P U B L I C H E A R I N G

before

ASSEMBLY HEALTH AND HUMAN SERVICES COMMITTEE

"The Impact of Lyme Disease in New Jersey
and Measures to Address This Problem"

November 2, 1990
Jackson Township Municipal Building
Main Conference Room
Jackson Township, New Jersey

MEMBERS OF COMMITTEE PRESENT:

Assemblyman George J. Otlowski, Chairman
Assemblywoman Ann A. Mullen
Assemblyman Nicholas R. Felice

ALSO PRESENT:

Eleanor Miller
Office of Legislative Services
Aide, Assembly Health and
Human Services Committee

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Hearing Recorded and Transcribed by
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New Jersey State Legislature
ASSEMBLY HEALTH AND HUMAN
SERVICES COMMITTEE
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NOTICE OF A PUBLIC HEARING

The Assembly Health and Human Services Committee will hold a public hearing on the following topic:

The Impact of Lyme Disease in New Jersey and Measures to Address This Problem

The hearing will be held on **Friday, November 2, 1990, at 10:00 A.M., in the Jackson Township Municipal Building, Main Conference Room, First Floor, Route 528 (Veteran's Way), Jackson Township, New Jersey.** The committee will receive testimony about the impact of Lyme Disease in New Jersey and current State and local activities to address this problem, as well as suggestions for additional prevention, treatment and research efforts.

The public may address comments and questions to David Price, Committee Aide and persons wishing to testify should contact Felice Astor, secretary, at (609) 292-1646. Those persons presenting written testimony should provide 10 copies to the committee on the day of the hearing.

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ASSEMBLYMAN GEORGE J. OTLOWSKI (Chairman): We want to get started. I would like to apologize for getting underway late, but some of you had a problem finding parking. We delayed purposely to give you an opportunity to do so and to get into the chambers here.

What we are going to do is, I have an agenda I am going to follow as much as I possibly can. It is my understanding that some of the children who are here want to testify. I hope, of course, that we are not going to be repetitious. We are building up a record here, and as long as the record is sufficient and embracing, there will be no need for repetition because it will only cloud up the record.

With that in mind, frankly I am going to try to hold everybody down to a reasonable time. The children who are going to testify-- I just want them to feel comfortable and, you know, we are past Halloween, so they don't have to be afraid of me. (laughter) In any event, with that I am going to call on the legislators first, and the first legislator I am going to call on will be Assemblywoman Marlene Ford. Assemblywoman, we are ready for you. All right?

A S S E M B L Y W O M A N M A R L E N E L Y N C H F O R D: Thank you, Mr. Chairman. It is nice to be back here in Jackson Township. I have actually spent a lot of time at this particular table as a municipal prosecutor here. Perhaps this morning we will be talking about something a little more pleasant than prosecuting people, although the issue of Lyme disease is one that has hit many, many, many residents of this particular community, as well as this particular area. You will hear later from Assemblywoman Clare Farragher, who represents the adjoining area, which includes Freehold. It seems that Jackson Township, Howell, and Freehold are really the center of the Lyme disease problem in New Jersey, while it is obvious that it has affected people from one end of the State to the other.

I had the opportunity a few months ago, in the beginning of my term, to accompany Dr. Drulle and to visit some of his patients in the Jersey Shore Medical Center. I can tell you, Assemblymen, that I was very moved by what I saw and what I heard from these young teenage victims of Lyme disease. We discussed some of the problems they had in school, and I hope you will hear about some of them a little later on from the victims themselves. We also discussed some of the problems as to the role the State should play in developing policy on Lyme disease.

As a result of these meetings, I came up with a preliminary package of legislation addressing the problems of Lyme disease which, by no means, do I think at this point in time is complete. Some of the legislation is in your Committee -- the Assembly Health and Human Services Committee -- and some of it has already been voted out of other committees and is in a position to be considered by the Assembly. I would hope that at an early opportunity your Committee would be able to review the bills that are currently before you.

But let me just speak briefly to some of the legislation that I have sponsored in an effort to develop a statewide policy on Lyme disease. One of the things I heard was that many new developments-- In the perimeter of the developments is where the deer tick is known to reside, and new residents coming into these developments are not aware of their exposure to potentially contracting Lyme disease. As a result of that, we thought it would be a good idea to allow municipalities to condition a development permit on the requirement that the developer treat the surrounding area for infestation from deer ticks. That is one of the bills that is in this package.

One of the other things we heard was that there are particular areas of the State, especially State parks, that are well-known areas populated by the deer tick. The public, not

knowing this fact, often visit these parks and do not take appropriate precautions against the Lyme disease carrying deer ticks.

A second bill I sponsored would require the Department of Environmental Protection to do an inventory, or an investigation of State parks to identify those State lands where there is a known problem of Lyme disease through the exposure to deer ticks.

A third bill I sponsored was really a result of some of my conversations with some of the high school students who are afflicted with Lyme disease. One of the problems they related to me was a lack of sensitivity, so to speak, really just out of ignorance on the part of school officials and so forth as to their particular problems, both socially and educationally, as victims of Lyme disease. The third bill I sponsored would require the Department of Education to develop a curriculum that would incorporate a Lyme disease awareness program and sensitivity for the victims of this disease into the curriculum of the local school districts.

We know that heightening sensitivity and identifying the problem is alone not enough in addressing this very serious health problem in our State. Another bill would appropriate $500,000 to the Department of Health to investigate ways by which we could prevent Lyme disease, provide therapy, and perhaps identify a cure for the disease.

Finally, one of the last problems that seems to be very prevalent is a bill that came out of Assemblyman Adubato's Insurance Committee. Many of the physicians and people involved as victims and family members of those with Lyme disease related stories to me that health insurance carriers oftentimes exclude treatment for Lyme disease from their insurance coverage. As a result of that, many families are carrying a very high insurance -- pardon me, health cost associated with the treatment and therapy for Lyme disease.

The last bill would require health insurance carriers to cover medical expenses necessary and related to Lyme disease treatment.

Recently I attended a meeting of many people throughout the State -- a coalition of victims of Lyme disease at the Governor's Office. As a result of that meeting, I think one of the most critical things I got out of it was a recommendation that what New Jersey really needs is an advisory board to look at and coordinate all of the efforts to fight Lyme disease in this State; a board that would be made up, obviously, of citizens, as well as the Commissioner of Health and commissioners of the appropriate departments, like the Department of Environmental Protection.

I have requested legislation that hopefully will be referred to your Committee, Mr. Chairman, that would establish a Governor's Advisory Board on Lyme Disease and provide sort of the coordinating and central unit to disseminate information on Lyme disease and take this information and the people who are closest to the problem hopefully to its solution. This Board would be able to advise the State Legislature and the Governor what their recommendations are for the course of action that we, as a State, should take.

I don't know what the purpose of government should be, if not, as the late Hubert Humphrey once said, to "care for the weakest members of society and those in the most need." I agree with that. I know, Mr. Chairman, that you also agree with that philosophy. I would hope that this Committee and the Assembly could be in the forefront of developing a State policy on Lyme disease to address the particular problems and concerns of the many, many people who are victimized by this disease, and whose lives have been changed as a result of it.

I thank you for coming to Jackson Township to hear this. It is an opportunity for many local people, who sometimes do not get to Trenton, to come here to tell you their

side of the story. So, thank you very much for providing us with this opportunity in this forum.

ASSEMBLYMAN OTLOWSKI: Thank you. Assemblywoman, will you please sit there for a moment? I want to do something before we go further, but I would like to ask you some questions, and it may be, too, that the members of the Committee might want to ask you some questions.

Before I do anything else, I want to introduce the members of the Committee who are here. First, of course, is Assemblywoman Ann Mullen. Ann, we are happy that you could make it. Then, of course, there is Assemblyman Nicholas Felice. We are delighted that he is here also.

Now, if the people from left to right would introduce themselves, so that everybody out there will know that they are not being attacked-- Can we start here?

MS. ALLEN: I am Theresa. I am a Hearing Reporter from the Office of Legislative Services.

MS. SYLVESTER: I'm Barbara. I am from the Hearing Unit of the Office of Legislative Services.

MR. HAINES: My name is Bob Haines. I work with the Assembly Majority staff.

MR. GANGES: My name is Kelly Ganges, Assembly Majority staff.

MS. MILLER: I am Robbie Miller, from OLS.

MS. WOLF: And I am Cheryl Wolf, Assembly Minority staff.

ASSEMBLYMAN OTLOWSKI: Assemblywoman, you pointed out that you have a number of bills which you have introduced. One of the bills that you talked about would have the State take more intensive action on properties that the State owns, to make sure that preventative measures were taken. Can you tell us just a little bit more about the purpose of that bill and the nature of that bill?

ASSEMBLYWOMAN FORD: Well, many of the victims of Lyme disease related to me that they oftentimes knew they had contracted Lyme disease while visiting particular State parks in New Jersey. There is no treatment in those areas. There have been few, if any, efforts by the State to identify and to publicize the identification of the State parks where the Lyme tick is known. We certainly don't want to deter people from visiting our State parks, but on the other hand I think it would be prudent for the State to identify State lands where there is a problem and to take steps to correct that problem, if possible. If it is not possible to correct the problem, I think the public has a right to know that when they visit those parks, they should take specific precautions against the deer tick.

ASSEMBLYMAN OTLOWSKI: That is one bill.

ASSEMBLYWOMAN FORD: I think that bill is in your Committee.

ASSEMBLYMAN OTLOWSKI: The other bill you talked about would--

ASSEMBLYWOMAN FORD: Another bill that was released from Assemblywoman Mullen's Committee would permit municipalities to condition treatment of new development areas for the deer tick -- for the prevention of the deer tick. Many people who are involved in this issue much more than I, have related to me that oftentimes the problem comes up with brand-new developments, where there were deep woods that are now cleared for a housing development. They have actually gone into the deep woods and cut into the perimeter area and created a new perimeter area, which is where the deer ticks like to congregate.

So, at least on the municipal level, if it is appropriate in a given case, the municipal governing body or the planning board or the zoning board that is granting development approval, can make it a condition, at a cost to the developer, to treat that particular area for this infestation.

ASSEMBLYMAN OTLOWSKI: I was told earlier this morning that at one development almost 50% of the people are infected with Lyme disease. So what you're saying is, if this were done, there would probably be some measure of control.

ASSEMBLYWOMAN FORD: That's right.

ASSEMBLYMAN OTLOWSKI: Assemblywoman Mullen, do you have any questions?

ASSEMBLYWOMAN MULLEN: Well, I would like to make a comment, Mr. Chairman. I am very happy to be here. I am sorry I was a few minutes late. I took the scenic route, I'm afraid.

ASSEMBLYWOMAN FORD: Ann, I think you have to use the other microphone for sound projection.

ASSEMBLYWOMAN MULLEN: Okay, I'm sorry. Thank you. There we go.

I am just very happy to be here in support of the Assemblywoman's bills, because oddly enough I removed a deer tick from my own husband this week. He works outdoors. I became very concerned because I can relate personally that I have a niece 13 years old who was in the very late stages of Lyme disease -- the arthritic stages -- before they even diagnosed it. She was in a new development. If your bill was passed at the time they moved into that development, and that surrounding area had been treated, that child might not have gone through what she went through.

So, I am very familiar with your bill. I really don't have any questions. I just wanted to congratulate you and make those comments.

ASSEMBLYWOMAN FORD: Thank you.

ASSEMBLYMAN OTLOWSKI: Assemblyman Felice?

ASSEMBLYMAN FELICE: I came down 86 miles from Bergen County today because it is not just a local problem anymore. I will give you two instances: Just recently, in the community next to us, one of the children supposedly, or theoretically on a field trip, picked up Lyme disease. Another more interesting

thing that people might not realize is the fact that we have, in our community-- In Fair Lawn, Bergen County, for many years an environmental center for bottles and cans and recycling, we also take the trees that we cut down and chop them up into chips. One of our leading persons who runs the Recycling Center in this area actually contracted Lyme disease from working around the chips that we cut up, which our citizens come and utilize for their flower beds, or whatever.

There are so many different versions and ways that this Lyme disease can be transmitted. In this case, of course, it was the fact that she was working near the chips that were chopped up from the trees. So I am very concerned and very interested in this particular phase of how it affects us on a broad basis. To me, it is worth the trip coming down here to get this started.

Thank you.

ASSEMBLYMAN OTLOWSKI: Thank you very much. Assemblywoman, I see that one of your bills -- A-3478 -- has a money package of $500,000. That bill, of course, would establish a research program in the Department of Health. Do you just want to develop that for a moment? There are some people here from the Department of Health. They are going to be testifying in a little while. But do you just want to develop that for a moment? You know, when you are talking about $500,000 in today's money market, it is something, of course, that isn't too easy to obtain.

But, in any event, would you just talk about that for a moment?

ASSEMBLYWOMAN FORD: Mr. Chairman, many, many people in New Jersey -- we don't even know the numbers, but I know from my own contacts here in Ocean County -- have been afflicted with Lyme disease, and their lives have been changed very, very dramatically -- citizens and taxpayers in New Jersey who have been affected by this terrible condition. While the

times are tight and the difficulties in finding money are obviously there, and this will obviously be referred to the Appropriations Committee for consideration at that level, I think it would be an expenditure that the State could make to prevent some very massive expenditures in terms of health insurance coverage, medical bills, and so forth.

It is an expenditure in preventative medicine. It is an expenditure to investigate a problem that is afflicting many, many people in the State of New Jersey. When you compare it, the number of people afflicted with Lyme disease, to some other problems that we justifiably fund, like AIDS, for example, I think you will find that $500,000 in that context is a very, very small amount of money to devote to this.

Many of the people you will hear today will say that $500,000 won't do it, you know, and that perhaps the funding should be even higher. But given the fiscal constraints that we are all working with with the State budget, I think it would be a start. There is definitely a need. I think you will hear today that there is certainly public support for an expenditure which would prevent a multiplicity of costs down the road for New Jersey citizens, as well as for the other taxpayers of New Jersey.

ASSEMBLYMAN OTLOWSKI: The other two bills do not involve any real money, as I see it.

ASSEMBLYWOMAN FORD: No. The Department of Education has the capacity right now to develop a curriculum -- a type of sensitivity training, if you will, as well as preventive training within the school systems for Lyme disease. I think some of our school districts are already doing that, especially around here. The other legislation is similar to that.

ASSEMBLYMAN OTLOWSKI: Thank you very, very much. Do you want to add anything else?

ASSEMBLYWOMAN FORD: No, Mr. Chairman.

ASSEMBLYWOMAN MULLEN: Mr. Chairman?

ASSEMBLYMAN OTLOWSKI: Yes?

ASSEMBLYWOMAN MULLEN: May I just comment, for the Assemblywoman's information? I sat in on a Committee hearing the Insurance Committee had one morning in Trenton, and a resident was there to testify. She had a problem with her insurance carrier. She was very much into the late stages of this disease, and her insurance company refused to cover her. They had to go to court and fight a court battle.

Unfortunately, because of the delay in her treatment, this poor woman actually had brain fever, lost her sight -- thank God, it was only temporary -- and went through some very, very serious matters before it was finally resolved. But that delay in her treatment, because she had to fight her own insurance company, probably has left her physically damaged for life.

ASSEMBLYWOMAN FORD: And it probably enhanced the cost of her treatment as her disease became more complicated down the road. I think if we can identify it early on -- as many of the people will indicate here this morning -- we can minimize the cost and minimize the pain, more importantly, of the person who is exposed to it.

Thank you.

ASSEMBLYMAN OTLOWSKI: Thank you very, very much. May we have Assemblywoman Clare Farragher? Good morning, Assemblywoman.

A S S E M B L Y W O M A N C L A R E M. F A R R A G H E R: Good morning, Chairman Otlowski and members of the Committee.

