

Rep. Chris Smith (NJ-04)
Addressing the Urgent Need for Federal Action on Cord Blood and Lyme and other Tick-Borne Diseases

I thank the Chairman and ask the Committee to consider two bills that were original ideas of mine 20 years ago – first, the Umbilical Cord Blood and Stem Cell Therapeutic and Research Act (HR 3520), which I introduced in 2001 after 5 long years of hard work, was enacted in 2005 and is up for reauthorization next year. The second bill, the TICK Act (HR 3073), is my 19th bill since 1998 to combat Lyme and other tick-borne diseases.

STEM CELL AND UMBILICAL CORD BLOOD

The umbilical cord blood and Stem Cell Therapeutic and Research Act, which will expire at the end of fiscal year 2020. HR 3520 provides for the continuation of two lifesaving programs, the National Cord Blood Inventory (NCBI) and C.W. Bill Young Cell Transplantation Program (the Program) through 2024.

Umbilical cord blood stem cells, obtained after the birth of a child, have proved highly efficacious in treating 80 diseases, including sickle-cell disease, lymphoma, and leukemia. And scientists are continuing to study and better understand the regenerative effects of cord blood cell therapies for other diseases and conditions. Bone marrow donations provide lifesaving transplants to treat diseases like blood cancer, sickle cell anemia, or inherited metabolic or immune system disorders.

The National Cord Blood Inventory (NCBI) provides funding to public cord blood banks participating in the program to allow them to expand the national inventory of cord blood units available for transplant. These units are then listed on the registry by the “Be the Match” Program. The funds appropriated thus far have led to an important increase in the overall number

of high-quality cord blood units available through the national registry, including 104,000 NCBI units.

The Program registry allows patients and physicians to locate matching cord blood units, as well as adult donors for marrow and peripheral blood stem cells, when a family donor is not available. The Program is the world's largest, most diverse donor registry, with more than 20 million volunteers and more than 295,000 public cord blood units. To date, the National Marrow Donor Program/Be The Match (NMDP), through its operation of the Program, has facilitated more than 92,000 transplants. According to Be the Match, more than 25,000 patients having received cord blood transplants.

The success of bone marrow transplants and cord blood stem cell therapies in treating diseases and alleviating suffering highlights the urgent, compelling case for reauthorizing this program. I urge the committee to quickly taken up and support HR 3520.

THE TICK ACT

The TICK Act – cosponsored by the Chairman of the Agriculture Committee, Collin Peterson, with 39 total cosponsors – would address the ongoing challenges posed by Lyme and tick-borne diseases. The federal Tick-Borne Disease Working Group, established by language within the *21st Century Cures Act (now Public Law 114-255)*, released its inaugural report to Congress late last year. In its comprehensive study, the Working Group was loud and clear.

They stated that:

- “Tick Borne Diseases have rapidly become a serious and growing threat to public health in the United States,” with an estimated 300,000 to 437,000 new cases each year.

- Chronic Lyme—10 to 20 percent of these patients suffer from persistent symptoms which can be chronic and disabling.
- Diagnosis of tick-borne diseases, including Lyme, are often inaccurate and complex to interpret.

The Working Group also stated that:

- “Americans need help, yet progress has been hampered by a lack of attention at the Federal level and by divisions within the field.”

Mr. Chairman, Lyme disease is one of the deadliest tick-borne diseases. We must do more to mitigate and over time eradicate this catastrophic disease. As such, I, along with my colleague and co-chair of the House Lyme Disease Caucus, Collin Peterson, introduced the *TICK Act* (Ticks: Identify, Control, Knockout Act) this Congress. The *TICK Act* is comprehensive, multiyear legislation (H.R. 3073) which creates a new national strategy to aggressively fight Lyme disease and other vector-borne diseases, expand research, and improve testing, treatment affordability and public awareness. The bill also targets \$180 million through CDC grants to state health departments and Regional Centers of Excellence to boost funding for research, prevention, and treatment programs.

