



PRESENTATION FOR THE STATE OF NEW JERSEY



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FOR GOVERNOR OF NEW JERSEY; **PHIL MURPHY**



AND HEALTH COMMISSIONER; **JUDITH PERSICHILLI**, R.N., B.S.N., M.A

LYME DISEASE 2020

SHARING INSIGHT & SOLUTIONS TO
UNRESOLVED CHALLENGES RELATED TO TICK-BORNE INFECTIONS

The mission of our meeting is to help create awareness of Lyme and its co-infections together with the state of New Jersey. We look forward to sharing insights, information and direction to be able to further create awareness.



LIFE FOR LYME

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AWARENESS

- Government sponsored Radio Campaigns all over the State
- Government sponsored posters detailing how to prevent tick bites in pharmacies and medical clinics
- In tick infested areas "Beware of Ticks" signs, with tips on what to look for and how to remove them.
- Education in schools and summer camps
- Tracking ticks and studies regarding amount of infected ticks
- Counting Lyme and other tick borne infection cases
- Government sponsored education and training for doctors
- Pamphlets in medical offices
- Tick report smartphone app
- Government sponsored tick testing lab for all infections
- Tick infections research
- Government sponsored Spraying in Public Areas
- Government sponsored tick infection clinic
- State Sponsored Tick Predator Reintroduction Program (Backyard Chickens or Quail)
- Research all credible global studies including private studies and not only government sponsored ones
- Grants for Medical achievements, research, testing and devices
- Grants for low income patients



INFECTIONS TICKS CARRY

Babesia Microti
Babesia Ducani
Bartonella Henselea
Bartonella Quintana
Ehrlichia Chaffeensis HME,
Q-Fever also called C.Burneti
Rocky Mountain Spotted Fever
Ehrlichia Equine also called Anaplasma Phagocytophilum
Mycloplasma Pneumonia
Rickestial Disease
Brucella
Chlamydia Pneumonia
Tularemia
Typhus
Parvovirus b19
Toxoplasma
Cytomegalovirus CMV
Epstein Barr Virus EBV
Human Herpes Virus
West Nile Virus
Coxsackie Virus



TESTING NEEDED FOR CHRONIC LYME PATIENTS

Due to testing inaccuracies expert Lyme Doctors need to rule everything out to get a proper diagnosis

- EIA enzyme immunoassay blood test
- IFA indirect immunofluorescence assay blood test
- Immunoblot test, called a "Western blot" blood test
- PCR Polymerase Chain Reaction Blood test
- Blood Smear test
- FISH Fluorescence in situ hybridization
- Urine Tests
- Biopsies
- Sonograms/Ultrasounds
- MRI
- X-Rays
- EEG
- EKG
- Spinal Tap
- many other medical tests



DOCTORS ISSUES COVERAGE AND MEDICAL BOARD

- Insurers do not cover the required time necessary for diagnosis and treatment
- Insurers do not cover necessary testing
- Doctors are afraid to treat or report anything to the government due to medical differences with medical boards who disagree on scientific studies
- Doctors are penalized by medical boards for treatment
- Doctors are forced to change states with better laws for treatment requiring patients to travel long distances for treatment
- Doctors to cover their expenses due to more oversight have to charge high prices to patients



INSURANCE ISSUES

Overall due to insurance companies being publicly traded corporations with investors they try to cover at least as possible in order to turn a profit. With legal and medical loopholes they are able to deny coverage easily. With the ongoing medical debate on diagnosing and treatment of tick born infections, insurance companies are able to use this debate to deny coverage to ill patients.

Here is the list of problems that Insurers use to their advantage in order to avoid coverage and how we need to solve them:

-General Diagnostic testing is inaccurate requiring multiple screenings which insurers want to deny.

The CDC admits tests are not 100% accurate (see the FAQ page question one under diagnosis, testing, treatment <https://www.cdc.gov/lyme/faq/index.html>)

The insurance companies try not to cover multiple screening of these tests saying they are not necessary when in fact a second or third test later on could be more accurate.