ASSEMBLYMAN OTLOWSKI: I don't want the Committee to be frightened by everything they see in front of you there.

ASSEMBLYWOMAN FARRAGHER: Visual aids, Mr. Chairman.

ASSEMBLYMAN OTLOWSKI: She's not going to read all of that.

ASSEMBLYWOMAN FARRAGHER: No, definitely not.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Pardon me, sir. Would it be possible to get the volume up a little bit for the benefit of those who are slightly hearing impaired?

ASSEMBLYMAN OTLOWSKI: I am not the engineer here.

UNIDENTIFIED SPEAKER FROM AUDIENCE: We can't hear you. (brief discussion about microphones)

ASSEMBLYMAN OTLOWSKI: How is that? Is that a little better?

UNIDENTIFIED SPEAKER FROM AUDIENCE: That's better.

ASSEMBLYMAN OTLOWSKI: Yeah, okay. Assemblywoman Farragher?

ASSEMBLYWOMAN FARRAGHER: Mr. Chairman, I have asked the public health officer for the Freehold Area Health Department to please come and join me today. He is here, and his name is R. Chadwick Taylor. May he come up, please?

ASSEMBLYMAN OTLOWSKI: Yes.

ASSEMBLYWOMAN FARRAGHER: Mr. Chairman, I want to thank you very much for holding this hearing here in the heart of Lyme disease territory, because so many of the people who are afflicted with Lyme disease do not have the energy to travel to Trenton to spend any time out there waiting around to testify before a committee. I want to commend you for that, and also for holding a public hearing on something that I have been trying to bring to the forefront in the State of New Jersey for almost two years.

In 1987, I met with two women who had founded a support group that runs on the first Wednesday of the month at Monmouth Regional High School. Both of these ladies expressed the need for some recognition in the State Department of Health that Lyme disease is a major public health problem in New Jersey. Because it was at the close of a term, Senator Gagliano and I decided to wait until the new session started in January 1988 before proceeding with the legislation.

That bill did pass both Houses of the Legislature. It appropriated $310,000 to the Department of Health for Lyme disease programs. I prefiled that bill this year. It is A-2249 and it is in this Committee. Before I prefiled it, I checked with the Department to make sure that $310,000 was still a good number in terms of what they would need to accomplish what they had set out to accomplish. They say that, indeed, that was a good number.

Since the fiscal constraints of the State caused the first bill to be conditionally vetoed by Tom Kean when he was Governor, with the message that it please be included in the 1990 budget with all of the other priorities and concerns of the State, I attempted to have that done by budget resolution last year. Unfortunately, it was not considered. It was caught up in the Christmas tree syndrome, which we legislators know well, and by omission, it was left out. So I went ahead and prefiled the bill and we have been moving along as best we can without that.

One of the things I attempted to do this year-- I attempted to get the State Department of Health to include Lyme disease in their narrative of goals and objectives. AIDS is in there, heart disease, cancer; all serious concerns. Lyme disease is not mentioned anywhere. Even though the State Department of Health has an excellent test -- they can find Lyme disease in a tick quicker than they can find it in a person -- it is not a separate item in the budget. It is included in the budget for Communicable Diseases, I do believe.

This pile of papers and folders you see here represents the accumulation over the past three years of information from scientific journals, articles from newspapers, and correspondence from victims of Lyme disease, and it has been greatly reduced. What I have in here are the copies of signatures and addresses of people who, this past May, signed a letter which I had written to the Governor. Almost 4000 people

signed the letter, asking the Governor to please consider including a line item of $310,000 in the State budget for Lyme disease, and to please recognize it as a problem in the State of New Jersey. Really, if everything were in here, it would be this high (demonstrates), but we have several on a page.

Putting that aside for the moment, I would like to address the concerns in terms of where the tick is. It is everywhere. The fact is, it is spreading out from the original endemic outbreak, which was the Earle Naval Weapons Station. It has radiated out from Earle. You will find a lot of cases clustered around the Earle Naval Weapons Station. In fact, on Wednesday of this week, I spoke at Earle. I asked how many people there had Lyme disease out of the 91 who were in attendance, and several hands went up. When I said, "How many people know someone with Lyme disease?" virtually every hand went up.

Farmingdale: It is estimated that probably over half the population of Farmingdale has, or has had Lyme disease. Howell Township, Freehold Township, Neptune, Ocean, Jackson, Freehold Borough-- I could go on. The numbers of cases here are absolutely incredible, and they don't all show up because they are not all reported. The misdiagnosis is incredible. The rate of mistaken lab tests is extremely high, which is why we need the Health Department to get involved in working on a good definitive test.

I, myself, had two negative tests. I was in the hospital with very serious neurological problems in 1988, before I showed a positive Lyme test. The original test had been done on me twice, and was done on me again this May when I collapsed with an encephalomeningocele syndrome caused by Lyme disease and was hospitalized. That same test still says that I do not have Lyme disease, even though spirochetes have been found in my spinal fluid, and I do have the characteristic brain lesion caused by Lyme disease. The need for a good

diagnostic test is important. More important than that, is a clinical diagnosis by a doctor who is familiar with the symptoms of Lyme disease and the fact that many of the conditions that appear are red herrings and, in fact, what a patient is suffering from is not necessarily arthritis or MS or lupus or any of the number of other diseases, but is, in fact, Lyme disease.

I would like to comment a little bit about some of the pending legislation and on the importance of, in particular, the health insurance bill that Assemblywoman Ford has in. To give you an example, medication for me for one week in September, $3021. Now, when I say medication, that also includes all of the associated equipment necessary to sustain a home therapy program. The Assembly members, and probably some of the committee aides, have seen me in Trenton with my IV pole at times, and at other times with a computerized infusion pump.

I am fortunate. I am able to function. All I need is someone to drive me. But I am able to work and keep up with my duties. Other people are not so lucky. I know people who have lost their jobs and, yes, even their homes because of Lyme disease and the extraordinary costs of it. Depending on the kind of medication you need, the costs can vary.

I had a treatment in 1989 for 35 days. Medication and the equipment necessary to administer it once a day, $7000. Well, who pays for all of that? In my case, the New Jersey State Health Benefits Plan. Were I to add up all of the costs for the MRIs, for the CAT scans, for the x-rays, for the EEG, for the doctors' visits, for the blood work, for the medication, for the nursing visits at home, my medical bills, out-of-pocket and insurance combined, would probably be well over $150,000 just in the last two years. I am not going to even mention the year-and-a-half I spent trying to figure out what was wrong with me.

Is there a serious problem in the State of New Jersey? You bet! It is a serious problem for the health insurance community because the people who normally pay premiums and stay healthy sustain those who are ill. It is a balance. The people who normally would be walking around perfectly healthy, perfectly fine, with maybe one checkup a year from their doctor, are now drawing from the funds of the health insurance companies at a phenominal rate. It is no wonder the health insurance companies are now beginning to look at this. I understand that in Connecticut, the Blue Cross and Blue Shield plans have now said -- or earlier this year said, before they will consent to pay for Lyme disease treatment, there must be evidence of a tick bite, a bull's-eye rash, and a positive test.

Ladies and gentlemen, I had none of those things. So if that was the requirement, these medical bills would not have been paid by the insurance company. To give you a further idea on costs, I have here an IV tubing. I have gone down now-- I get treatment three times a day. I am down to reusing these, because each one costs $75. There are all kinds of equipment required for home treatment: the needles you need to put on the end of the IV tubing, and alcohol swabs to clean the heparin lock which is installed in your hand. Unfortunately, at 3:00 this afternoon that is exactly what is going to happen to me again, for one more week, bringing the total number of days that I have been on IV treatments since January of this year to almost five months, just out of this year alone, not to mention the oral antibiotics I have taken.

Much has been said about where the tick is, and who gets it, and how they get it. In the case of a new development -- and Assemblywoman Ford has a bill that would require developers to treat those areas-- I would like to ask Mr. Taylor to speak a little bit to that, because absent State action on Lyme disease, some things were done in Freehold Township that I would like him to tell you about.

ASSEMBLYMAN OTLOWSKI: May we have your name for the record, please, and the position you hold?

R A Y M O N D C H A D W I C K T A Y L O R: Yes, sir. My name is Raymond Chadwick Taylor. I am the health officer for western Monmouth County. I provide health services for Freehold Township, Freehold Borough, Millstone Township, and Upper Freehold Township. We share with Howell and Jackson Township as probably being one of the most dangerous spots in New Jersey, possibly in the United States, for the incidence of Lyme disease. That is unfortunate, but we have also been very fortunate to have the cooperation of the State Health Department and Assemblywoman Farragher, who has been very instrumental in getting a lot of impetus toward developing the different programs that I am about to discuss.

We have obviously been to all of the different schools and civic organizations. We have slide shows. I, personally, have talked to probably 5000 or 6000 people over the course of the last two years. But that is pretty much to be expected of any public health department.

What we have also done is-- We have been working with Dr. Terry Schulze from the State Health Department, and we have come up with a study -- it's a matrix -- where we assess the potential and real risk of Lyme disease at selected sites throughout western Monmouth County. This included schools and parks that are municipally owned. We broke it down into two parts. We rated them for potential of transmission. We rated the habitat, the accessibility of the public, and the amount of the habitat.

Then we went a step further. We assessed the real threat of Lyme disease. By doing that we actually went walking through these areas with full suits on, and we would count, after a period of time, how many ticks we had collected. You could walk through a certain area and possibly pick up 20 or 30 ticks in a period of, like, 20 minutes. We would then also dissect these--

ASSEMBLYMAN OTLOWSKI: Excuse me. What is the Department doing by way of trying to eliminate the tick population?

MR. TAYLOR: Okay, then I will skip ahead to that a little bit. We are very skeptical about calls we get from people who would like to have their lawns sprayed. It is pretty well established that the deer tick does not really favor living on lawns. As a matter of fact, it is a very wet and slobbery type creature that does not like living on lawns. As soon as the sun hits it, it will desiccate and dry out. It really much prefers the understory of the woods where it is moist.

So, spraying a lawn is really not the answer. It is really not that cost-effective. Spraying in parks doesn't really do that much good because you are going to get this very fine mist all hung up in the leaves of the trees. The problem is really down in the understory in the leaf litter where the deer tick, the nymphs, and the larvae, actually live. It has been established that most of these cases of Lyme disease -- probably, I think, 30% of them -- come from the nymph, which is much smaller. We have heard about the smallness of the deer tick. The deer tick itself in the adult stage is fairly easy to see, but the nymph is virtually the size of a poppy seed. Because of its small size, it can be much more dangerous. It is also dangerous in that it lives down in the leaf litter, where sprays really do not get to.

Last year, we were able to work with the State Health Department, with Dr. Schulze. We were able to get a granulated diazinone and granulated carbryl, which when applied through, like, a fogging machine, was able to go through the trees and down into the leaf litter. Now, prior to this application, we went out on several occasions and trapped mice. We trapped them over a period of two weeks. We etherized them, and we counted the number of larvae and nymphs on each mouse. After

the application, we went from an average of about 2.3 ticks per mouse down to zero. It was virtually 100% effective.

The only hang-up with this was that we found out at the eleventh hour before we were going to do this, that this granulated diazinone and carbryl were not permitted for aerial use. The Monmouth County Mosquito Commission was all ready to use a helicopter to distribute this, but we were informed by Fish and Game that this was not allowed.

So, the study we did was very instrumental, in that we will possibly get that -- or will work toward possibly getting that aerial application permitting.

ASSEMBLYMAN OTLOWSKI: Let me say this: I have people here from the State Health Department I want to testify to get some greater detail. I am going to have to limit you to the testimony you have given so that I can hear from them. But the interesting thing about your testimony is the prohibition to do something that is effective.

Is there anything else, Assemblywoman?

ASSEMBLYWOMAN FARRAGHER: Yes, Mr. Chairman, just to sum up. You are going to be hearing from many more people who will detail problems which are even more serious than mine. I would like to mention also that someone who is very close to your side of the aisle, Assemblyman Byron Baer-- Byron's stepdaughter has a very serious case of Lyme disease. It has caused her to have to drop her career goal of being an attorney -- I hate to say down to being a teacher; I don't mean it in that way -- but she has had to change her plan of study at Rutgers University. She has also been assigned to handicapped housing and, unfortunately, has to walk with a cane. While they live in Bergen County and she attends Rutgers up in Middlesex County, believe it or not, she is treated by my doctors in Neptune. I can't say enough about the Jersey Shore Medical Center, the doctors associated there, and the work they have done for Lyme disease.

I thank you for this opportunity to come once more to speak out. I, of course, have stuck my neck out now for almost two years on a personal level, because one of the things I was told, politically, was, "Don't let people know you're sick." I said, "Hey, this is something that an awful lot of people have, and if I can turn my misfortune to someone's good, I fully intend to do so. I won't quit."

Thank you.

ASSEMBLYMAN FELICE: Mr. Chairman?

ASSEMBLYMAN OTLOWSKI: Asemblywoman, will you please stay there? Assemblyman Felice?

ASSEMBLYMAN FELICE: Mr. Chairman, if I may, I would like to commend Assemblywoman Farragher for the ordeal she has been going through, and for the information she has supplied us as a legislative group, and also individually. When I look at this map here, it shows that there is nothing up in my area. As you mentioned, we know of two or three cases personally.

I think the main gist of our legislation is the fact that the education and prevention and treatment are really, how should I say it, ambiguous to many people in the communities. Most local municipalities have enough problems, naturally concerning themselves with financial and other matters, garbage, and so forth.

But more and more they are beginning to realize internally that they have this problem, and I think this type of legislation to provide that kind of a program is very commendable. I really, more than ever before in the last couple of months, have realized how much this is affecting our areas in the northwest part of the State. If you look at the map, it doesn't show anybody there, but we know from just personal experience that there are six or seven people in our own home communities.

I thank you for the information you have given us, and for taking the time to appear here today.

ASSEMBLYWOMAN FARRAGHER: Mr. Chairman, just to touch on that for one moment-- As important as the education of children, schools, and the public at large is, there needs to be a better awareness among doctors. I had a call from a man who lives in Elizabeth, New Jersey who had all the classic symptoms of Lyme disease. He went to his doctor in Elizabeth and the doctor said, "There is no Lyme disease in Elizabeth, New Jersey. You can't have Lyme disease." However, the man, who is 72 years old, failed to mention that he is a hunter. He did have Lyme disease. I sent him back to his doctor. I said, "Go right back and tell him that you are a hunter, that you crawl around in the bushes all the time, and it is possible."

So, there needs also to be education for doctors. I have contacted the Medical Society of the State of New Jersey and let them know that there is a lack on their part, and that they need to do some education of their members.

Thank you very much.

ASSEMBLYMAN OTLOWSKI: Assemblywoman, thank you very, very much.

May we have Dr. Marc Lory, from the University of Medicine and Dentistry of New Jersey? Doctor, I am doing this because it is my understanding that you have to be back by 12:00. If you are brief, you'll make it. All right?

D O N A L D B. L O U R I A, M.D.: Yes, I appreciate it. I want to thank you for letting me appear here. I have just a small number of points that I think are worth making.

We all know that Lyme disease in this State is, of course, a major problem. I'll tell you the other side of the coin in balancing the issue: Clinicians are being faced not only with an increasing problem with the disease itself and its complications, but also with what amounts to substantial community anxiety and panic over it, which makes it very difficult from a diagnostic point of view. Now, I know everybody here is aware that the early manifestations relate to the skin. The arthritis can occur years later.

ASSEMBLYMAN OTLOWSKI: Excuse me. Am I correct? Are you Dr. Marc Lory?

DR. LOURIA: No, I'm Donald Louria, Chairman of the Department of Preventive Medicine.

ASSEMBLYMAN OTLOWSKI: For the?

