

Clock is Ticking: The Time to Fund Lyme and TBD Research is Now

DAPHNE JORDAN March 28, 2022

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Hyde Park, NY—With zero new dollars included in either the Assembly or Senate One-House Budget Proposals to combat the spread of Lyme and tick-borne diseases (TBDs), Senators Sue Serino, Daphne Jordan, and Alexis Weik today joined researchers, patients, and advocates from across New York in a virtual press conference to urge legislative leaders to invest in research, education and prevention initiatives in this year's State Budget. The coalition is pushing for at least \$1.5 million to be included in the final enacted budget that is slated to pass by April 1st.

"As the number of Lyme and tick-borne disease cases continues to climb, and the state sits on a significant budget surplus, now is the time to make meaningful investments in research, education, and prevention initiatives that can protect New Yorkers from the spread of Lyme and TBDs for generations to come," said Senator Serino. "Not including any funding to help prevent the spread of these diseases that impact thousands of New Yorkers each year defies logic. With only days to go before a final budget is expected to be voted on, we are asking our colleagues to do the right thing, ensure that the voices of New Yorkers who live with these devastating diseases are heard, and include significant funding to help put an end to the Lyme and tick-borne disease epidemic in the final state budget."

"With a mere three days remaining before the State Budget must be passed, there isn't a moment to lose in getting a minimum of \$1.5 million in funding for Lyme and Tick-Borne Disease into the final 2022-23

State Budget. There's still time IF our colleagues on the other side of the aisle share our commitment. I believe many of them do, it's just a matter of them joining us and saying this investment must be a priority. The urgent need to invest in Lyme and Tick-Borne Disease research, education, and prevention initiatives is bigger than partisan politics. It's about protecting the health, safety, and well-being of our fellow New Yorkers from the ravages of Lyme Disease and Tick-Borne illnesses. We should continue our focus on public health by making necessary, smart investments that are needed in the 2022-23 State Budget to keep New York moving forward in the fight against Lyme and Tick-Borne Disease. The clock is ticking – let's not come up short when the health of our fellow New Yorkers hangs in the balance," Senator Daphne Jordan (R,C,I-Halfmoon) said.

Senator Alexis Weik (R-C, Sayville) says, "New York and Suffolk County, where I live, have long been among the hardest hit by Lyme, a disease whose health effects are still not fully understood, but which can have long-lasting consequences for its victims. New York needs to be a leader in researching and finding ways to prevent infection and find cures for this disease, and this additional funding is essential to that fight."

"The gains made as a result of previous initiatives funded through the NYS budget process include tick and tickborne pathogen surveillance program in the Adirondack region by Dr. LeeAnn Sporn at Paul Smith's College. For my lab at SUNY Adirondack, State funding allowed for the establishment of a biorepository of clinical samples from across New York State which has been used repeatedly for research applications, notably for the identification of biomarkers that could be used for development of accurate diagnostic tests for Lyme disease and other tickborne coinfections, such as tickborne relapsing fever (TBRF), Babesia, Anaplasma, Bartonella. I'm excited to report that we are moving forward with commercialization of a diagnostic test for Lyme disease that far exceeds the clinical accuracy of the existing diagnostic, an outcome made possible through New York State funding, as well as private philanthropic donations. As a state with one of the highest rates of Lyme disease in the country, now is not the time for New York State to withdraw funding for Lyme disease research, education or prevention,"

said Holly Ahern, MS, MT (ASCP), Associate Professor of Microbiology at SUNY Adirondack and Vice President of the Lyme Action Network.

"In New York State there are over a dozen different tick species which can cause ~11 human illnesses. New York State has historically taken a national (and even global) lead on addressing public health issues, It's time that our state take the lead and increase/continue to support research, education, and outreach on ticks and their diseases," said Brian Leydet, Ph.D., Assistant Professor of Environmental Biology at SUNY College of Environmental Science and Forestry.

"Common sense dictates that you don't go from a normal, energetic, high functioning individual, to complete system failure without something causing your sickness, yet you are subjected to indignity, humiliation, and degradation, because Lyme and Tick Borne Diseases are so misunderstood, marginalized, or undiagnosed. Let's do something about this!" said Ann Desotelle, MSPT, DPT, Patient and Advocate from Western New York/Adirondacks.

"Yes, COVID has been in the forefront. However, Ticks, Lyme & TBDs are increasing in numbers and spreading geographically like wildfire. Ticks and their pathogens will continue to spread un-abated as they have for over 40 years bringing us to this point! It will not go away by ignoring it, and will only continue to increase unless research is funded! There are so many prestigious research institutions in NYS which need funding to continue to STOP ticks & disease! NYS Legislators must protect citizens by appropriating a minimum of \$1.5 million. This amount is a pittance of the horrific damage in NYS! Shame on NY for not including it in the proposed budget," said Jill Auerbach, Patient and Advocate from Hudson Valley Lyme Disease Association.

With New York being home to the second highest number of confirmed Lyme disease cases in the nation, presenters argued that the number of ticks and the diseases they transmit are increasing across the state. According to the Centers for Disease Control and Prevention (CDC), among the infections that can be transmitted to humans through the bite of a tick, Lyme disease makes up over 80% of the cases reported to the agency. The CDC also estimates that there are nearly a half million new cases of Lyme disease in the US each year, which makes Lyme the third most common bacterial infectious disease in America. However, due to inaccurate diagnostic testing, the actual number of cases remains illusive.

In November, with bipartisan support, Senator Serino sent a letter urging Governor Kathy Hochul to include funding to address the scourge of Lyme and tick-borne diseases in her historic first Executive Budget Proposal. The request went unanswered, and Governor Hochul ultimately did not include any new funding to address this issue in her proposal. On March 3rd, Senator Serino and a number of her colleagues also sent a letter to the Senate's Legislative Leaders requesting that \$1.5 million be included in the Senate's One-House Budget Proposal, however, when the proposal was debated on the Senate Floor last week, the Senate's Majority confirmed that no new funding was included in their proposal.

A copy of both letters are attached.