-There is more advanced testing from such labs as Igenex, Galaxy and others that the insurance companies refuse to cover. If Doctors can testify that they work insurers should be required to cover them.

-Complicated cases that are hard to diagnose due to inaccuracies of testing and the symptoms mimicking other diseases require a lot of different testing such as MRI, Biopsies etc. which the insurance companies deem unnecessary and don't want to cover

-Insurance companies provide only 15 min patient intervals for regular Doctors to see patients and 30 min for specialists. Insurance companies refuse to cover this time it takes for this disease.

With the complicated cases of chronic Lyme disease it can take 1-4 hours of the first consult to review all of a patient's symptoms, all their tests over the lifetime of the illness and finally discussing a diagnosis and treatment plan. Subsequent appointments can take at least an hour going over each symptom and changes in treatment.

-Lyme experts recommend long term treatment with antibiotics either oral or IV and possibly other medical treatments that the insurance companies refuse to cover saying that it is unnecessary.



LAWS TO ENACT

NJ Assembly Bill A678 tries to alleviate some of these concerns.

http://www.njleg.state.nj.us/2018/Bills/A1000/678_11.PDF

Main points from the bill:

- Insurers must cover what the patients doctor says is medically necessary for their treatment
- Insurers cannot deny Lyme treatment by saying it's experimental

(Problem with this bill only mentions Lyme but no mention of the other infections like Bartonella)

IDEAS OF LAWS FROM OTHER STATES

-Massachusetts, Rhode Island and Connecticut, Minnesota, New York already have laws requiring insurance coverage on long term antibiotics

West Virginia just passed the law this March

-NY law insulates Lyme Doctors from investigation into giving long term antibiotics

-California law has Lyme literate experts review the cases of other Lyme Doctors instead of the regular medical board

-Delaware law made task force to make recommendations for the prevention of Lyme disease and educational programs to raise awareness about long term effects of misdiagnoses of Lyme disease

-Connecticut had a bill introduced but it failed requiring Doctors to administer Lyme disease test for nonspecific pain it failed because they said it will lead to unnecessary testing

-New York bill passed in Senate requires a report to study insurance coverage denials and cost of expanding coverage.

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PATIENT ISSUES

- Unclear diagnoses from doctors requiring to go on average to 10-15 specialists before getting Lyme or other tick infection diagnosis
- Misdiagnosed for other diseases for which they do years of treatment that does not help
- Not enough Doctors trained in tick borne illnesses
- Medical debt even with insurance paying out deductibles, premiums, and copays
- Medical Debt going up to \$100,000 covering expert Lyme doctors, testing, treatment protocols, medication and supplements not covered by insurance
- Travel to appointment expenses
- Delayed diagnoses leading to longer treatments
- Disability issues unable to work for several years
- Problems with applying for disability, unemployment, and catastrophic insurance due to the controversy over the illness
- Backlash from others uneducated in facts about tick borne illnesses
- Problems of mental illness and depression
- Problems in marriage leading to divorce
- Unable to manage a household
- Unable to afford household help and pay bills
- Can remain sick for several years
- Racking up massive credit card debt
- No family support
- No government support
- No community support



COSTS TO STATE MEDICAL SYSTEM AND INSURANCE COMPANIES

- People with low immunity especially childdoctoren and seniors who get bitten are more likely to be sick for several years costing the state Medicaid and Medicare services and insurers hundoctoreds of millions in payments of constant treatment that they do cover
- Insurances spend hundoctoreds of millions on the constant specialists and hospital visits that patients go to get properly diagnosed
- Loss of employment revenue in State from increase in disabled patients
- Increase in government and insurance mental health spending for patients that didn't get treated in time
- Loss of expert doctors in the State
- Increase in patients with chronic illness that are a burden on the State and insurers



PRESENTED BY DUVI HONIG

A distinctly energetic and visionary entrepreneur, Duvi Honig has built a world class network of diverse businesses and biz services to enhance prospects of commerce, Education and Job Creation through innovative programs and public policy initiatives. His work is based upon a down to earth understanding of the economy. Duvi issued correct advance warning about several major economic downturns, including the 2008 financial and real estate collapse, the 2015 “Flash Crash” stock market fall, and the global market panic that followed the Brexit vote in June 2016.