DR. LOURIA: For the UMDNJ.

ASSEMBLYMAN OTLOWSKI: All right. Are you representing him?

DR. LOURIA: No, I'm representing me.

ASSEMBLYMAN OTLOWSKI: You're speaking for the University of Medicine and Dentistry?

DR. LOURIA: Sure. I am Chairman of the Department of Preventive Medicine.

ASSEMBLYMAN OTLOWSKI: Do we have your name correctly, Doctor?

DR. LOURIA: I don't think you do. It's: Dr. Donald Louria, L-O-U-R-I-A. I chair the Department of Preventive Medicine. Marc Lory is the administrator of the hospital.

ASSEMBLYMAN OTLOWSKI: Oh, I see.

DR. LOURIA: I doubt that he would be testifying on Lyme disease.

ASSEMBLYMAN OTLOWSKI: Did Dr. Leon Smith of St. Michael's Medical Center talk to you?

DR. LOURIA: Yes, he did.

ASSEMBLYMAN OTLOWSKI: All right.

DR. LOURIA: He and I work together.

ASSEMBLYMAN OTLOWSKI: Go ahead, please.

DR. LOURIA: The manifestations of Lyme disease, as you well know, can appear years later. I think one thing that has not been stressed is that there is concern about pregnant women. In one study of 19 pregnant women infected with Lyme, five had very bad birth outcomes, including congenital defects, fetal death, abortion, and severe congenital abnormalities.

I think in looking at the problem from our point of view, there are four groups. I think everybody has to understand that there are these four groups. Group one are those who have a clear-cut clinical disease and a positive blood test for Lyme. There, there is no question at all about the diagnosis.

The second group are those who have clinical disease where they have the skin lesions, they have the history of a tick bite, but their blood tests are negative. Now, there are two problems in that: One is that early on when you get the skin lesion, you frequently have a negative blood test. The second is that the blood tests are far from ideal and there can be false negatives; that is, people have the disease, but they have a negative blood test. So, under those circumstances, good clinical history, negative serology, the treating doctor should depend on the clinical picture, not on the blood test.

Then there is group three, and it gets more tricky. Group three are those who have poor clinical evidence of Lyme, no good history of tick bite, no good skin lesions, and a positive serology. Those people invariably get treated, but the fact of the matter is, there are a fair number of false positives in the serologic tests. So a lot of those do not have Lyme disease. What we tell them is, if you don't have a good history but you have a positive blood test, you get treated once. If the treatment does not improve you, you should go to another diagnosis.

Now, what's happening is, as community anxiety increases and the severity of the problem increases, there is a larger number of people in group four. Group four are those who have poor clinical histories. Most of them suffer from lethargy, fatique, headaches, aching muscles, aching joints, a poor clinical history, and a negative blood test. The evidence now is that the overwhelming majority of those people do not have Lyme; did not have Lyme; will not benefit from treatment;

may be hurt by treatment; and the true diagnosis may be delayed because of the focus on Lyme.

That is the issue we all face from the clinical point of view. One, a bad problem with a lot of Lyme disease in this State; an increasing problem, and also an increasing number of people who are afraid they have Lyme, but do not have it. It is costing them an enormous amount of money for treatment of non-disease. And we have not sorted out that issue.

Now, you just talked about spraying. Spraying, obviously, would be nice if it would get rid of the ticks. I think everybody in this room realizes it is not just the little deer tick. There are multiple ticks that can carry the organisms. Now it's big ticks, little ticks, and you cannot feel particularly safe if the tick you pull of is a big tick rather than a little tick.

Because spraying has not yet proved to be persuasively effective, for the reasons you just heard, and because there are going to be ecological concerns about the kinds of sprays we use, it is still up to the individual. There is an awful lot we can do with education. Perhaps you have already heard that here today, and you certainly will later; namely that the people who go into areas where there are ticks-- I live in an area where there is that type of a problem. It really makes sense to wear long sleeves, and make sure that the long sleeves are closed at the wrist. Wear pants that you can tuck in. After you have been in an area, as soon as you can, take a shower. Look for ticks, particularly in the hair. When you do find them it really is easy to remove them with a tweezer, realizing that if they are not engorged, then they haven't eaten and they are not a danger to you.

In places other than that, we do have insect repellents and they do work. So, if there is good education, people can do a lot toward preventing the disease themselves. It is absolutely clear that people are not being educated

effectively in that regard, and if they are, they are not following the educational precepts that could help them to prevent the disease.

Now, I was asked in coming down here to talk a little about what I thought might be done at the State and local levels. You are going to hear from the people in the State Health Department. I'll just make several points about how the money might be used if it is appropriated.

What we need in this State, and we do not now have, is not so much investigations of better techniques for doing serology. It is true, we do need that, but there are groups that are very well funded all over the country doing that, looking for improvements on the Elisa test, on the Western Blot test. So I think that might be a long-term proposition, getting the expertise to compete against the other groups that are doing it. But I know one thing we do need in this State, and we need it badly, and the State Health Department is in an ideal position -- nobody else is -- to do it; namely develop a reference serologic laboratory for the State.

As you have already heard, one of the big problems is with the serologic test. Now, we do have some good labs in the State. Roche is good; MetPath is good. But a lot of people are not getting good blood tests, and the State could do a marvelous service by serving as a reference laboratory with a highly credible test. If somebody has either a positive or a negative test, but they appear to have the disease on the one hand, or they have a positive test but you are not sure of the disease on the other hand, you could refer this to the State for final judgment.

Second, it seems to me that the State, if it is given the money, can conduct much more extensive epidemiologic tests -- and we very badly need them -- so we can know exactly what the Lyme burden is and, more importantly, how much we have of the subtle disease. That we do not know in this State.

Third, I think the State Health Department could very well take a major role in looking at the effects of Lyme disease on pregnant women. Clearly, that is going to be an increasing problem. If a pregnant woman is bitten by a tick, if she gets Lyme disease, she has to be treated early. I am afraid the fact of the matter is, even early treatment is no absolute guarantee that the baby will be normal. But surely we need more studies in this area, and I think the State Department could do a very effective job in doing that.

In regard to local health departments, you have already heard that they are doing a lot. Obviously, we need more education. We need more education about exactly what the nature of the disease is. I think that could be done much more effectively if more money were made available and, as you have heard, it is not only the public that needs the education, but in addition the medical profession. Local health departments could do a marvelous job in keeping local physicians up-to-date on the rapidly expanding literature.

So I think there is a major role to be played both at the State and local levels. Funds available for those purposes could be used very effectively.

I would like to end with, again, the word of caution I started with. Where I am, which is northern and central New Jersey-- Actually, I am President of the Infectious Disease Group in that area. These are the people who daily have to face the issue of Lyme disease. So I can reflect our problems. Our problem number one is that we are seeing more of it. The diagnosis can be difficult. But our problem number two, is that we are seeing more and more and more people referred to us with a vague disease, with no good history that suggests Lyme, with negative serologies. They are importuning us to treat them, even though we are absolutely convinced they do not have the disease.

So on the one hand we have to face the problems, appropriate more money, work on prevention, and the other things I have talked about. The other thing is, we have to avoid public panic about the Lyme problem and place it in perspective. I would remind you that we have recently just been through a period of the chronic fatigue syndrome with Epstein-Barr virus, the virus of infectious mononucleosis, in which people were getting all sorts of treatments because everybody said the chronic fatigue syndrome was due to the EB virus, even though the data were flimsy.

Now we know that there is no such thing as EB virus related chronic fatigue syndrome as of now. Maybe we will have better data a year from now, but as of now this disease, which we all talked about and we all tried to treat, does not exist. We do not want that to happen with Lyme disease. We want those who need better diagnosis, better treatment to get it. We want to get a good handle on our problem. We want to appropriate the money we need, focus on prevention, education, and the studies I have talked about, but avoid public panic that results in misdiagnosis and delay in the proper diagnosis because we are focused on the wrong disease.

ASSEMBLYMAN OTLOWSKI: Doctor, thank you very much.

I just have to deviate for a minute, because I am told that some of the children who are with Peggi Sturmfels are not feeling well. I want to put Peggi on.

Doctor, thank you very, very much. I really appreciate your testimony.

DR. LOURIA: You're welcome.

ASSEMBLYMAN OTLOWSKI: Peggi, is this young lady the lady we want to hear and get her out of here as quickly as we can because she is not feeling well?

P E G G I S T U R M F E L S: Yes. She recently got out of the hospital, I believe -- yesterday?

L Y N N H U N T E R: Wednesday.

MS. P. STURMFELS: Wednesday. She has had a really bad bout this past week.

My name is Peggi Sturmfels. I am the Legislative Chairperson for New Jersey PTA, and I am also a member of the Central Jersey Lyme Association. I have that backwards, and I do that a lot lately. And also the Lyme Disease Coalition of New Jersey.

One of the things I want to do is apologize to the press. We need to have an active role from the press in this, but one of the problems with this disease -- especially in Lynn's case and some-- The deterioration of the eyesight and the problems we are having with our eyes have caused us to ask them to please remove the lights. That has caused a problem here this morning. That is why we were sort of a little bit crazed.

Lynn does not have a prepared statement, but she could certainly answer some questions for you.

ASSEMBLYMAN OTLOWSKI: Peggi, do you have a prepared statement?

MS. P. STURMFELS: No. I am going to turn over the prepared statement by the child over here. I do want to tell you that our Association numbers 236,000 members in the State of New Jersey -- the New Jersey PTA. At the beginning of this year, in an effort to educate our membership and the parents of this State, we sent out information to every local unit on Lyme disease, with information also for schools to put up on how to identify the tick and the rash and the symptoms. We have also spoken with Commissioner Dunston, and we will continue to do mailings through our local unit to get information out to the parents.

One of the things I would like to talk to you about, though, today, is the impact of Lyme disease. We are concerned about the--

ASSEMBLYMAN OTLOWSKI: Peggi, excuse me. Just so I get the record cleared up here, do we have the name and address of this young lady you are making reference to?

MS. P. STURMFELS: This is Lynn Hunter.

ASSEMBLYMAN OTLOWSKI: Would you let us have that for the record, please?

MS. P. STURMFELS: Lynn, do you want to give your address?

MS. HUNTER: Two Jackson Mills--

ASSEMBLYMAN OTLOWSKI: We're not picking you up, honey. Will you please speak into the microphone?

MS. HUNTER: Two Jackson Mills, Township of Jackson, New Jersey 08527.

ASSEMBLYMAN OTLOWSKI: All right.

B L Y T H E S T U R M F E L S: I am Blythe Sturmfels, 297 Ambassador Street, Jackson.

ASSEMBLYMAN OTLOWSKI: Blythe, do you have a prepared statement?

MS. P. STURMFELS: Yes, you have that, sir.

ASSEMBLYMAN OTLOWSKI: Have you submitted it here?

MS. B. STURMFELS: Yes.

ASSEMBLYMAN OTLOWSKI: Do the members of the Committee have the prepared statement?

MS. MILLER: Yes, they do.

MS. B. STURMFELS: My name is Blythe Sturmfels. I am 17 years old and a Lyme patient. For the past four years I have been sick. I was not diagnosed until two years after I had been sick. I was out of school most of my freshman year in high school and most of my junior year.

It was two years before I was diagnosed. Before that, I was an equestrian. I competed in dressage and combined training. I was on my way to fulfilling my dream of becoming an Olympic hopeful. I had the gift, so they said. My heart is still in it, but the energy and strength aren't. Since I was diagnosed, I have not seriously been on a horse. I have tried

to make my way back to being the best that I was, but every time I start I get set back because I don't have the energy or the strength. I couldn't sit there and watch because it wasn't me. I used to be able to ride four or five horses a day, but now I am lucky if I can make it through an hour riding lesson.

That gets me even more angry, because now I am not affected just physically, but emotionally, too. The way I see it is, I am 17, and I have everything going for me except for my health. Well, that is supposed to be the most important thing in your life. I am supposed to be going away to college next year. I am scared. What if I get sick? There goes all the tuition money my parents and I worked for; gone, because treatment runs about six weeks, and I have to be near a hospital that is familiar with the disease.

Everything in your life is affected -- your friends and your basic social life. My school work is affected, too. I am not pulling the grades to make it into the college I want. Missing school has caused me to miss classes which would have helped me to score decently on the SATs.

Your family is also put on hold, because one of us needs more attention than the other. Your whole life begins to revolve around this disease, but there is nothing you can do about it. After a while it begins to bother you, but there is your future because there is no cure. So you learn to live with it.

Someday I will get better. I will start to ride again and I will be good again, I hope. Life goes on. You can't let it get you down. I did, and it was the biggest mistake I ever made. Someday I will be in the Olympics. That is my dream, the dream I am going to live out with or without this disease. Just don't let it get you down. Fight it; it helps. Maybe, just maybe you can beat it, or there will be a cure. I hope it happens soon because this disease is way too expensive, and a major pain.

Thank you for letting me speak to you today.

ASSEMBLYMAN OTLOWSKI: Thank you. Peggi, did you want to add anything else?

MS. P. STURMFELS: Yes. Sir, one of the problems we have seen in the school districts is that the ability of these children to function in school, even on the days they are there, is so limited that they are having a major problem being successful in school. Part of that now is going to be reflected-- If we do get them recuperated, if we do get them well, their lives have changed so much that they are now, for the next three or four years-- This will affect them in their college and career choices, and, really, well into their early 20s.

Lynn has been out of school. She hasn't been to school yet this year. She was out of school last year much of the time, but she did make it to graduation and we were really--

ASSEMBLYMAN OTLOWSKI: Excuse me. Is she getting special tuitoring?

MS. P. STURMFELS: Yes, she is, sir, but part of the problem with the disease is that either you are so ill-- There is a lot of confusion with this disease. There is a lot of disorientation. Your short-term memory is affected. Your eyesight is affected. My daughter has stood in the middle of the hallway in school at her locker and not known where she was. This is a major problem, on days that you are able to get out of bed.

So for us, in Jackson, we have been fortunate in that -- and I don't mean to say that I am glad our teachers have it-- But we are fortunate that we have had staff members who have been infected with the disease who have been able to translate the problems of it to their colleagues, so they have been very sympathetic and very helpful to our students. That is not the case across the State.

I am getting calls from all over the State, and from other states, because children are being classified -- are

being exempted from school. Part of our problem is the way we classify ill children. If you are a chronically ill child in this State, or under the special ed laws, you can receive home tuitoring, but sometimes we can get these children--

ASSEMBLYMAN OTLOWSKI: Excuse me. The home tuitoring, you just said a moment ago, is totally ineffective--

MS. P. STURMFELS: Sometimes. Sir, sometimes it is ineffective if the patient is very sick.

ASSEMBLYMAN OTLOWSKI: Yes.

MS. P. STURMFELS: But then there is the matter of trying to catch these children up, where we can get them home tuitoring. Oftentimes, that takes 10 days to start. They have already missed 10 days of school, then they have two days of home tuitoring. Then they are sick again, and they can't even have that. When they come back to school, the home tuitoring stops. They are now in school, they are really behind, and then they end up in the hospital or back home again within three weeks. Then you have to wait another seven to 10 days to start the home tuitoring again. We need to develop a program that meets the chronically ill child's needs.

ASSEMBLYMAN OTLOWSKI: From an educational point of view, how are you going to cope with the intermittence of the disability -- the total disability that takes place?

MS. P. STURMFELS: It is very difficult. What some of the children do now, especially at the high school level, is drop classes. Then they end up in their junior and senior years far short of what they need to graduate high school.

But what we can do is allow a system where there can be supplemental schooling in the daytime and home tuitoring. There can be half-day schools for children who can attend for a few hours a day, and then have supplemental. But we need to be allowed to cross those different little boxes and categories that block children into one way of learning and one way of receiving services. There is a myriad of services out there,

and we need to be able to establish a cooperative effort between the Department of Health and the Department of Education to meet the needs of these kids.

