable for potential insights and eventually treatment and a cure for Fragile X.

I appreciate this committee's ongoing support of the Spina Bifida community and again request that the National Spina Bifida Program be funded at \$11 million. In the United States, there are an estimated 166,000 individuals living with this condition. Spina Bifida is a birth defect for which there is no cure and results in a spinal cord injury before a baby is born. The National Spina Bifida Program is the only place in the federal government exclusively dedicated to studying this chronic, complex disease affecting children and adults. I ask that you continue to support this vital program at the CDC.

Finally, I ask that you fund include \$31.5 million for the Alzheimer's Disease Programs Initiative (ADPI), now administered by CMS, as well as total funding level of approximately \$4.2 billion for Alzheimer's research at the NIH. More than 6 million Americans currently have Alzheimer's disease. In 2023, friends and families of those with Alzheimer's and other dementias provided an estimated 18.4 billion hours of unpaid care annually, a contribution to the nation valued at nearly \$346 billion. I ask that Congress provide much needed support to caregivers and work to better understand this devastating disease.

I appreciate the Committee's consideration of my requests and ask that you continue to prioritize these vital programs.