These five Centers of Excellence are:

- located at universities in New York, California, Florida, Texas, and Wisconsin.
- specifically: Cornell University, the University of California (Davis and Riverside), the University of Florida, the University of Texas Medical Branch in Galveston, and the University of Wisconsin, Madison.

H.R. 3073 and the companion bill, introduced by Senators Susan Collins and Tina Smith are supported by more than 25 organizations dedicated to combatting Lyme including the

Entomological Society of America, the National Association of Vector-Borne Disease Control Officials, the National Association of County and City Health Officials, the Northeast Regional Center for Excellence in Vector Borne Diseases, and the LivLyme Foundation. Once enacted, the *TICK Act* will enable additional federal agencies to step up their effort in the fight against Lyme.

Through its whole-of-government approach, this legislation will bring greater support to the overwhelming number of patients currently suffering from Lyme disease; the more than 300,000 Americans who will be diagnosed with Lyme just this year alone; and the hundreds of thousands who are unknowingly suffering from Lyme due to misdiagnosis or lack of clear symptoms.

We cannot shortchange our federal responsibility. We owe it to the countless patients suffering from tick-borne diseases and their families. I have included for the record a list of my previous legislation on Lyme disease, and urge support for this bill. We must act now.

Legislation Introduced by Rep. Chris Smith on Lyme Disease:

- 1) [H.R. 3116](#) - an amendment to the *Department of Defense Appropriations Act, 1994*, which appropriated \$1 million to establish a Lyme Disease research program through the Environmental Hygiene Agency of the U.S. Department of the Army. It passed and became law.
- 2) [H.R. 3795](#) – the *Lyme Disease Initiative Act of 1998*, to establish a program to provide for a reduction in the incidence and prevalence of Lyme disease, with the goal of ensuring that patients, advocates, and scientists with diverse viewpoints would be fairly represented in public health policy decisions affecting Lyme. The bill also called for establishing a Lyme Disease Task Force to provide advice to the Secretaries on achieving the goals. The bill authorized \$45 million over five years, from 1999 through 2003.
- 3) [H.R. 2790](#) - the *Lyme Disease Initiative of 1999*, which directed the Secretaries of Health and Human Services, of Agriculture, of the Interior, and of Defense to: (1) establish a specified detection test, improved surveillance and reporting system, and prevention goals to provide for a reduction in the incidence and prevalence of Lyme disease and related tick borne infectious diseases; and (2) establish a five-year plan of activities toward achieving those goals, and carry them out. It also established the Lyme Disease Taskforce to advise the Secretaries with respect to achieving such goals. The bill authorized \$40 million over five years, from 2000 through 2004.
- 4) [H.R. 1254](#) - the *Lyme Disease Initiative of 2001*, which established a program to help reduce the incidence and prevalence of Lyme disease, with the goal of ensuring that patients, advocates, and scientists with diverse viewpoints would be fairly represented in public health policy decisions affecting Lyme. The bill also called for establishing a Lyme Disease Task Force, authorized \$40 million over five years, from 2002 through 2006.
- 5) [H.R. 2877](#) - the *Act for Lyme Education and Research and Tick-Borne Diseases*, which focused on establishing a five-year plan providing for Lyme and studying chronic Lyme. The plan authorized \$500,000 over two years—2006 and 2007.
- 6) [H.R. 3427](#) - the *Lyme and Tick-borne Disease Prevention, Education, and Research Act of 2005*, which authorized \$1 million over five years— from 2006 through 2009. H.R. 3427 also required the Secretary of Health and Human Services (HHS) to establish a Tick-Borne Diseases Advisory Committee.
- 7) [H.R. 741](#) - the *Lyme and Tick-Borne Disease Prevention, Education, and Research Act of 2007*, which authorized \$1 million over five years— from 2008 through 2011. H.R. 741 also required the Secretary of Health and Human Services (HHS) to establish a Tick-Borne Diseases Advisory Committee.