I thank you for your time.

ASSEMBLYMAN OTLOWSKI: Thank you very, very much.

MS. P. STURMFELS: If you would like the members of the Committee to ask Lynn questions--

ASSEMBLYMAN OTLOWSKI: Assemblywoman Mullen, do you have any questions?

ASSEMBLYWOMAN MULLEN: I just want to ask one question. I am curious to know just what happened when you first became ill and how the doctors handled you, because I keep thinking about my niece who-- First they decided to grind her teeth, and when that didn't work -- they thought that was causing her headaches -- her family was told to have braces put on her. And, of course, that didn't work. She went through so much before a neighbor, who was a doctor from Spain, actually alerted her parents.

What happened to you when they were trying to find out what was wrong?

MS. B. STURMFELS: I was diagnosed as having Epstein-Barr virus. After two years of being off and on medication for Epstein-Barr virus, my parents took me to a different doctor and he tested me for Lyme disease. My blood test came back negative/positive. Then they ran the urine test and my (indiscernible) was very high. They just kept telling my mom that it was all in my head.

ASSEMBLYWOMAN MULLEN: That is exactly what this child was being told by the doctors when she persisted that she had terrible headaches. How sad. I am so sorry. I wish a full recovery for you.

MS. HUNTER: I had the rash, I guess, two years ago, and then they tested me. I had the symptoms of Lyme disease so they tested me for it. All of the tests came back negative.

So they just treated me for the headaches and the joint pains and losing my concentration.

ASSEMBLYWOMAN MULLEN: Thank you for sharing that.

ASSEMBLYMAN OTLOWSKI: Assemblyman Felice?

ASSEMBLYMAN FELICE: The different problems, both medically and, of course, emotionally and educationally-- It is important to be able to give them as much help as possible. It is a great support to them when they are feeling ill but yet want to keep up with their school work.

I think early recognition is one of the things that will have to be a major part of the program, to avoid the stages you get into because you are not diagnosed quickly enough. Also, we should look into programs on the educational level. Today, with some of the technology available-- You may not be up to par to have to have a tutor come in and work with you, but some of the closed circuit systems we have from classrooms today, where they can actually put the video and audio through a telephone line, might be a thing for not just students of your category, but for any child who has an illness where he or she is kept from participating in the classroom. They would be able to absorb at least some of the education that is going on. Those are the things that the Education Department of the State will have to look into, too.

I'm sure that some day you will be in the Olympics and I will watch them put that gold medal on you. I hope it works out for you very soon -- both of you.

ASSEMBLYMAN OTLOWSKI: Thank you; thank you very, very much. Obviously, you have been very helpful. I'm sure your appearance here is going to make a contribution.

I want to get to the younger people who are here who want to testify, but I want to call upon the State Health Department first. Then I will be able to get to you. Dr. Parkin, please.

A S S T. C O M M. W I L L I A M E. P A R K I N: I am Dr. William Parkin. I am the Assistant Commissioner for Epidemiology and Disease Control. Most of the Department of Health's Lyme disease activities have been from my Division. The Department gave you prepared testimony that I will simply skim over very quickly, hitting the high points rather than reading the entire testimony.

Lyme disease has been a reportable disease in New Jersey since 1980. The first case we know of occurred in New Jersey in 1978. At the current time, we, this year, will have over 1000 cases of Lyme disease reported and accepted as Lyme disease, by the Health Department in New Jersey. Just 10 months into the year, we are almost at 1000 cases already. Every year since 1980, when it became reportable, we have had more cases of Lyme disease reported to the State. New Jersey currently ranks third in the United States for the number of cases of Lyme disease occurring within its jurisdiction.

There are two ticks that we know of in New Jersey that--

ASSEMBLYMAN OTLOWSKI: Doctor, excuse me.

ASSISTANT COMMISSIONER PARKIN: Yes, sir?

ASSEMBLYMAN OTLOWSKI: Why should we be third?

ASSISTANT COMMISSIONER PARKIN: We would be third because other states simply have reported more cases. New York State-- Just give me a second here (looking through his papers). I do have the figures pulled out. New York State, between 1986 and 1989 reported 7220 cases of Lyme disease. Over the same time period, Connecticut reported-- Whoops! I dropped down one line too low. This says we were second over that four-year period. Connecticut reported 1351 cases. New Jersey over that time period reported 1656 cases -- over that four-year period. It is simply what physicians report to us as having been diagnosed as Lyme disease.

We know that in New Jersey we do not get complete reporting. The most conservative estimate is-- Perhaps we hear about 50% of the cases, but there have been a couple of informal surveys conducted that indicate that there may be five to 10 times as many cases of Lyme disease actually occurring in this State as are reported to us. So we know that the case count we have is low.

ASSEMBLYMAN OTLOWSKI: But we're still in third place in the nation?

ASSISTANT COMMISSIONER PARKIN: The notes that were prepared for me by my staff said "third place," but the list they gave me here shows us second in the nation.

ASSEMBLYMAN OTLOWSKI: Second in the nation?

ASSISTANT COMMISSIONER PARKIN: Second in the nation over the period 1986 to 1989.

ASSEMBLYMAN OTLOWSKI: Is there something peculiar about New Jersey that we should be second in the nation?

ASSISTANT COMMISSIONER PARKIN: I think it is the environment in which we live. It is the disease itself and where the disease normally occurs. The disease is not normally a disease of man. The spirochete that causes Lyme disease normally lives, from what we believe, in the white-footed mouse. The coastal plain in this area is definitely an area where the white-footed mouse lives. So we are becoming accidental victims, if you will, of an organism that normally is found in the white-footed mouse. This same coastal plain, basically, goes up through New York State, Connecticut, Rhode Island. That is still the same environment in which this specific animal lives.

ASSEMBLYMAN OTLOWSKI: The western states, the interior of the United States is more or less free of this disease? Is that what you're saying?

ASSISTANT COMMISSIONER PARKIN: No state is free, within certain limits. A couple of states have not reported

any cases yet, but only a very few. Nevada, Nebraska, and a few other states have not reported any cases, but there have been cases reported from virtually every state in the continental United States. In the early '80s, one of the states that was in the top five or six was Wisconsin. Wisconsin is obviously in the center of the country. Obviously in that area there are hosts for the organism that are satisfactory for it. We cannot say why some states have not reported many cases -- whether the disease is really not there or it has not been recognized.

One of the interesting things in the national data that has come up is, the State of Georgia for years had only reported two, three, or four cases. In 1989, suddenly they had 600-and-some cases. I cannot believe in that state, for example, that there wasn't any Lyme disease before 1989. It was not recognized as such. Physicians started identifying it.

In New Jersey we really don't believe that there has been a massive increase in the disease. There has probably been an increase in the disease, but just as importantly, we think there has been an increase in recognition of the disease by physicians. If a physician does not recognize Lyme disease as Lyme disease, he does not report it as Lyme disease. So probably there are two things going on here. There is, we believe, an increase in the range for Lyme disease in New Jersey, and probably the United States. Additionally, there is an increase in recognition of the disease.

ASSEMBLYMAN OTLOWSKI: Doctor, it was said here earlier -- I don't know whether Assemblywoman Ford said it or someone else while they were testifying -- about the possibility of the intensity of the disease existing in Earle, or the possibility of it coming from Earle. Is the State Health Department aware of that?

ASSISTANT COMMISSIONER PARKIN: The first cases of Lyme disease we were aware of came from Colts Neck, New

Jersey. A lot of interest went on, and Earle is close to Colts Neck. We did all of our early work at the Naval Weapons Station Earle. Four of us went there. I was one of the four at that time. We went out and did animal trapping, did tick collection, worked with the Department of the Navy and--

ASSEMBLYMAN OTLOWSKI: You worked with the Department of the Navy and the United States Health Department? Did I understand--

ASSISTANT COMMISSIONER PARKIN: The New Jersey Department of Health has done research with the U.S. Navy. I would say that for the first six or seven years we worked on Lyme disease, we worked primarily at the Naval Weapons Station Earle. The last two or three years, most of our work has been done at Fort Monmouth with the Army. So we have been working with them, yes, sir.

ASSEMBLYMAN OTLOWSKI: In the meantime, here in this area where there is such a prevalence of the disease-- Are you working very closely with the Health Department in this area?

ASSISTANT COMMISSIONER PARKIN: Yes. As Mr. Taylor indicated, we have been conducting a study on how to treat residential areas, etc. for Lyme disease. We have been working with Mr. Taylor in particular, and also representatives of the Ocean County Health Department.

ASSEMBLYMAN OTLOWSKI: Is there anything being done to enlist the help of the physicians in this area, to make them more aware, and to give them the benefit of better diagnostic approaches?

ASSISTANT COMMISSIONER PARKIN: To make physicians more aware? Every year since 1982, we have mailed to all licensed physicians in New Jersey a three-page letter on Lyme disease, describing the disease, trying to alert them that it, indeed, does exist. Additionally, we have given grand rounds, gone to hospitals and given presentations on Lyme disease. We have also spoken to several county medical associations over

the years on Lyme disease. So those types of activities have been going on.

Our laboratory and the people in my program have participated in two CDC -- Centers for Disease Control -- sponsored studies on the biological -- the serological tests for Lyme disease. So those have been the activities in that area, predominantly.

ASSEMBLYMAN OTLOWSKI: It is my understanding that the New Jersey School of Medicine in New Brunswick is the Lyme disease center for the State of New Jersey. Am I correct about that?

ASSISTANT COMMISSIONER PARKIN: They have a program there. I believe the title they use for the program is the "Lyme Disease Center." That program started, I think, about two years or so ago, when an individual came to the UMDNJ -- the University of Medicine and Dentistry of New Jersey -- from the original clinical Lyme disease program up at Yale University.

ASSEMBLYMAN OTLOWSKI: Do you know if they have been enlisted to look into this area here?

ASSISTANT COMMISSIONER PARKIN: Not into the tick control aspects. I know they are trying to do research into treatment, etc. for Lyme disease. That is an area of the disease that we really don't have expertise in. We don't treat individuals for Lyme disease. We are not thoroughly knowledgeable in that area.

ASSEMBLYMAN OTLOWSKI: What do you think of the suggestion that was made by Assemblywoman Ford about a $500,000 appropriation for research, to be made available to the State Health Department? What would that do? Would it do anything to get a better strike at this disease?

ASSISTANT COMMISSIONER PARKIN: I am not going to sit here and tell you that money to do research wouldn't be appreciated, couldn't be utilized. Any money that would become

available we could certainly utilize. Some of the areas where we would like to do more work would deal with the preventive aspects of the disease, research into prevention, which is what we are trying to do with Mr. Taylor in Freehold Township. Our State laboratory could do more work on diagnosis tests. We, the Health Department, could not do anything basically, I would feel, meaningful ourselves on treatment, but there are mechanisms such as health service grants, etc. that could accomplish that.

ASSEMBLYMAN OTLOWSKI: Say there was that kind of money available, where would be the best place to put that money so that the kind of research that is being contemplated here would get the best and most effective results?.

ASSISTANT COMMISSIONER PARKIN: I am a public health expert. I believe in preventing disease before disease ever occurs. Most of the people who are here testifying-- The young lady before me is at the opposite end of the spectrum. Disease has already occurred. I really believe that prevention is very important. I would think that both areas--

ASSEMBLYMAN OTLOWSKI: But, Doctor, wasn't there some testimony here today about the fact that there is difficulty in diagnosing; that a lot of times there is a misconception? Would research help to clear that up?

ASSISTANT COMMISSIONER PARKIN: There is no acceptable Lyme disease test -- one that I would consider an acceptable test. One that says if the test is positive, the person definitely has Lyme disease; if it is negative, they definitely do not have Lyme disease. Research is very needed there yet.

ASSEMBLYMAN OTLOWSKI: Doctor, as you indicate, if a test is not reliable-- As a matter of fact, if a test has not been developed, wouldn't there be a possibility that that could be accelerated if you had research money?

ASSISTANT COMMISSIONER PARKIN: Yes, definitely; definitely.

ASSEMBLYMAN OTLOWSKI: I'm sorry. I just wanted to develop some line of testimony from you. I just wanted to pick your brain for a moment.

ASSISTANT COMMISSIONER PARKIN: Well, frequently many people can't find my brain, I don't think.

ASSEMBLYMAN OTLOWSKI: I had no difficulty in finding it.

ASSISTANT COMMISSIONER PARKIN: I don't know. Do we want to turn this into a question and answer, or do you want me to--

ASSEMBLYMAN OTLOWSKI: Doctor, do you have anything else you want to add?

ASSISTANT COMMISSIONER PARKIN: Pardon?

ASSEMBLYMAN OTLOWSKI: Do you have anything else you want to add?

ASSISTANT COMMISSIONER PARKIN: I have already given you my prepared testimony, which you can read at your leisure.

ASSEMBLYMAN OTLOWSKI: Great. I just want to ask our Assemblypeople here on the Committee if they have anything to ask you. Assemblywoman Mullen?

ASSEMBLYWOMAN MULLEN: Just one question, Mr. Chairman: Doctor, if someone is bitten by what they think is a deer tick and he or she does the usual things -- remove it, cleanse it -- should they go for testing, or should they just wash it? What I am confused about is misleading signals. In some literature it says, "You will develop a bull's-eye rash." Others say, "You don't necessarily get that kind of a rash." I am just wondering, what should people do?

ASSISTANT COMMISSIONER PARKIN: That is a question that has commonly come into the Health Department. First, on the latter part of your question, I will state for the record, etc., that you do not necessarily develop the typical bull's-eye rash, so you cannot count on that. There is no point in going to be tested immediately. If an individual is

going to develop antibodies -- which is what you test for -- to Lyme disease, in all likelihood, even if they are not treated or anything, it is probably going to be six to eight weeks before the antibodies develop.

So, removing the tick today and rushing out to get your blood tested cannot be expected to show anything. What we normally recommend is that individuals be aware that they have been potentially exposed, and if they develop the rash, get immediately in to see a physician. If they start developing an obscure, if you will, disease and they can't figure out what is wrong with them, they don't feel right, etc., get to a physician immediately. A physician really cannot do that much for you at the point where you have just removed the tick. If you rush into his office, what is the physician going to do for you, other than be aware that if you become sick in the near future, that Lyme disease is one of the things that should be considered?

ASSEMBLYWOMAN MULLEN: I see. I appreciate that information personally. Is it valuable to save the tick?

ASSISTANT COMMISSIONER PARKIN: It could be. A tick isn't that hard to save. Many of us have small medicine bottle vials at home.

ASSEMBLYWOMAN MULLEN: I have mine in a little plastic bag here -- my husband's, rather.

ASSISTANT COMMISSIONER PARKIN: The one thing you would want to do is make sure the tick doesn't dry out. You can put the tick in a small medicine bottle with a small piece of paper towel that has been moistened with a drop of water. Put that in there. That keeps the tick from drying out. The tick lives a long time between meals. It doesn't need to be fed or anything. It only takes two or three meals in its whole life anyway. The first time it takes a meal as a larva, 40% to 50% of the deer tick in New Jersey become infected at that time. Then as a nymph or as an adult, when it takes the blood

meal at those stages, that is when it transmits the disease to -- if it takes it from a human being -- to the person.

ASSEMBLYWOMAN MULLEN: Thank you very much for that information.

ASSEMBLYMAN OTLOWSKI: Assemblyman Felice?

ASSEMBLYMAN FELICE: Doctor, a few things, one just to clarify for myself. The tick, once it is infected and it goes through the reproductive stage, is the larvae-- Is that infected automatically, or does that new larvae -- the new tick have to go to a host deer or the white-footed mouse, or whatever? In other words, is the new generation of tick born with the disease built into the bacteria?

