

days then I would like an explanation to Congress and 700,000 Illinois veterans.

America was built on the sacrifices of our service members. And as a grateful nation, we are indebted to our veterans who unselfishly served to fight for the freedoms we enjoy. No veteran who has served should be left for weeks without a proper and dignified burial.

Sincerely,

MARK KIRK,
U.S. Senate.

THE ADVANCING HOPE ACT

Mr. CASEY. Mr. President, today I wish to speak about S. 1878, the Advancing Hope Act. This is a bill I introduced with the support of my Republican cosponsor, Senator JOHNNY ISAKSON. This is a bipartisan bill that brings hope to some of our most vulnerable citizens: children living with rare diseases.

Despite significant unmet medical need, private companies seldom pursue new therapies for rare diseases because it requires making an investment in products that will likely not recoup the high costs associated with their research, development, marketing, and distribution. Developing products for children is particularly challenging because of the difficulties associated with conducting clinical trials in this population.

So, several years ago, former Senator Brownback authored the Creating Hope Act with Senator SHERROD BROWN. In 2011, I became the Senate leader on this bill, which provided an incentive for drug developers to pursue therapies for rare pediatric diseases. The goal was to bring hope to the millions of American children living with a rare disease.

Provisions based on the Creating Hope Act were included in the Food and Drug Administration Safety and Innovation Act, which became law in 2012. The new FDA program established three "priority review vouchers" that would be awarded to companies who develop a new drug for a rare pediatric disease. A company that earns a voucher can then sell it to another company, which can use the voucher to speed up the FDA's review time for one of its own new drugs. Companies that earn and then sell their vouchers can use that money to fund additional drug development to treat rare pediatric diseases. So far, seven vouchers have been awarded, including on the 19th of this month.

However, the pediatric priority review program is due to expire on September 30, just days away. In fact, it would have expired in March of this year, but Congress passed an extension through the end of fiscal year 2016 as the House and Senate worked on legislation to extend and improve the program. In July of 2015, I introduced S. 1878, the Advancing Hope Act, with Senator ISAKSON, to extend the pediatric priority review program. We had extensive consideration of the bill in the Committee on Health, Education, Labor, and Pensions, which voted fa-

vorably on the Advancing Hope Act in April 2016. Thanks to an agreement we reached here in the Senate on September 21, we were able to pass S. 1878 with an extension of the program through the end of this year, which included important policy changes to the program. I would like to thank my colleagues for working with me on this agreement. I hope that we will be able to come to further agreement later this year for a longer extension to the program.

The pediatric priority review program is important for families, and a longer extension is warranted. If this program is allowed to lapse, Congress will have broken faith with these children with rare diseases.

Last year, I went to the Children's Hospital of Pittsburgh and met with the Rinaldi family. I met Jennie Rinaldi and her daughter Adelyn, who was receiving treatment at the hospital. Adelyn was born with congenital hypophosphatasia, an extremely rare bone disorder. There are only a handful of children in the world with this disease.

At the time, Adelyn was receiving an experimental therapy for her condition. That drug, Strensiq, was later approved by the FDA in October 2015, and the drug sponsor received a priority review voucher. Strensiq is the first drug to treat hypophosphatasia. There are no other options. It is now available commercially, and Adelyn continues to receive treatment.

Just imagine for a moment the uncertainty that families like the Rinaldis live with every day. We owe it to these families to give them the peace of mind in knowing that this important incentive for drug development will continue. We cannot let this program expire. I am pleased that the House passed S. 1878 yesterday, and I hope that we can continue to work in good faith on a longer-term extension before the end of the year.

We need to provide certainty for drug developers so that they can count on this incentive when deciding to invest the time and money into drugs for rare pediatric diseases. We need to provide hope for the other children like Adelyn. On behalf of these children, we must incentivize companies to take on the challenges of developing new treatments for rare pediatric diseases.

LYME AND TICK-BORNE DISEASE PREVENTION, EDUCATION, AND RESEARCH ACT OF 2015

Ms. AYOTTE. Mr. President, today I wish to speak on the importance of passing legislation to address a serious issue that impacts New Hampshire, New England, and the rest of the country each year, the issue of Lyme and other tick-borne diseases.

This fall, as the leaves begin to turn and temperatures start to drop, millions of Americans will head outdoors to hike and otherwise experience the beauty of nature. In my home State of

New Hampshire, hiking is one of the State's most popular recreational activities. New Hampshire is also among the 14 States through which the Appalachian Trail runs. Stretching from Georgia to Maine, the Appalachian Trail spans nearly 2,190 miles, and is hiked annually by 2 to 3 million people.

While our attention in the Northeast usually turns to the dangers of ticks in the spring and summer months, adult blacklegged ticks, also known as deer ticks, are still active in the fall. Approximately half of these deer ticks carry Lyme disease, and they have played a leading role in our Nation's dramatic rise in tick-borne diseases. While approximately 30,000 cases of Lyme disease are reported annually by State health departments, according to the Centers for Disease Control and Prevention CDC, the actual number of cases each year is about 300,000, making Lyme disease the most commonly reported vector-borne illness in the country. Underscoring that Lyme is no longer simply a regional problem, the CDC reports that the species of ticks that spread Lyme disease now live in 46 percent of the Nation's counties.

That is why I am continuing to urge my colleagues to join me in supporting the bipartisan Lyme and Tick-Borne Disease Prevention, Education, and Research Act, S. 1503. Working with Senator Blumenthal, I coauthored and introduced this legislation which is designed to better coordinate the Federal Government's response to Lyme and other tick-borne diseases by creating an advisory committee within the Department of Health and Human Services HHS. The committee established under our bill would be tasked with identifying best practices to combat tick-borne diseases and would be comprised of patients, advocates, researchers, medical professionals, and government officials. Our legislation would also require the HHS Secretary to coordinate efforts to strengthen disease surveillance and reporting, develop better diagnostic tools and tests, create a physician education program, establish epidemiological research objectives for Lyme and other tick-borne illnesses, and report to Congress on the progress of efforts to combat these devastating diseases.

The significant increase in cases of Lyme and other tick-borne diseases over the past decade is extremely troubling, and it demands a strong and coordinated effort at the Federal level. This critical legislation has been endorsed by nearly 100 Lyme and tick-borne disease patient groups, along with the Appalachian Trail Conservancy.

Despite the staggering statistics, the voices of those who are living and struggling with Lyme and other tick-borne diseases have not adequately been heard. Senator Blumenthal and I have put forth a commonsense, bipartisan legislative proposal that will bring greater attention to Lyme disease and give patients and their families a greater say in their care.