- 8) [H.Res. 337](#) - *Supporting the goals and ideals of a Lyme Disease Awareness Month*. Education and public awareness are key in the fight against disease, particularly for Lyme disease. H.Res.337 sought to build on this principle by increasing awareness for Lyme disease through a nationally-recognized Lyme Disease Awareness Month.
- 9) [H.R. 1179](#) - the *Lyme and Tick-Borne Diseases Prevention, Education, and Research Act of 2009*, which authorized \$1.2 million over five years— from 2010 through 2014. H.R. 1179 also required the Secretary of Health and Human Services (HHS) to establish the Tick-Borne Diseases Advisory Committee.
- 10) [H.R. 2557](#) - introduced in 2011 to establish a Tick-Borne Diseases Advisory Committee and which authorized \$1.2 million over five years— from 2012 through 2016.
- 11) [H.R. 611](#) - the *Lyme and Tick-Borne Diseases Prevention, Education, and Research Act of 2013*, which required the Secretary of Health and Human Services (HHS) to establish the Tick-Borne Diseases Advisory Committee and authorized \$1.2 million over five years— from 2014 through 2018. The Committee would advise the HHS Secretary regarding: (1) interagency coordination on efforts to address tick-borne diseases, (2) opportunities to coordinate efforts with other federal agencies and private organizations addressing such diseases, (3) interagency coordination and communication with constituency groups, (4) ensuring that a broad spectrum of scientific viewpoints is represented in public health policy decisions and that information disseminated to the public and physicians is balanced, and (5) advising relevant federal agencies on priorities related to Lyme and tick-borne diseases.
- 12) [H.R. 610](#) - introduced in 2013 to establish a Tick-Borne Diseases Advisory Committee and which authorized \$1.2 million over five years— from 2013 through 2017.
- 13) [P.L. 114-255](#) - the *21st Century Cures Act (P.L. 114-255)*, to establish an Interagency Lyme and Tick-Borne Disease Working Group in order to further facilitate research, development, and collaboration on Lyme disease. Under the *21st Century Cures Act*— which became law in December 2016—the HHS Secretary established a Tick-Borne Disease Working Group comprised of federal and public members with diverse disciplines and views pertaining to tick-borne diseases.
- 14) [H.R. 2029](#) - secured in the *Consolidated Appropriations Act of 2016*—for the first time ever—**\$5 million in funding for Lyme and other tick-borne diseases research** through the DOD’s Congressionally Directed Medical Research Program (CDMRP).
- 15) [H.R. 665](#) - introduced in 2015 to establish a Tick-Borne Diseases Advisory Committee and which authorized \$1.2 million over five years— from 2015 through 2019.
- 16) [H.R. 1625](#) - secured in the *Consolidated Appropriations Act of 2018* a necessary increase—\$353.6 million— in funding for the National Institutes of Allergy and Infectious Diseases (which funds Lyme disease research and other infectious diseases), bringing total funding for these institutes to \$5.26 billion.

- 17) [H.R. 5900](#) - the *National Lyme and Tick-Borne Diseases Control and Accountability Act of 2018*, to establish the Office of Oversight and Coordination for Tick-Borne Diseases (TBD Office) to oversee the creation and implementation of a national strategy.
- 18) [H.R. 220](#) - the *National Lyme and Tick-Borne Diseases Control and Accountability Act of 2019*, to establish the Office of Oversight and Coordination for Tick-Borne Diseases (TBD Office). This office will oversee the much-needed creation and implementation of a national strategy to help combat the threat of Lyme disease.
- 19) [H.R. 3073](#) - the *TICK Act (Ticks: Identify, Control, Knockout Act)* to create a new national strategy to aggressively fight Lyme disease and target an additional \$180 million to boost funding for research, prevention and treatment programs.