ASSISTANT COMMISSIONER PARKIN: There is no easy answer on that one, but I do know the answer. We know there is transovarial -- through the egg transmission of Lyme disease. In about 2% of the deer tick larvae -- the first stage of the tick -- we tested, we found them to be positive for Lyme disease. But 40% to 50% of the second stage -- the nymph or the adult -- are infected. So most of the infection of ticks occurs when they take the blood meal as larvae, when they feed, usually, on the white-footed mouse, perhaps a ground squirrel, a shrew, or various other small animals. We definitely know the white-footed mouse is involved, and we are collaborating with New York State in investigating the role of the other small mammals in this also.

There can be transovarial transmission. We feel it is relatively unimportant; that most of the ticks become infected by taking a blood meal as a larva.

ASSEMBLYMAN FELICE: From the host. The other question is: Are there any studies being done on the white-footed mouse, or anything else, to find out if maybe there could be some means of sterilizing these animals on a large scale to prevent population expansion, as they did with certain flies and so forth?

ASSISTANT COMMISSIONER PARKIN: Right. I am not aware of any such studies. I can't even think right now how you would begin doing such a thing. The one control measure I know focuses on the white-footed mouse, and that is the use of a specific commercial product. It is basically large chunks of cotton that have been treated with pesticides. These are thrown out into the areas that people are concerned about. The mouse takes these back to -- takes chunks of the cotton back to the nest. Then when they are in contact with the nest material with the cotton, the ticks on them are destroyed.

A study was done once. It caused a little bit of scientific skepticism, hopefully healthy skepticism, because the individuals who did the study and published it, also happened to be the owners of the company that produces the product. So right now New York State is double checking their study to determine the efficacy of this product, and we are collaborating with them. They are doing the work. Our Dr. Schulze, who was mentioned earlier, consults with them. So, we are remaining very much abreast of what is happening with that.

ASSEMBLYMAN FELICE: One other question: You talked about preventive action if someone thinks they have been bitten by a tick. Would it hurt that person to start immediately-- You said they should hold off before starting antibiotic treatment. What would be the problem of starting antibiotic treatment immediately, whether or not they knew for sure that the tick carried Lyme disease?

ASSISTANT COMMISSIONER PARKIN: I am going to have to punt on this one. I am not a physician. I am a veterinarian and a doctor of public health. But in general, we tend to regard any medication as having potential hazardous side effects. So if an individual is not actually ill with a disease, we are very reluctant, from the Department, to recommend treatment for them. There is always a hazard from--

One of the first questions you are usually asked when you go to a doctor's office is: "Are you allergic to any medications?" Antibiotics are among the medications that people do become allergic to. So we tend to be conservative along those lines and not make the type of recommendation that you just suggested.

ASSEMBLYMAN FELICE: One last thing I just thought of. I know this is a loaded question, but due to the fact of the great increase in Lyme disease in the last, let's say, eight to 10 years, is this a by-product because we stopped using some very destructive insecticides, like DDT, which certainly had a fallout policy and certainly hurt many living animals, including human beings? Is this possibly a reason for the outbreak now, because we have stopped using such heavy-duty insecticides? Do you think that might be a reason for the outbreak?

ASSISTANT COMMISSIONER PARKIN: We don't know for sure. To be absolutely truthful with you, we have heard that discussed, the programs to stop destroying the gypsy moth, etc. People have said: "Gee, isn't that a coincidence? We stopped widespread spraying with those pesticides, and then we started to find Lyme disease." Is that really a cause/effect relationship? We don't know. Or is it just happenstance that people became more aware of the disease that was always there? We can't say; we don't know.

ASSEMBLYMAN FELICE: Wouldn't it be nice if we could develop an insecticide just for the Lyme disease tick and not anything else? (no response)

Thank you very much.

ASSEMBLYMAN OTLOWSKI: Doctor, thank you very, very much.

I want to push on. Hopefully I will be able to hear from everyone who wants to testify. I am now going to call on Dr. John Drulle, please.

J O H N D R U L L E, M.D.: Good morning.

ASSEMBLYMAN OTLOWSKI: Doctor, you're with the Lyme Disease Coalition of New Jersey?

DR. DRULLE: That's correct. I practice medicine here in Jackson Township. I have been here for the last three years. Over that time Lyme disease has become the bulk of my practice. Between 80% and 90% of the patients we see in our office have Lyme disease related problems. I, myself, have been a sufferer for nine years. My wife and three small children have it, and we have another five members of our immediate family who have been infected with Lyme. This is one of the reasons why I am so concerned and active in this disease. I spend at least 20 hours of my free time each week on Lyme related affairs, talking to other physicians, and talking to groups of citizens in New Jersey and all around the country.

As someone in private practice, I look at Lyme disease a lot differently than someone in a university setting. Essentially you can say that there are two types of Lyme disease in New Jersey. There is the Lyme disease that the university tertiary referral center sees, someone who may possibly have been given the diagnosis of Lyme and treated and, in desperation, has seen an infectious disease specialist in Newark or in New Brunswick. They have their preconceived idea of what Lyme disease is. For them, it is a classic, straightforward diagnosis easily cured with two or three weeks of antibiotics, and whatever remains afterwards is not considered Lyme anymore. It is considered something vague -- call it Epstein-Barr virus or chronic fatigue or fiber myalgia. That is how they deal with these patients. They don't have to follow them and listen to them any further. They give their opinion.

The reason they are in academic medicine is because they like to do laboratory tests. They like to publish

papers. They do not particularly like listening to patients and following their problems. If they did, they would be in private practice. The private practitioner, on the other hand, knows his patients very well. In my case, I have lived in this area for 40 years. Many, or most of the Lyme patients I have, I have known since I was a child. I have known these people through their healthy years and have seen them suddenly come down with these debilitating problems.

One of the major problems we have is, again, making the diagnosis. The blood tests that have been alluded to are very inaccurate; at best, they are poor. They don't directly measure the presence of a disease. They look at the exposure of the body to bacteria sometime in the past. The immune system has produced some antibodies. These are proteins which circulate in the blood, and the blood test detects these. Depending on what studies you read, anywhere from 25% to 40% of the patients who really do have Lyme disease will test negative on these tests.

What we really need is improved testing. We have to develop tests that directly measure the presence of the Lyme bacteria. We have had some success doing this. I collaborated with some of the doctors at UMDNJ in Newark. There is a new technology called PCR, also known as a DNA probe, which can actually detect the presence of the Lyme bacteria, be it in a tissue sample, blood, spinal fluid, or urine.

Unfortunately, Dr. Steve Schutzer at UMDNJ has virtually no funding to proceed on this. I have dozens of biopsy specimens frozen in my freezer. We are awaiting an opportunity to test these, to help make diagnoses in difficult cases. There are other experimental investigational tests currently available. I just recently participated in a study with the National Institutes of Health, where I sent the urine of a number of my chronically ill Lyme patients who had had months of antibiotic treatment. We were actually able to find

the presence of the spirochete in the urine of these patients, in 14 of the 21 cases.

So this, to me, in conjunction with some of the recent literature out of Europe, Germany especially, where they have actually been able to culture Lyme bacteria from urine, blood, spinal fluid, joint fluid, and skin biopsies of patients who had "curative" treatment in Lyme disease-- We know that our current treatments are often futile in eradicating the infection. This may cause the persistence of symptoms of people who have been "cured," yet have all the same symptoms that they had when they originally went to the doctor. For the doctor, the definition of cure was perhaps the administration of two or three weeks of an antibiotic. By his thinking, this should have eradicated the infection. We have very good, solid evidence at this point that this is not true.

The recognition of the disease is still basically a clinical diagnosis, only supported by laboratory testing, but in no way can a negative test exclude the diagnosis of Lyme disease. There is no test for a cure. Depending on how you want to define "cure," you can make cure as simple as the administration of two weeks of antibiotics, or you can be very harsh with your definition of cure, and say cure is the complete absence of any live or dormant organisms from the body. Currently we have no way to test for that, and we probably won't for many, many years.

The other thing I would like to address is the definition of what Lyme disease is. Up until April of this year, the definition of Lyme disease, as presented by the Centers for Disease Control, was quite liberal. In fact, a physician's own clinical judgment was given weight as to whether this was a reportable case or not. They have tightened the definition of Lyme disease so tightly -- and New Jersey is following this now also -- that 60% to 70% of known Lyme cases in my own practice do not qualify as reportable cases any

longer. They don't fit the definition of the disease. Of all of the people who were here this morning -- the 20 or so who are afflicted with Lyme disease -- according to the CDC, perhaps two or three of them might have Lyme disease. The rest of them would not be counted.

In my speaking engagements around the State, I frequently ask for a show of hands of how many people in the audience have been diagnosed and treated for Lyme disease. I invariably get 20 or 30 hands. When I ask them how many of these cases have been reported, usually there are only one or two hands. So the disease is much more prevalent than the official numbers belie.

Our major problem, as clinicians -- primary care practitioners -- is treating these people for what is called chronic Lyme disease. Making the diagnosis early, at the time of the rash and treating it at that time, prevents most people from getting into the chronic state. But since only half of the patients who develop Lyme clearly recall a tick bite or the classic bull's-eye rash, it may be months or years before the diagnosis is made. It is not unusual to have a patient say they have gone to 16 different physicians before they were finally diagnosed with Lyme disease.

It is quite clear to me that antibiotics do not cure many cases of Lyme disease in these late stages, and it is not really clear what the disease is we are dealing with at this time. Certainly some of them have persisting infections, but in many other cases we are not able to find evidence of continuing infection with the bacteria. Yet these people are still very ill and are not functioning. This problem is not being addressed in this State.

ASSEMBLYMAN OTLOWSKI: Doctor, just from a legislative point of view with some of the bills that may be before us, you, as a practitioner, who evidently is dealing with this extensively-- Where do you think money should be spent for research, if money is to be spent?

DR. DRULLE: Well, right now I think the most efficient way to spend the money would be on prevention.

ASSEMBLYMAN OTLOWSKI: On prevention?

DR. DRULLE: Prevention and education.

ASSEMBLYMAN OTLOWSKI: You would spend money now on prevention and education?

DR. DRULLE: Well, the bulk of it should go for that. By preventing 10 cases of Lyme disease, you will pay for the money that is appropriated. You could conceivably run up--

ASSEMBLYMAN OTLOWSKI: In the area of prevention and education, would there be a set plan and proposal that would be made to deal with that?

DR. DRULLE: I am not an expert in this area. I think other people can address that much better.

ASSEMBLYMAN OTLOWSKI: But from your testimony you indicated, you know, that there aren't any sure methods of making a diagnosis. There aren't any sure methods of labeling Lyme disease. And there aren't any sure methods of cures, or, as a matter of fact, any sure method that antibiotics are effective. That prompted the question I asked: If money is to be spent for research, where do you think it ought to be spent, from your point of view as a practitioner?

DR. DRULLE: Well, we need to come up with better diagnostic tests. I mean, the current blood testing that is done is, from my point of view, a very poor way of diagnosing the disease. We can't even use the blood test to follow the progress of the disease. Once a person has received antibiotics, it is more or less meaningless to even repeat the blood test.

As far as getting into research on drugs or different pharmacologic approaches dealing with chronic Lyme disease, I think this probably can be better done by the pharmaceutical companies, and we have quite a few in New Jersey.

ASSEMBLYMAN OTLOWSKI: In that connection, are any of the big pharmaceutical companies in New Jersey spending any money, to your knowledge, in this--

DR. DRULLE: Roche and Hoechst are involved in Lyme research.

ASSEMBLYMAN OTLOWSKI: They are?

DR. DRULLE: Yes, they are.

ASSEMBLYMAN OTLOWSKI: Doctor, thank you very, very much. You have been very helpful.

I'll tell you, I want to speed this thing up, because I want to hear from some of the-- May we hear from Ken Fordyce, of Jackson?

K E N N E T H F O R D Y C E: Hello, I am Ken Fordyce of Jackson. I live at 15 Bates Road.

ASSEMBLYMAN OTLOWSKI: Ken, what is your connection with this proposition that is before us?

MR. FORDYCE: Number one, my wife is in the chronic stage of Lyme disease and has been for three years. My son had Lyme disease, but was cured by a course of treatment from Dr. Drulle, as far as we can tell.

ASSEMBLYMAN OTLOWSKI: What positive testimony do you think you can give us?

MR. FORDYCE: Well, I am currently a member of the Lyme Disease Association of Central Jersey and the Lyme Disease Coalition of New Jersey. Although I do not practice pest control at the current time, I am a former member of the National Pest Control Association, and I designed and directed the Pest Control Program for the Housing Authority of Denver.

ASSEMBLYMAN OTLOWSKI: What do you think should be done that isn't being done, from your point of view, and from your experience?

MR. FORDYCE: Well, I wanted to address two of the bills that Assemblywoman Ford has proposed: First the amendment to the Municipal Land Use Act to allow townships to

require developers to treat property; and second, the posting of public parks. On the first issue of tick control, some central facts you should know are these:

The tick is a very focal creature that tends to stay very close to where it was born, unless it is carried somewhere else by a small mammal.

It is most active on the borders between the woodlands and the open areas. Let's assume you have a woodland of 200 feet bordering a road. When you develop that area and you cut back into it to form a normal acre size lot in Jackson, you have 200 by 200 by 200, and all of a sudden you have 600 feet of border, where you previously had 200. You have increased the surface area that the ticks are very active in. So I believe, personally, that it is very important to require developers in this State to treat the properties they are developing.

Now this is not necessarily a very onerous burden. Treating the properties can cost less than $200 per property. As a matter of fact, in New York, in Westchester County and on Long Island, developers are doing this at the current time, and they are even advertising the fact. They are saying: "We are using Damminix," or, "We are using Permethrim, and we have pretreated these properties." They use it as a selling point in these endemic areas for Lyme disease.

ASSEMBLYMAN OTLOWSKI: What you are saying, in effect, is that from your point of view you think the legislation that Marlene Ford is proposing is effective and would be helpful. This is the proposition you are advancing?

MR. FORDYCE: Yes, I believe it would be very helpful.

ASSEMBLYMAN OTLOWSKI: Have you talked to her about that? Have you talked directly to her about that?

MR. FORDYCE: Yes, indeed. As a matter of fact, she was kind enough to come to Jackson a couple of months ago to discuss these issues, and we did have input to that. So, yes, she has been very helpful.

Second, to the issue of posting public parks, this is nothing unusual. In Westchester County they do this already. They have fairly large signs that have pictures of ticks on them. Epidemiologists have said over and over in conferences that I have attended that one of the best ways to get people to protect themselves against ticks, is just to create that psychological barrier. You just put up that sign, and it triggers something in people's minds: "Yes, I better be careful."

ASSEMBLYMAN OTLOWSKI: Have you made that known to our Department of Health in the State?

MR. FORDYCE: Yes, we have.

ASSEMBLYMAN OTLOWSKI: You have made that known to them?

MR. FORDYCE: Indeed. We have had several conversations with Dr. Parkin and Dr. Deborah Bloom.

ASSEMBLYMAN OTLOWSKI: And you have discussed that with them?

MR. FORDYCE: Yes. About six months ago that was the topic of discussion. I believe these things will ultimately be acted upon in a favorable manner.

I want to make one last point: As Assemblywoman Ford alluded to previously, we did have a meeting with the Governor last week. You should be aware that the majority of the people at that meeting were part of an organized group called the Lyme Disease Coalition of New Jersey. It is a coalition of Lyme disease groups, support groups.

ASSEMBLYMAN OTLOWSKI: Did you submit written memoranda to the Governor?

MR. FORDYCE: Yes, and I have copies here that I would like to present to you.

ASSEMBLYMAN OTLOWSKI: Do we have copies of this?

