Smith continues tireless advocacy for Lyme patients

Be aware of the dangers of Lyme disease

Next month is Lyme Disease Awareness Month and as May brings warmer weather with families ready to enjoy New Jersey's expansive outdoor landscapes, exposure to ticks carrying Lyme disease is more likely—and more threatening. Be on your guard.

Tragically, Lyme disease and other tick-borne illnesses are exploding all over the United States and are especially highly endemic in our state—which ranks third in the nation for Lyme disease prevalence.

Far too many people are suffering from this terrible disease.

According to the 2020 report by the Health and Human Services Tick-Borne Disease Working Group-which was created by legislation I authored in the House of Representatives in 2016there are an estimated 300,000 new cases of Lyme disease diagnosed in the United States each year.

Unfortunately, many instances go unreported or misdiagnosed, leading

experts and researchers to conclude that there could be as many as 476,000 new Lyme cases every year.

In recent years we have made some progress identifying: (a) sources of the disease; (b) preventive measures; and (c) some better treatment strategies. Still, more must be done to enhance our understanding of the huge risk posed by Lyme and other tick-borne diseases, and over time, eradicate this catastrophic disease.

In Congress, I have been leading the fight to ensure that medical and public officials have the critical information they need to help those exposed to Lyme and those who suffer greatly from chronic Lyme disease.

Regrettably, the vast majority of federal officials still do not have a good grasp on Lyme and its impact, let alone the newly emerging tick-borne diseases and the myriad of co-infections that can result from a single tick bite.

It was Pat Smith of Wall Township,

now the President of the Lyme Disease Association, who first asked me to help push federal health policy leaders to more effectively combat Lyme and tickborne diseases 30 years ago.

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- SHOWER SOON AFTER **BEING OUTDOORS**
- CALL YOUR DOCTOR IF YOU **GET A FEVER OR RASH**

For more information; www.cdc.gov/ticks



LYME DISEASE

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I've been all in ever since.

Immediately after speaking with Pat in 1992, I arranged meetings in Washington—and several times since—with top public health officials from the Centers for Disease Control (CDC), National Institutes of Health (NIH) and the Department of Health and Human Services.

Everyone was civil at that first, twohour expansive meeting 30 years ago (this past March). But they remained dismissive of our well-founded assertion that chronic Lyme exists and was/ is devasting the lives of many, especially children.

Our greatest concern-that a onemonth regimen of the antibiotic doxycycline doesn't cure chronic Lymewas trivialized and rejected by the top public health officials from CDC and the NIH. They argued that chronic Lyme did not even exist despite the persuasive cases we brought to light, backed up by the experiences of those suffering greatly from Lyme.

Since those early, daunting days, I've authored more than a dozen comprehensive bills to combat Lyme diseasefocusing on the need for a national strategy which includes more accurate prevalence studies, world-class affordable diagnostic tools, more aggressive



Rep. Chris Smith, a fighter for those suffering from Lyme disease, hosts a congressional town meeting at the Wall Township Municipal Building in 2019. As co-founder and co-chair of the Congressional Lyme Caucus, Smith has authored more than a dozen comprehensive bills to combat Lyme and other tick-borne illnesses, focusing on the need for a national strategy including more accurate prevalence studies, world-class affordable diagnostic tools, more aggressive prevention initiatives and effective treatment options for patients.

prevention initiatives, effective treatment options, and training for medical and public health officials.

At the core of most of my bills has been the establishment of an advisory commission or working group that would include Lyme-literate physicians, researchers and patients—a group of people who had been systematically excluded for years from the policy debate.

When the 21st Century Cures Act

was under consideration by the House in 2016, we succeeded and added the Tick-Borne Disease Working Group to the Act-achieving the long-sought goal of truly studying Lyme.

Much of what we have argued for more than the past 30 years has now been scientifically validated by the Working Group, including the fact that hundreds of thousands of peopleespecially and including more than 800,000 New Jersey residents according to estimates based on CDC datahave gotten seriously ill from ticks and that the federal response to date has been woefully inadequate.

Yet even today, with these advances and new documentation, many patients are still being told that their diseasechronic Lyme-does not exist.

Only years after that first meeting in 1992, the CDC finally conceded that "approximately 10 to 20 percent of patients treated for Lyme disease with a recommended two to four-week course of antibiotics will have lingering symptoms of fatigue, pain, or joint and muscle aches." They call this "Posttreatment Lyme Disease Syndrome." We know it to be chronic Lyme.

Our work continues. The TICK Act, which I authored in the House-and which became law as part of an endof-year budget bill in 2019-mandates, for the first time, a national strategy to coordinate a whole-of-government approach and enables our federal agencies to step up and work together in their efforts in the fight against Lyme. The law authorizes through 2025 five national regional centers of excellence that should finally open doors to longawaited innovative therapies, treatments, better diagnosis and more accurate information for doctors and their patients with Lyme.