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FOR IMMEDIATE RELEASE

Advocates to Rally on State Capitol, Calling for Fair Insurance Coverage of Lyme Disease Treatment

Interview Opportunities: PA Lyme leadership, advocates and patients available on-site for interviews on May 9

HARRISBURG, PA (MAY 4, 2017) – On May 9, 2017, Lyme disease advocates, patients, family members and friends will converge on the Capitol steps in Harrisburg from 11 am – 1 pm for a critical rally for the Lyme disease community calling for passage of SB100 and HB174 – The Lyme and Related Tick-Borne Disease Diagnosis and Treatment Act, which would close the gap in insurance coverage and make Lyme disease treatment accessible for the residents of Pennsylvania. Our commonwealth has led the country with the most new cases of Lyme disease for six years running, with more than 12,000 state residents contracting the disease in 2016. Due to under-reporting, the CDC estimates this to be 10x this, or 120,000 new cases, of which approximately 30,000 are children. 40-50% of Lyme cases do not respond fully to short-term antibiotic treatment, yet insurance companies are denying coverage of longer-term antibiotic treatment as prescribed by patients’ physicians.

The primary underlying issue is that there are two sets of medical treatment guideline for physicians—an outdated set from the Infectious Disease Society of America that dismisses long-term antibiotic use for Lyme disease treatment, and a newer set of guidelines from the International Lyme and Associated Diseases Society (ILADS) that recommend the use of longer-term antibiotic treatment as an option for persistent Lyme disease cases. The ILADS guidelines are the only guidelines accepted as meeting the stringent standards of the Agency for Healthcare Research and Quality and listed on the National Guidelines Clearinghouse, a website that provides a public searchable database and resource for summaries of evidence-based clinical practice guidelines.

Repeated CDC studies have established that long-term treatment is in fact the standard of care...fully 56% of patients were treated longer than the legacy guidelines called for, and much longer than the treatments covered by most insurers. The medical community agrees that there are persistent symptoms in Lyme disease – from 10-40% of patients fail short treatment. This means that the standard of care is actually longer-term antibiotics. Yet insurers are denying such treatment as being “experimental.” Why? Because the old guidelines from IDSA dismissed long-term antibiotics, and historically have been the guidelines endorsed by the CDC. However, in February 2016, the IDSA guidelines were removed from the National Guidelines Clearinghouse for being outdated and not meeting the new stringent standards...leaving the ILADS guidelines as the only approved standard of care for physicians. So the question and issue lays in the fact that while physicians can and are prescribing longer courses of antibiotic for Lyme disease, insurance companies are denying patients’ coverage of the treatment they require.

Advocates to Rally on State Capitol, Calling for Fair Insurance Coverage of Lyme Disease Treatment

PA Lyme Resource Network (May 4, 2017)

PA Lyme Resource Network president Julie Wagner, MBA, explained, “Without proper access to treatment, persistent Lyme disease can devastate and rob lives. Insurers need to pay for treatment as prescribed by the physician...they cannot cherry-pick the evidence-based guidelines they think a patient should be treated by. The physician is licensed to evaluate the available evidence and make the best decision for their patient. How can insurers deny treatment options being recommended as the most up-to-date guidelines available and which are clearly a standard of care? Multiple schools of thought and standards of care are common in the practice of emerging medicine, especially in rapidly emerging diseases, like Lyme/Tick-borne diseases. This is how innovation occurs.”

The consequences of not treating are real, and can be serious. CDC studies reviewing insurance records found that children ages 5-9 are a significant portion of cases, with the average age of 30 years old. Published reports document the negative impact on children’s cognitive functioning, academic progress, fatigue, headaches, and other serious neurological symptoms. In PA, Lyme is impacting 20,000 – 30,000 children every year. Chronic Lyme disease has a serious impact on quality of life, which may lead to congestive heart failure, and other serious chronic conditions. In PA, the Department of Conservation and Natural Resources indicated that the vast majority of their disability cases were related to Lyme/Tick-borne diseases. According to a Johns Hopkins 2015 study, improperly treated Lyme disease costs the medical system \$1.3 billion annually.

The impact and cost of Lyme disease is seen around the state repeatedly by PA Lyme Resource Network’s regional support groups. Stories and letters collected by PA Lyme in support of these bills tell the harsh and sad reality PA citizens face with Lyme disease...becoming bed-bound, unable to work, losing their jobs, having to sell everything they own to pay for their treatment, even having to be admitted to nursing homes to be cared for around the clock due to their extreme decline. Children missing months of school, facing a drop in their IQ, and becoming wheelchair bound.

“It is critical that this barrier be removed to provide options when short-term treatment is not enough for treating the persistent form of Lyme disease,” Wagner said frankly. “This approach to longer-term antibiotic use is no different than that used in many other serious diseases with similar persistence issues, like TB or Mycoplasma, or Q-Fever. The bill is a ‘correction’ required to ensure insurers are covering a standard treatment provided in many other diseases and specifically recommended as an option in the most current, approved Lyme Treatment Guidelines...similar to what was needed with breast cancer to provide coverage and the option of Lumpectomies. All we ask for on behalf of the Lyme community is fair coverage of standard, prescribed treatment. Treatment needed to help people return to health, resume their jobs, and be able to care for their families. SB100 is not a mandate – it is a necessary course correction. Cancer patients are not refused life-saving treatments on the basis of potential side-effects; nor should Lyme patients. It’s as simple as that. In PA, more than 40,000 people per year could become sick with persistent Lyme, with no options available to them. That simply is not acceptable.”

PA Lyme Resource Network (www.palyme.org) is an all-volunteer 501(c)(3) non-profit organization that provides education, patient advocacy, support and resources to help others navigate this exceedingly complex and controversial disease. The state-wide group, founded in 2012 by individuals with personal experiences with the diseases, provides education in the form of speakers, seminars, patient networks, and research updates for the general public, medical professionals, schools, private businesses, and government entities; it also supports regional and independent Lyme groups that hold local meetings to provide support, education, and resources to their local communities.

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