MR. FORDYCE: Not yet.

ASSEMBLYMAN OTLOWSKI: May we have them, please?

MR. FORDYCE: Certainly. I just want to let you know that there is an organized group of people out here who are quite willing to assist with any committee at a statewide level.

Thank you.

ASSEMBLYMAN OTLOWSKI: Thank you very much. May we have that copy, please? (witness complies)

Phyllis Gowa? Am I pronouncing that correctly? (no response) Oh, I see, there are two people.

Before I do this, the lady with the two infants-- Are you scheduled to testify?

UNIDENTIFIED SPEAKER FROM AUDIENCE: No.

ASSEMBLYMAN OTLOWSKI: You're just here to listen?

UNIDENTIFIED SPEAKER FROM AUDIENCE: Right.

ASSEMBLYMAN OTLOWSKI: All right. Phyllis, where are you? Phyllis and Heather Gowa? Do you want to come up here?

P H Y L L I S G O W A: My name is Phyllis Gowa. This is my daughter, Heather Gowa. We are both Lyme victims.

I have battled Lyme disease since the fall of 1988. The worst battle, however, has been watching my little girl, Heather, be transformed from a healthy, energetic child to a seriously ill child, whose life has become painful and frightening.

In the last two years, Heather and I have taken countless antibiotic pills. Heather has had four series of IVs and six hospital stays. I have had two series of IVs.

Last year, my husband and I coped with over $63,000 worth of medical bills. Luckily, most of it was covered by medical insurance. But many in New Jersey aren't as fortunate as we were. Many fear opening their morning mail because of the ever-mounting uncovered medical expenses.

New Jerseyans need to be assured that coverage will not be denied or terminated because they have been afflicted with this often devastating chronic disease. In the last two years, we have found that life is not always fair. We bought a

house that was sorely in need of landscaping. We did it as a family project to save money. What we didn't know was that it would change our lives forever. Heather will have memories of a childhood filled with countless hospital stays, doctors' visits, homebound school instruction, visiting nurses, and, worst of all, pain.

I urge you to do whatever you can in your power to pass the bills that are before you -- before the Legislature. However, these bills are just a beginning. Lyme disease research needs money. New Jersey lags behind other hard-hit states in research appropriations and adequate lab facilities. All of us understand the financial mess New Jersey is in, but I believe I can offer you possibly a partial solution for funding some of the research.

My suggestion to you is a checkoff on the State income tax forms. This approach is not a novel one. Presently there are checkoffs for the Wildlife Conservation Fund and the Children's Trust Fund. Why not create one for a Lyme Disease Research Fund? This newly created fund could be administered by an appointed commission of medical personnel, legislators, and laypeople. Money, in the form of grants, could be awarded to researchers committed to what has become a New Jersey fight. Mind you, this solution is not a quick fix. I understand that. It could be a partial remedy to drum up needed money fast to help us to battle a disease which, if left unchecked, will claim thousands more New Jersey victims than it already has.

Thank you. Now my daughter, Heather, would like to say something, too.

ASSEMBLYMAN OTLOWSKI: Bring that microphone closer to her.

H E A T H E R G O W A: My name is Heather Gowa. I am 10 years old and in the fourth grade. I have Lyme disease. There have been many times when I couldn't walk or remember things.

Since I couldn't remember anything, I had to repeat the third grade. I was in the hospital six times for two-and-a-half months altogether last year. I was on lots of IVs for four months between last year and this year.

The reason why I got sick with Lyme disease was because my family and I were in the backyard cleaning up the leaves in the fall of 1988. So can you please pass the laws that will help other kids get better from Lyme disease; or, even better, help us to never get bitten by deer ticks again.

By the way, my best friend's name is Melissa. She can't walk right now either because she has Lyme disease, too.

Thank you very much for listening to me.

ASSEMBLYMAN OTLOWSKI: How old are you, dear?

MS. H. GOWA: Ten.

ASSEMBLYMAN OTLOWSKI: You're 10? What grade are you in?

MS. H. GOWA: Fourth grade.

ASSEMBLYMAN OTLOWSKI: Thank you very, very much.

MS. P. GOWA: Thank you.

ASSEMBLYMAN FELICE: Mr. Chairman?

ASSEMBLYMAN OTLOWSKI: Just a minute, please, Ms. Gowa. Yes, Assemblyman Felice?

ASSEMBLYMAN FELICE: Both of you, then, contracted Lyme disease in the yard cleanup?

MS. P. GOWA: I'm sorry?

ASSEMBLYMAN FELICE: Both of you contracted the Lyme disease when you were doing your landscaping?

MS. P. GOWA: Yes, two years ago, as soon as we bought our house in Manalapan.

ASSEMBLYMAN FELICE: Were you both positively diagnosed with Lyme disease, or was there a delay in one or the other diagnosis?

MS. P. GOWA: I suspected I had it. However, the five doctors I had gone to before Dr. Drulle began treating me

successfully claimed that I either had lupus or multiple sclerosis, even though I had read enough about the disease to know that I had it.

Heather was luckier in one respect. By the time she began showing symptoms, which was simply the swelling of her knee for seemingly inexplicable reasons, the doctor had been able to diagnose her, hospitalize her, and treat her almost immediately.

ASSEMBLYMAN FELICE: Thank you, and thank you, Heather.

ASSEMBLYMAN OTLOWSKI: Excuse me, the Assemblywoman has a question.

ASSEMBLYWOMAN MULLEN: I just wanted to say to Heather, Heather, I am so sorry you had to repeat the third grade because you were ill. That was too bad, but you will catch up, I'm sure. Thank you for talking to us.

MS. P. GOWA: Thank you very much for hearing us.

ASSEMBLYMAN OTLOWSKI: Thank you. Susan Rauch? Am I pronouncing that correctly, Susan?

S U S A N R A U C H: Yes.

ASSEMBLYMAN OTLOWSKI: Susan, do you have written testimony?

MS. RAUCH: Yes. Well, it's notes.

ASSEMBLYMAN OTLOWSKI: It's not typed, is it?

MS. RAUCH: Yes, it is.

ASSEMBLYMAN OTLOWSKI: All right. Are you going to give it to us?

MS. RAUCH: Yes. Good morning, Mr. Chairman. My name is Susan Rauch. I live in Marlboro Township. Last year, my entire family was stricken with Lyme disease. We have four people in our family: myself, my husband, my 13-year-old son, and my 10-year-old daughter. None of us experienced a rash, nor did we find a tick bite. We were less fortunate than most. My husband was the first to become ill with Lyme. He was hospitalized for an extensive period of time beginning in

March of '89, but it was quite a while until he was diagnosed properly.

Then last April, my 13-year-old son was experiencing such symptoms as stiffness in his back and legs, a stiff neck, and he started limping. His behavior changed drastically, in that when he wasn't totally hyper and impulsive, he was sleeping endlessly. Our family doctor tested his blood and did a Lyme test, and he tested positive. He was immediately put on oral antibiotics. At the same time, my daughter, who at that time was nine years old, was experiencing the symptoms of memory loss; for instance, not remembering how she got from one place to another in school. She was also falling a great deal and had a bad concussion. Our family doctor found that she had a weakness on her right side, which accounted for her frequent falls. She had a blood workup with a Lyme test, and it came back high positive for Lyme. She was immediately hospitalized in May of '89, and my son was put in the hospital, too, at that time, because he was not responding to the oral antibiotics.

As ludicrous as it may seem, we are very good friends of the Gowas, who just testified. My children and Heather ended up in the hospital together. To me, they should have been going to the movies, not spending time in the hospital. I think it shows how many children really do have it in our area.

They were both treated on IVs for 30 days. Then in August of '89, I was experiencing classic Lyme symptoms -- stiff neck, memory loss, numbness in my fingers and toes, and my knees were swollen. I was put on oral antibiotics shortly thereafter, because even though I tested negative, I had the classic symptoms.

In October of '89, my son had a total relapse when his entire body locked. He was then hospitalized and was put back on intravenous for another month. Throughout the year my children and myself and my husband all were treated on oral antibiotics, as we were still not well.

In May of '90, I was stricken with Bell's palsy and was then put on IV for the first time, and my Lyme test finally came up positive. I was on it for three weeks, and then I had to go off because my white count dropped. Then I was put on oral antibiotics. Right now I think maybe I have licked it. I have been feeling pretty good.

In late May of '90, my daughter was again hospitalized for total relapse and was again put on IV, which she did not respond to after six weeks. We went through the whole summer. She couldn't go swimming. She had absolutely no fun this past summer. After six weeks, she had to go back into the hospital because she had severe pain and muscle spasms in her legs, and she could no longer walk. She was on crutches since July, and just recently graduated from a walker to a cane, with the help of intense physical therapy and finally finding the right oral antibiotic.

During this period of time, she also experienced Bell's palsy, in conjunction with blurred vision and a substantial hearing loss, but, thank God, all of these have come back.

Our lives have not been the same since we caught this dreaded disease. We live in constant fear of what tomorrow will bring, and hope that a cure will be found very soon. We have many friends in the very same predicament. Many of my neighbors have it. Around the corner from me there are whole families that have it. People in my development are starting to have the classic symptoms. They are coming back negative in tests, but it is obvious to me that they are probably coming down with it. Others have not been touched by this illness, and therefore do not understand what we are going through. There is a lot of apathy in my area. When people don't have it, they think of you as not dealing with a full deck, unfortunately.

We are very grateful that our insurance company has covered most of our astronomical insurance costs for this illness. Others are not as fortunate. Please, we urge you to pass whatever legislation will help us to raise enough money for Lyme research and to spray our lands so that these insects cannot multiply. We would like nothing more than to enjoy life as we did once before. All of our children deserve to have a normal childhood, as others do. We don't just need a preventative; we need a cure.

I thank you.

ASSEMBLYMAN OTLOWSKI: Thank you very, very much.

May we hear from Lindsey Radeer, please? Lindsey, are you with a group, dear, or are you by yourself?

L I N D S E Y A. R A D E E R: No, Mandy is with me.

ASSEMBLYMAN OTLOWSKI: Who are with you?

MS. RADEER: Mandy and Bonnie.

ASSEMBLYMAN OTLOWSKI: Do you want to call them up so we can get you in a group? Do we have Scott in here? (indiscernible response from audience; no microphone) Oh, you are not with this group. All right.

Lindsey, do we have everybody who is with you? (affirmative nod from witness) You're on. Lindsey, please identify the people who are with you, honey. All right?

MS. RADEER: Okay. This is Bonnie Molloy.

ASSEMBLYMAN OTLOWSKI: Yeah, and that's Kathleen?

MS. MILLER: No, no. She is introducing-- That's Bonnie and that's Mandy.

ASSEMBLYMAN OTLOWSKI: Bonnie and Mandy, give us your full names and your addresses, please. All right?

B O N N I E M. M O L L O Y: My name is Bonnie Molloy. I live at 164C1 Frank Applegate Road, Jackson.

M A N D Y B A I L Y: My name is Mandy Baily, 396 Maplewood Road, Jackson.

MS. RADEER: My name is Lindsey Radeer. I live on Elm Street in Jackson.

ASSEMBLYMAN OTLOWSKI: Lindsey, pull that microphone closer to you so you will be comfortable. All right?

MS. RADEER: For the last two years, I have been going to a lot of doctors and none of them actually said I had Lyme disease. My doctor is just waiting for another Lyme disease test to come back to say that I have it, because I have been tested so many times and I pretty much have all of the symptoms. It is a real strain on my family. My brother has Epstein-Barr, and it makes my mother really upset. It's really something that is hard to deal with.

ASSEMBLYMAN OTLOWSKI: All right. Thank you, honey. Thank you very, very much. Do you want to pick it up from there, Bonnie?

MS. B. MOLLOY: (speaking off-mike) I'm 16. I go to Jackson High School. I am a junior. I first got sick with Lyme disease when I was nine. They didn't really know it. They just thought it was some kind of a virus. I was in the hospital. Then, in the beginning of ninth grade, we had an exchange student from Sweden, and she got Lyme disease. My mom didn't understand why she was sick and I wasn't, when I had the same symptoms. So they brought me to the doctor, who gave me a test. Eight years ago this month I was put into the hospital for my first time. I was there six weeks or something. Ever since then I have been in and out of the hospital, missing school, and not being able to do the things that the other kids do.

But I have played soccer. My grades haven't been too good, but this year they are getting back up. I worked full-time all summer, even though I was in the hospital. I don't get to act like other kids, but after a while you learn to put up a front. You learn how to fake it. You feel really bad. You just want to go home and go to sleep, but you learn

how to say, "I don't feel sick. I can do what everyone else does. I don't feel sick."

After a while it gets to be really bad. When you are on the medicine, you feel a little better, but you don't feel totally better. When you are off the medicine-- I have been off the medicine since August, because that is the last time I was in the hospital. I am waiting for a bed now so I can go back on IV, because I have been really sick. I don't want to go to school sometimes, but I do because if I don't go to school I can't keep my grades up, and I want to go to a four-year college. That is really hard. You have to have IVs, and that is really embarrassing when you roll up your sleeve and you have this thing sticking out of your arm, and people are looking at you really weird. Or you want to sleep over at your friend's house and you have to drag two bags of medicine, IVs and needles. When you have friends in, they look at you and say, "What's that? Can I get it? What is it?"

Me and my brother, we had IVs in our chests. I got mine out this summer because it got infected and it was giving me high fevers. It left two scars right here (demonstrates) and I couldn't wear a bathing suit. I can't really wear strapless dresses or anything that goes real low, because you can see the scars.

But I am learning to handle it. I'm okay. I go to school; I play soccer; I work. I go out with my friends all the time. This weekend I made plans. I didn't know if I was going to be able to go out, because I thought I was going to go into the hospital. But I didn't, so I am going to go out. Other than that, everything is pretty okay.

ASSEMBLYMAN OTLOWSKI: One thing is, it hasn't affected your speech. (laughter) Do you want to add something, dear, or do you want to pass the microphone on?

MS. B. MOLLOY: Mandy?

MS. BAILY: I am 15. (speaking very softly; indiscernible) I have had this for about 10 years now.

ASSEMBLYMAN OTLOWSKI: For 10 years?

MS. BAILY: Yes. I first contracted it-- What happened was, I had pneumonia and bronchitis at the time. I had the rash for a couple of days, and it was the exact type of rash. They thought it was just an allergic reaction. Every year I was taken out of school for about a month because I got sick. They just figured it was the virus that was going around.

About two years ago, they tested me for Lyme, and it came out positive. I was put on IV right away, and I am back on it now. The last two years I haven't been on it. I have been treated orally with antibiotics, and I haven't felt good. I am starting to feel the emotional strain of it right now. It's getting hard.

ASSEMBLYMAN OTLOWSKI: Girls, I just want to tell you this, and I think I speak for the whole Committee: We are very, very grateful that you came, and that you sat throughout this whole hearing, and that you have made the contribution that you have made. I just want you to know that we deeply appreciate it. I'm sure that I speak for the whole Committee. We want to assure you that we are concerned about it, and we are going to do everything we can to be helpful from a legislative point of view. But a lot depends upon yourselves. I just hope, of course, that you are going to maintain the courage you have had, and are going to keep on going.

So, thank you very much. Oh, wait a minute. Assemblywoman Mullen wants to say something.

ASSEMBLYWOMAN MULLEN: I just wanted to say thank you, Mr. Chairman. You are very brave, and I am very grateful that you shared this with us.

ASSEMBLYMAN FELICE: Thank you. Your testimony certainly will help others, too, and it is most appreciated.

MS. B. MOLLOY: Thank you.

ASSEMBLYMAN OTLOWSKI: Thank you very much.

May we have Scott Molloy? Scott, are you by yourself? Where is Scott?

