## Ulster County Legislature

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## The Lyme Disease Controversy

(Kingston, NY) A walk in nature in the Northeast has become synonymous with Lyme Disease prevention. Yet, the education and awareness, to avoid a bite from an infected tick the size of a poppy seed, has done little to help those already infected by the bacteria and the controversy over a confirmed method of treatment is leaving many Ulster County residents devastated. While the Ulster County Legislature established the Lyme Disease Advisory Committee and unanimously passed numerous Resolutions, residents continue to present the Legislature with their experiences of insurance claim denials, 2<sup>nd</sup> mortgages and loss of homes in the attempt to keep themselves or their family members alive.

This is not a Hudson Valley specific controversy. The Boston Globe reported on June 2, 2013, "Angry patients question treatment — or lack of it — yet with tests often inconclusive, some doctors think the condition is over-diagnosed. And the split is widening." The Globe has followed up with many articles since, such as Lyme disease controversy is on the rise. These articles indicate doctors are concerned when stepping out of traditional treatment that they will be accused of malpractice.

"When I started the Lyme Disease Advisory Committee in 2012, I sought a public forum for the patients and the doctors to speak about this spreading epidemic," stated Legislator Robert Aiello, Chairman of the Health & Personnel Committee and Legislator from the Town of Saugerties. "What I never expected was the overwhelming response I received from patients all over Ulster County who have been struggling with this deliberating illness in isolation and doctors who expressed frustration over the lack of a standard treatment. It is time for this County and this State to work collaboratively with the medical community and move this decade's long controversy to cutting edge treatment and solutions."

At the June 18<sup>th</sup> General Session, Legislative Chairman Terry Bernardo gave Privilege of the Floor to Legislator Aiello and Dan LeFever of Shokan, Scott Owens of Kerhonkson, Beth Capen of Kingston, Carol Connolly of New Paltz and Doreen Peone of Saugerties, to speak about the need for legislation to ensure the many victims of Lyme Disease receive appropriate treatment. All recounted personal experiences of multiple, incorrect diagnoses, months of being bed ridden and unable to move, mountains of prescriptions just to function daily, insurance denials, and the depletion of family life savings.

The Lyme Disease treatment controversy is reportedly centered in the medical community. When the medical researcher who first identified the disease in the United States, Dr. Allen Steer,

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determined, based on his own tests, that not all who were being diagnosed with Lyme actually had the disease, many doctors and insurance companies followed suit. As a result, patients were being denied their insurance claims for the long-term antibiotic and other alternate treatments that seemed to save their lives. Dr. Steer currently works at Massachusetts General as the Director of the Laboratory of Translational Research in Lyme Disease and Rheumatoid Arthritis in a secure facility to protect this world renowned researcher as he continues his work to find solutions.

Legislator Robert Aiello remains a vocal advocate for the Ulster County victims of Lyme Disease; promoting community education and continued dialogue among the medical community. He noted, "There is not one mode of treatment these doctors can follow and produce successful results. Even medical experts at Massachusetts General, Brigham Women's, and Yale New Haven Hospitals are unable to agree with a common treatment. It is time the medical professionals come together and find one proven treatment."