The dual pillars that Duvi founded – the Orthodox Jewish Chamber of Commerce and non-profit Parnassah Network organization – encompass thousands of diverse businesses and fourteen divisions. Over 100k people from across the United States and other countries took advantage of OJC/PN resources, including the flagship annual - J Biz Expo – ParnassahExpo-Nationwide Business Networking Event, the world’s largest Jewish community biz Conference & B2B event.

Duvi effectively utilizes the clout of these networks to influence public policy at the local, state, federal and international level to benefit businesses. Duvi’s work was recognized in writing by the White House and, in 2016, he was honored by a bipartisan group of influential U.S. senators during Jewish Heritage Month. Duvi and other members of the OJC Executive Public Policy Committee have a particular interest in U.S.-Israel economic ties, protecting the world from threats such as BDS, Business Discrimination and UN anti-Semitism. Duvi was recently interviewed by Forbes to share his highly skilled Networking tips. The OJC hosted a news conference at the UN in December 2016, with former Ambassador John Bolton, articulating the dangers of US diplomatic abandonment of Israel. In January 2017, the OJC led a historic “U.S.-Israel Business Alliance” mission to Israel, headlined by Governor Mike Huckabee, to boost economic ties and battle contemporary threats.



LIFE FOR LYME

Life for Lyme is a non-profit organization that offers a range of services and support for individuals suffering from Lyme Disease, especially late stage or chronic Lyme. We feel that with the proper knowledge and information patients can make better decisions about their treatment and ultimately their general well-being. Our goal is to help people make well-informed choices so they can reach optimum health.



LIFE FOR LYME



WHAT THE PATIENTS ARE SAYING

"If you are looking for anyone in NJ, turn back around and head north. I have been looking for doctors for the past 5 years. There are no Lyme Literate Medical Doctors in this area. That's probably why it took me over 10 years to get diagnosed. Honestly, it's disgraceful. We are at ground zero in this epidemic yet the doctors here are clueless."

Beverly M., Monmouth County

"I've been treated by a doctor in Toms River but he realized that it may be risky to treat Lyme disease and now he is a skiing instructor up north. Sad."

Jeanette C., Ocean County

"The system is broken, its not like my doctor studied Lyme and stated that my child doesn't have it. He just shut down the question and wouldn't hear from it. When you deny something you have to first learn about it, otherwise it looks suspicious to shoot it down. This shouldn't be happening in a medicine."

Tami L., Bergen County

"I was referred to a top infectious disease specialist due to a positive Rocky Mountain Spotted Fever result from Labcorp. After waiting weeks for the approvals and her availability, we finally got an appointment. She looked at me with a straight face, and said "This is nothing because there is no RMSF in New Jersey, so it's of no value." She didn't ask about my hiking trip in New Hampshire, or my vacation in Vermont. She just disregarded the positive lab test. \$75,000 in specialist consultations later, I found a doctor would treat me."

Merryl B., Ocean County

"Shame on New Jersey. There is no one to help us and so many ticks to bite us. I've seen it with my own eyes, doctors shaming patients for bringing up the possibility of Lyme Disease. Some acknowledging Lyme but not its co-infections and some even calling patients crazy or fakers looking for attention. Children are getting bites on a daily basis and there is no uniform protocol. Even within one pediatric practice you will have different views among doctors. Something must be done."

Evelyn P., Ocean County

"I haven't heard of any Lyme sympathetic doctors in Marlboro. If you have a good experience, please let us know!"

Leah M., Monmouth County