S C O T T A. M O L L O Y: Right here.

ASSEMBLYMAN OTLOWSKI: Scott, are you going to be introduced, or are you going to go on immediately by yourself?

MR. MOLLOY: I don't really know, but--

ASSEMBLYMAN OTLOWSKI: Let's hear from you, Scott.

MR. MOLLOY: Well, I got it in third grade. I wasn't feeling good. I got the Lyme test. It didn't show anything, so they just put it off. Then I was getting sicker in fourth grade, and they tested me again. It didn't show anything. But then I went to the doctor, and she put me in the hospital. I was on an IV for--

G A I L M. M O L L O Y: He was on it for a total of 28 weeks in a year's time span.

ASSEMBLYMAN OTLOWSKI: Excuse me. Would you please identify yourself?

MS. G. MOLLOY: I am Gail Molloy, his mother. It was a total of 26 weeks -- total IV time; not continuous but intermittently.

MR. MOLLOY: I have been in the hospital five times.

ASSEMBLYMAN OTLOWSKI: Scott, how long have you been ill now? How long?

MR. MOLLOY: Two years.

ASSEMBLYMAN OTLOWSKI: Two years.

MR. MOLLOY: I had to have the thing in my chest, and it wasn't really pleasant. I would go to the beach and have to keep my shirt on because it was embarrassing if I took it off. When we went to Florida I had to keep my shirt on, and that wasn't pleasant either.

In school, in fourth grade, I would get to the point where I would have to go into Ms. Villecco's (learning consultant) office and lay down for a half-an-hour or so. But

I was in school, because I didn't want to get left back or anything like that.

ASSEMBLYMAN OTLOWSKI: Are you in school now, Scott?

MR. MOLLOY: Yes.

ASSEMBLYMAN OTLOWSKI: Does your mother want to add anything?

MS. G. MOLLOY: I would really like to talk more about the learning problems. He was in school 40 days from September to January in his third grade year. The second half of the year when he was feeling a little better, he didn't miss any time except for about three or four days.

The reason I would like to see the bill passed is-- Besides the devastation to the kids, and besides what it does to a family-- The family is not a normal family when three-quarters of the family has Lyme disease. The other person who suffers is the one-quarter who doesn't have it. They suffer almost as much, because their lives are on hold. My daughter was the middle one, my son had it, and I had it -- not to any great extent -- and I have one son who is fine. He suffers because everybody else is sick.

The other thing is the financial aspect. People have talked about that. Between the two of them, it has been $300,000 in two years.

ASSEMBLYMAN OTLOWSKI: Are you covered by insurance?

MS. G. MOLLOY: Yes. I have paid a little out-of-pocket, I will be honest. My insurance is wonderful, but if I did not have a million-dollar cap on each child, and I had a $250,000 cap on each child, then what would happen? I would be almost at the top, and then nothing would be covered. That is the real problem.

You can deal with almost anything, but when you start to lose your job, or your house, or you can't pay your bills, that pressure becomes enormous.

I would like to have Ms. Villecco talk about the learning problems.

ASSEMBLYMAN OTLOWSKI: You're Elizabeth?

E L I Z A B E T H V I L L E C C O: I'm Elizabeth Villecco. I am a learning consultant on the Child Study Team at the Switlik School, which is just around the corner -- just down the road.

ASSEMBLYMAN OTLOWSKI: You're part of the school system?

MS. VILLECCO: Yes. The school is a kindergarten through fifth grade school. My concern is what I am seeing in school. As much confusion as there is in the world at large with the medical profession, so there is also in the schools. There are also misdiagnoses. Scott, in particular. We have worked closely because his mother is an advocate, thank God, and has pushed for certain things to happen for her children.

The disease itself is confusing to educators. We have children who have average abilities, and all of a sudden they don't. All of a sudden they are irritable; they have mood swings; they can't concentrate. They can't stay with their work; they don't do their work. They have trouble with short-term memories. We have had children become disoriented, where they lose their thought in the middle of a sentence. People look at them and say, "Does this child have a serious emotional problem? What is going on at home?"

We are not getting the information from the doctors to know that the children are sick. We are not having people come in. We give them homebound instruction when they are sick, and by that I mean hospitalized. Just now, in this town, we are just catching up so that there isn't a two-week delay. The homebound instruction is usually-- You have to be sick for two weeks, and then you can get homebound. These children are well for two weeks, and then they're out for a week. They're in for a week, they're out for two, or for a month. It is very different from other illnesses in that regard.

We give them supplemental, which is an ongoing tuitoring thing. Nonetheless, we feel we are missing it with some of these children. I don't think we are educating our own people in education. As skeptical as people at large are of Lyme disease, I think educators are, too, because the children can carry on at certain times of the day and under certain circumstances, but they can't persevere and they can't stay with it and they can't achieve at the average levels they were able to achieve at before.

So I think as part of whatever legislation comes about, there should be a big move to educate everyone, including the educators. And there needs to be a counseling component, a strong counseling component for these children who are chronically ill, to help them to deal with the emotionality in view of the frustration.

ASSEMBLYMAN FELICE: Mr. Chairman, may I ask a question?

ASSEMBLYMAN OTLOWSKI: Yes, Assemblyman Felice.

ASSEMBLYMAN FELICE: In this particular school that Scott is in, how many children, would you say, at this point, or as far as the records show, have or have had Lyme disease?

MS. VILLECCO: I'm sure that could be made available to some extent by the school nurse. We have had a parade of children with the heparin locks. Unfortunately, the confusion is a big part of the problem. A lot of the children are not diagnosed. A lot of the parents are not advocates. They don't realize that they have to go and fight for their children. My own son is on an oral antibiotic. I have made changes at home. There must be changes in the school. If I don't tell the school, and if I don't make a point of it, there is not going to be anybody paying any heed to that.

It is so underrated as an illness that a clear answer is just not possible. There are chronic cases where you really see that the children look like they are learning disabled. It is enough to frighten me.

ASSEMBLYMAN OTLOWSKI: Thank you very, very much. Thank you, Scott.

I am going to call Assemblywoman Ford. She wants to supplement her testimony.

ASSEMBLYWOMAN FORD: Thank you, Mr. Chairman and members of the Committee. I have to leave shortly because I have an appointment down in Toms River, but I want to thank you once again for coming and listening to the people of this area. They are the experts on Lyme disease because they have lived through it.

I just hope you have had the experience I have had, and that is being truly moved by their plight, and gaining a greater understanding through their testimony which you heard earlier as to what the problems are. They range from everything -- the sheer cost of the treatment, the availability of the treatment, the level of medical knowledge to identify the Lyme problem, the educational and social problems that come from it, and the impact it has on young people, especially on young women.

I hope what you have heard today has changed you. I know the day I spent with Dr. Drulle changed me. I hope we can work together to put together some type of policy. I don't know if my bills are the whole answer, but at least they are a start and we can build upon them as a foundation.

Thank you for all of your efforts in listening to all the people here today.

ASSEMBLYMAN OTLOWSKI: I think it has been a moving experience for all of us. You hear the words "Lyme disease," but you never have the complete concept, or the feeling that was developed here today. It is a feeling, of course, that is going to stay with us for a long time. I am sure I speak for the whole Committee, again. We are going to apply ourselves vigorously to this thing, and do everything we possibly can legislatively.

Thank you very, very much for spending the day with us. Thank you.

ASSEMBLYWOMAN FORD: Thank you.

ASSEMBLYMAN OTLOWSKI: May we have Jo Lanko, please?

J O A N N L A N K O: Good morning.

ASSEMBLYMAN OTLOWSKI: Good morning.

MS. LANKO: Or, I guess it should be "good afternoon."

ASSEMBLYMAN OTLOWSKI: Would you give us your name and address, please?

MS. LANKO: Yes. Jo Lanko, RD 1, Box 14N, Jackson. I am a resident, as my address indicates. I am also a Lyme disease victim. I am also the parent of two sons who have Lyme disease; and my husband also. My husband has had extended medical problems ever since he was diagnosed. I am also a teacher in the school district at the local high school. So I have seen, from all different perspectives, just how much this disease has affected our community, our children, and our students in the local school district.

Just very quickly-- I know you have heard a lot about the different ways of being diagnosed. I am in favor of all the legislation, but I particularly want to highlight some of my concerns.

Even though my last blood test indicated that Lyme has pretty well been driven out from all the treatment I have had, the next six months will tell whether or not it will come back. I still suffer from chronic arthritis in my hips, which has given me lots of problems over the past three years. I went to a number of doctors, and was told a number of different conditions. I have been a health and physical education teacher for 22 years, and this was quite devastating to me because I pride myself on being a role model for someone who is fit. When I could not live up to even my own values, it really bothered me, and was depressing.

I am now -- since the last few years -- a health specialist, so I have always been an advocate of wellness, prevention, and so on. In addition to that, one of the secondary illnesses I suffer from now is fibrositis, which attacks the muscles. It is something now which I can live with under anti-inflammatory drugs. Not being a person who is very happy with prescription medicine taking, it has been quite an adjustment on my part.

My two sons were treated early. They had no symptoms whatsoever, but it was recommended since many family members tend to have it. My older son has learning disabilities. I am very concerned about the long-term effects. He struggles day to day just to do things that a lot of us take for granted. I don't know what research is being done on any long-term effects for either him or myself.

My husband, who has been a very strong physical fitness advocate and so on himself, has been devastated by this illness, as being diagnosed with very severe chronic asthma. There hasn't been a lot of research done on that in connection with Lyme, but the doctor I go to -- Dr. Schwartzberg, out of Nepture -- is also involved in the Resource Center out of the Jersey Shore Medical Hospital, and he thinks this could be a link.

Health insurance: I am very lucky that my health insurance did cover most of my expenses, but I still have ongoing expenses with all of my family. Even though I am lucky, there are a lot of people I know who do not have the health insurance help.

I would also like to see more research done on the diagnostic part of this illness, because it took three years for me to be diagnosed and, of course, it brought me into the chronic stage with the arthritic condition. Research, also -- as I said before -- in conjunction with any possible long-term effects-- We really don't know when or if we will get rid of this, and what might attack our bodies next.

I am also concerned with the Centers for Disease Control definition and the fact that at a prior meeting last year, we were told that unless you have had the bull's-eye rash and a positive blood test, at that moment you are not considered to have Lyme disease. That really upsets me. As you have heard mentioned today, a lot of people do not have that rash. None of my family, nor myself, had the rash.

I am also very concerned as a teacher about services for the students. As was just indicated by Ms. Villecco, I know from my own child and myself, in my classroom, it was pretty devastating when I was giving a lecture -- and I pride myself on being a good teacher, and an active teacher -- and had to stop in the middle because I was a complete blank. I had no idea what I was talking about, where I was going, what I was saying, and almost got into several car accidents because I couldn't remember if I had looked before I made the turn. You felt as if you were going senile. I can very well see with my own students and my own children and myself that these other services are very much needed.

A lot of people are still not educated. We have to continue education throughout the State, because a lot of people do not take it seriously. You can see a person one day and he or she will look great, and then the next day they might look a little bit different or a little bit better, and then be out of school for a couple of days. A lot of teachers think the kids are playing games. It certainly is not a game.

I appreciate your listening to me.

ASSEMBLYMAN OTLOWSKI: Thank you very, very much. We really appreciate your appearance.

May we have Kathleen Conway? Kathleen -- if you don't mind my calling you Kathleen--

K A T H L E E N C O N W A Y: That's fine.

ASSEMBLYMAN OTLOWSKI: Will you please express our thanks to the Mayor for the courtesy he has extended to us by

making these facilities available to us? Will you convey that to him, please?

MS. CONWAY: I certainly will. I really decided to speak at the last moment today, so it is going to come from here. (demonstrates) I wanted to let you know that I am also a victim of Lyme disease. That has put a little bit of emphasis on our town in looking at how serious Lyme disease is, because my husband watched me go through the very bad, ill stages of swollenness where I couldn't walk; the headaches being so severe that you just wished it was all over. There were days that I would say, "I wish I were dead." That is how bad the pain was.

My husband helped me to put a conference together here in Jackson last winter, and it was very successful. What I am trying to say is, within our town, because we have so many people with the disease -- and I see many of the children because I also work in the school system, and I know what they are going through -- I wanted to do the conference to educate our community. We are still doing that. My husband has also seen that we have had spraying this past spring in our little parks and our soccer fields. We will continue to do that. We are hoping that other townships will follow what we are doing.

I just want to let you know that we, in this town, are trying as hard as we can to educate our community, but we obviously-- As you have heard many people testify, it has to be widespread. One of the most important things is, yes, we need a lot of research, and we do need doctors-- How we are going to do it, I don't know, but we need doctors to realize that this is very serious.

We have had Dr. Parkin say before that the information is being sent out to doctors, so they should be aware of things, but they are not. I am convinced that they do what a lot of people do when they get a lot of paperwork. They set it aside. It's not important. But they haven't seen the children

that you have seen today, or the others that some of you have seen in the hospitals. Lynn Hunter is a very close friend of mine -- the girl who came up earlier. It breaks my heart. I know what she is capable of. She was an honor student.

Thank you.

ASSEMBLYMAN OTLOWSKI: Thank you very much.

Just before we conclude, I would like to point out that I am going to ask the staff to make this record available not only to members of the Assembly, but to the leadership of both houses, to the Governor's Office, and to the Cabinet members who would fall under the umbrella of what we are talking about today. In addition to that, I would ask the staff to prepare a running narrative on the highlights of this hearing. I suggest a running narrative because there has been so much talk about education here, and I would like to use that running narrative as much as possible in the general media. We would make that running narrative available to the general media, and we would probably make it available to the Medical Society and to other associations which, again, would fall under the umbrella of this particular subject we are talking about.

In addition to that, I think a tremendous impression was made upon the Committee. In my judgment and from observing the Committee members and their participation in this, I am positive that it made a tremendous impression upon them. The Committee now is armed with what they heard at this hearing; armed with a whole new emotional approach to the subject. I am sure they are now armed, too, with the seriousness of this disease and with the kinds of ramifications it has on total family life, the cost of trying to keep the family together, and trying to return to a normal life.

For all of you who participated in this hearing, I am very, very grateful. Before we adjourn, I would ask if there is anyone else we may have skipped, that we didn't hear from? (no response)

Assemblywoman Mullen, do you have a comment to make before we adjourn?

ASSEMBLYWOMAN MULLEN: I would just like to echo your own comments, Mr. Chairman. I have been moved, worried, and motivated by this hearing. I am so glad you held it and that I had an opportunity to hear these folks.

Something just dawned on me when I heard some of the testimony. I have a young mother who works in my office, who I had to transfer because of an arthritic condition that developed and her sheer tiredness. Now, her doctor thinks she has lupus. I had to transfer her to an office where there wasn't as much stress as there is in my office -- my Mayor's office I am talking about.

I am just wondering now if this young mother actually has Lyme disease, because she lives in a wooded area. Maybe it is not lupus, and I am going to go back and impart the information I received here today to her.

So I thank you.

ASSEMBLYMAN OTLOWSKI: Thank you, Ann. Assemblyman Felice?

ASSEMBLYMAN FELICE: Yes, Mr. Chairman. I really feel that this has been an important hearing. I must say, for the last couple of years especially, the courage -- she is not here now -- that Assemblywoman Clare Farragher has shown, knowing what she has gone through and what she has done, not only to help to educate us, but to really spend the time to bring forth to the State of New Jersey the importance of education, prevention, and, of course, the treatment of Lyme disease, my hat goes off to her. I have seen her many times walking around with the IV completing her tasks as a legislator.

Also, knowing what is happening here is also happening throughout the State has been an experience and an education to me, because we are experiencing this problem now in the northwest part of the State. As I said, the map shows

practically nothing in our area, but, believe me, it is coming upon us in leaps and bounds. This is a problem that we have to resolve for all of us.

I thank you for the ability to come down here today.

ASSEMBLYMAN OTLOWSKI: Again, thank you all very, very much. The Committee stands adjourned.

(HEARING CONCLUDED)

APPENDIX

New Jersey State Legislature
ASSEMBLY HEALTH AND HUMAN
SERVICES COMMITTEE
STATE HOUSE ANNEX, CN-068
TRENTON, NEW JERSEY 08625-0068
(609) 292-1646

MEMORANDUM

November 2, 1990

TO: MEMBERS OF THE COMMITTEE

FROM: DAVID PRICE, COMMITTEE AIDE

SUBJECT: BILLS ON LYME DISEASE IN COMMITTEE

The attached bills are those currently pending in the Assembly Health and Human Services Committee pertaining to Lyme Disease. They are as follows:

A-2249 (Farragher) Provides a $310,000 supplemental appropriation to the Department of Health to establish a Lyme disease program.

A-3455 (Ford/Doyle) Permits a municipal land use ordinance to include as a condition for local municipal approval the submission of proof that the property for which application is made has been treated on its perimeter with appropriate materials to combat deer ticks.

A-3478 (Ford/Doyle) Establishes a Lyme disease research program in the Department of Health and appropriates $500,000.

A-3515 (Ford/Doyle) Requires the Department of Environmental Protection and the Department of Health to investigate Lyme disease in State parks, forests, and fish and game lands.

ASSEMBLY, No. 2249

STATE OF NEW JERSEY

Introduced Pending Technical Review by Legislative Counsel

PRE-FILED FOR INTRODUCTION IN THE 1990 SESSION

By Assemblywoman FARRAGHER

A SUPPLEMENT to "An Act making appropriations for the support of the State Government and the several public purposes for the fiscal year ending June 30, 1989 and regulating the disbursement thereof," approved June 30, 1988 (P.L.1988, c.47).

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. In addition to the amounts appropriated under P.L.1988, c.47, there is appropriated out of the General Fund the following sum for the purpose specified:

DIRECT STATE SERVICES
46 DEPARTMENT OF HEALTH
20 Physical and Mental Health
21 Health Services

02-4220 Community
Health Services $310,000
Special Purpose:
Lyme Disease program ..... ($310,000)

2. This act shall take effect immediately.

STATEMENT

This bill provides a supplemental appropriation of $310,000 to the Department of Health to establish programs for education, prevention and treatment of Lyme disease.

Lyme disease, which is spread by deer ticks, is one of the fastest growing public health problems. Although the disease is the most common tick-borne illness in the United States and New Jersey is one of the states in which the disease is most prevalent, it is still relatively unknown among both the medical community and the general public and consequently is often misdiagnosed or not diagnosed, which results in more serious health problems for the affected person. Lyme disease, if untreated, can result in neurological disorders and severe arthritis in its advanced stages.

HEALTH

Supplemental appropriation of $310,000 to DOH to establish a Lyme Disease program.

2X

ASSEMBLY, No. 3455

STATE OF NEW JERSEY

INTRODUCED APRIL 26, 1990

By Assemblywoman FORD and Assemblyman DOYLE

AN ACT concerning Lyme Disease prevention and control and amending P.L.1975, c.291.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. Section 39 of P.L.1975, c.291 (C.40:55D-39) is amended to read as follows:

39. An ordinance requiring approval by the planning board of either subdivisions or site plans or both may include the following:

a. Provisions for off-tract water, sewer, drainage, and street improvements which are necessitated by a subdivision or land development, subject to the provisions of section 30:

b. Provisions for standards encouraging and promoting flexibility, and economy in layout and design through the use of planned unit development, planned unit residential development and residential cluster; provided that such standards shall be appropriate to the type of development permitted; and provided further that the ordinance shall set forth the limits and extent of any special provisions applicable to such planned developments, so that the manner in which such special provisions differ from the standards otherwise applicable to subdivisions or site plans can be determined;

c. Provisions for planned development:

(1) Authorizing the planning board to grant general development plan approval to provide the increased flexibility desirable to promote mutual agreement between the applicant and the planning board on the basic scheme of a planned development and setting forth any variations from the ordinary standards for preliminary and final approval;

(2) Requiring that any common open space resulting from the application of standards for density, or intensity of land use, be set aside for the use and benefit of the owners or residents in such development subject to section 31 of this act;

(3) Setting forth how the amount and location of any common open space shall be determined and how its improvement and maintenance for common open space use shall be secured subject to section 31 of this act;

EXPLANATION--Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

(4) Authorizing the planning board to allow for a greater concentration of density, or intensity of land use, within a section or sections of development, whether it be earlier, later or simultaneous in the development, than in others;

(5) Setting forth any requirement that the approval by the planning board of a greater concentration of density or intensity of land use for any section to be developed be offset by a smaller concentration in any completed prior stage or by an appropriate reservation of common open space on the remaining land by grant of easement or by covenant in favor of the municipality; provided that such reservation shall, as far as practicable, defer the precise location of common open space until an application for final approval is filed, so that flexibility of development can be maintained;

(6) Setting forth any requirements for timing of development among the various types of uses and subgroups thereunder and, in the case of planned unit development and planned unit residential development, whether some nonresidential uses are required to be built before, after or at the same time as the residential uses.

d. Provisions ensuring in the case of a development which proposes construction over a period of years, the protection of the interests of the public and of the residents, occupants and owners of the proposed development in the total completion of the development.

e. Provisions that require as a condition for local municipal approval the submission of proof that no taxes or assessments for local improvements are due or delinquent on the property for which any subdivision, site plan, or planned development application is made.

f. Provisions for the creation of a Site Plan Review Advisory Board for the purpose of reviewing all site plan applications and making recommendations to the planning board in regard thereto.

g. Provisions that require as a condition for local municipal approval the submission of proof that the property for which any subdivision, site plan, or planned development application is made has been treated on its perimeter with appropriate materials to combat deer ticks.

(cf: P.L.1987, c.129, s.2)

2. This act shall take effect immediately.

STATEMENT

This bill permits a municipal land use ordinance to include as a condition for local municipal approval the submission of proof that the property for which application is made has been treated on its perimeter with appropriate materials to combat deer ticks.

Lyme disease is spread by deer ticks and is one of the fastest

growing public health problems in New Jersey. Lyme Disease is the most common tick-borne illness in the United States, and New Jersey is one of the states in which the disease is most prevalent.

The disease is still relatively unknown among both the medical community and the general public and consequently is often misdiagnosed or not diagnosed, resulting in more serious health problems for the affected person. Lyme disease, if untreated, can result in neurological disorders and severe arthritis in its advanced stages.

In essence, the bill employs the municipal land use approval process on a permissive basis to combat Lyme Disease.

LOCAL GOVERNMENT

Employs on permissive basis the municipal land use approval process to combat the tick-borne illness Lyme Disease.

ASSEMBLY, No. 3478

STATE OF NEW JERSEY

INTRODUCED APRIL 30, 1990

By Assemblywoman FORD and Assemblyman DOYLE

AN ACT establishing a Lyme disease research program in the Department of Health and making an appropriation therefor.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. The Legislature finds and declares that:

a. Lyme disease is a bacterial infection which is spread by deer ticks and is one of the fastest growing public health problems in New Jersey.

b. There is evidence that the disease may also be transmitted through blood products, shared needles, raw milk and blood-sucking insects.

c. Lyme disease, which is the most common tick-borne disease in this country, is present at all times in 23 states and appears to be spreading, with New Jersey one of the states in which the disease is most prevalent.

d. Because Lyme disease, which was not widely recognized in the United States until 1975, is still relatively unknown among both the medical community and the general public, it is often misdiagnosed or not diagnosed, which results in more serious health problems for the affected person.

e. If untreated, Lyme disease, in its later stages, can result in neurological disorders, including chronic and severe fatigue, encephalitis, meningitis, memory loss, dementia and seizures; severe arthritis; cardiac complications; vision difficulties and stomach disorders.

2. As used in this act:

"Commissioner" means the Commissioner of Health.

"Program" means the Lyme disease research program established pursuant to this act.

3. The commissioner shall establish a Lyme disease research program to study and develop the most effective means for the prevention, detection, treatment and cure of the disease, according to guidelines established by the commissioner.

4. The commissioner shall report to the Governor and the Legislature no later than 18 months after the effective date of this act, and annually thereafter, on the results of the program, and shall accompany the report with any recommendations for administrative or legislative actions regarding Lyme disease.

5. The commissioner shall seek such funds as may be available from the federal government, private foundations or other sources to supplement those funds which are appropriated or otherwise made available from the General Fund for the program.

6. The commissioner, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), shall adopt rules and regulations to effectuate the purposes of this act.

7. There is appropriated $500,000 from the General Fund to the Department of Health to carry out the provisions of this act.

8. This act shall take effect immediately.

STATEMENT

This bill establishes a Lyme disease research program in the Department of Health to study and develop the most effective means for the prevention, detection, treatment and cure of the disease. The bill includes a $500,000 appropriation to establish the research program.

The bill requires the Commissioner of Health to report to the Governor and the Legislature no later than 18 months after the effective date of this act, and annually thereafter, on the results of the Lyme disease research program in achieving its objectives, and to accompany the report with any recommendations for administrative or legislative actions regarding Lyme disease.

HEALTH

Establishes Lyme disease research program in the Department of Health and appropriates $500,000.

ASSEMBLY, No. 3515

STATE OF NEW JERSEY

INTRODUCED MAY 14, 1990

By Assemblywoman FORD and Assemblyman DOYLE

AN ACT concerning Lyme disease in State parks and forests and in lands managed by the Division of Fish, Game and Wildlife, and supplementing Title 13 of the Revised Statutes.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. The Legislature finds and declares that Lyme disease, which is spread by deer ticks and is one of the fastest growing public health problems, was first identified in the State in Monmouth county in 1978, and the reported incidents of the disease have since spread to other counties in New Jersey; that Lyme disease is the most common tick-borne illness in the United States, and New Jersey is one of the states in which the disease is most prevalent; that the disease is still not widely understood among both the medical community and the general public and, consequently, is often misdiagnosed or not diagnosed, which results in more serious health problems for the affected person; and that Lyme disease, if untreated, can cause neurological disorders and, in its advanced stages, severe arthritis.

2. The Department of Environmental Protection, in conjunction with the Department of Health, shall, within two years of the effective date of this act, conduct an investigation of the occurrence and transmission of Lyme disease in State parks and forests and in lands managed by the Division of Fish, Game and Wildlife of the Department of Environmental Protection; identify those State parks and forests and those lands managed by the Division of Fish, Game and Wildlife with high rates of occurrence and transmission of Lyme disease and high populations of deer ticks and other Lyme disease vectors; and identify methods for controlling and treating the disease and controlling the population of deer ticks and other Lyme disease vectors in State parks and forests and in lands managed by the Division of Fish, Game and Wildlife.

The departments shall, within 90 days of the completion of their joint investigation, prepare and transmit a report thereon, together with any recommendations for legislative or administrative action, to the Governor and the Legislature.

The departments shall thereafter continue to monitor the occurrence and transmission of Lyme disease in State parks and forests and in lands managed by the Division of Fish, Game and Wildlife, and prepare and transmit an annual report thereon to the Governor and the Legislature.

3. This act shall take effect immediately.

STATEMENT

This bill would require the Department of Environmental Protection, in conjunction with the Department of Health, to conduct, within two years, an investigation of the occurrence and transmission of Lyme disease in State parks and forests and in lands managed by the Division of Fish, Game and Wildlife of the Department of Environmental Protection. The departments would also be required to identify those State parks and forests and those lands managed by the Division of Fish, Game and Wildlife with high rates of occurrence and transmission of Lyme disease and high populations of deer ticks and other Lyme disease vectors, and identify methods for controlling and treating the disease and controlling the population of deer ticks and other Lyme disease vectors in State parks and forests and in lands managed by the Division of Fish, Game and Wildlife. The departments would be required, within 90 days of the completion of their joint investigation, to prepare and transmit a report thereon, together with any recommendations for legislative or administrative action, to the Governor and the Legislature. The departments would also be required to thereafter continue to monitor the occurrence and transmission of Lyme disease in State parks and forests and in lands managed by the Division of Fish, Game and Wildlife, and prepare and transmit an annual report thereon to the Governor and the Legislature.

HEALTH

Requires DEP and Dept. of Health to investigate Lyme disease in State parks, forests, and fish and game lands.

Suggestions from the Lyme Disease Coalition of New Jersey

The Lyme Disease Coalition of New Jersey is a group of laypeople and physicians who have been heavily affected by Lyme Disease. The suggestions which follow come from our realization that no single traditional way of diagnosis and treatment will succeed against this disease. We need to broaden our approach. The multisystemic and rapidly-changing nature of Lyme disease makes this imperative. Many New Jersey residents are now chronic sufferers, and research must be broadened to include treatment of those whom traditional clinical treatment has failed to help. New Jersey has the sufferers. New Jersey has the resources. Now New Jersey has to make the commitment. We urge the Governor to consider the following:

(1) Direct the Department of Health to review the current, restrictive case definition and recommend changes. The existing definition denies treatment to many clinically diagnosed Lyme disease victims.

(2) Establish an Advisory Council on Lyme Disease, composed of clinicians, patients, and patient advocates.

(3) Conduct more clinical research on a state-wide basis into vaccines and chronic Lyme disease treatment, including antibiotics and experimental therapeutic measures (e.g. recent proposals from Dr. Heimlich). Possible funding from pharmaceutical companies for this as well as following research items.

(4) Establish a pathology laboratory to study chronic Lyme disease and review case histories.

(5) Direct the Department of Health to reinstitute research and education on tick/vector control.

(6) Ask the Department of Health to establish a database of ongoing research and treatment programs around the country. This can be placed on a simple, inexpensive PC.

(7) Encourage the Legislature to designate a check-off on the N.J. State Income Tax return for Lyme disease research.

(8) Set up a toll-free Lyme Disease Hotline.

(9) Direct the Departments of Health and Education to design and implement a thorough educational program for students, faculty, and parents. Further programs for school health care professionals should be offered.

(10) Hold ongoing seminars for the medical community, and annual conferences on Lyme disease. (Possible funding from pharmaceutical companies.)

(11) Lobby our Congressional delegation to focus national attention and funding towards Lyme disease. Support local legislative efforts with the signing of the 10 bills currently in the Legislature.

We appreciate the interest you have shown and the time you have spent in meeting with us today. We hope that today's efforts will be the beginning of a unified effort from your office on down to fight for the elimination of Lyme disease in New Jersey.

Thank you very much.

Russ Conklin
L.D.Coalition

Ken & Kerry Fordyce
L.D. Assn.of Central Jersey

Emilia Eiras,M.D.
L.D. Assn.of Central Jersey

William Moskowitz, D.D.S.
L.D.Coalition

Carol Gabriel
N.J.L.D. Support Group

Mary Ellen Monahan
Morris-Essex-Warren Support

Cyndi Monahan
Morris-Essex-Warren Support

Michelle Jones
L.D.Coalition

Roslyn Lashin
L.D.Coalition

Libby Waldmann
S.New Jersey Lyme Assn.

Kathy Conway
L.D. Assn.of Central Jersey

Alice Giunta
Sussex Co.Lyme Support Group

Barbara Cole
Sussex Co.Lyme Support Group

Peggi Sturmfels
L.D. Assn.of Central Jersey

Ann Frank,R.N.
L.D. Assn.of Central Jersey

Kim Uffleman
L.D. Assn.of N.New Jersey

Sallie Timpone
L.D. Assn.of N.New Jersey

John Drulle,M.D.
L.D.Coalition

Howard & Phyllis Gowa
L.D. Coalition

Niki Giberson
S.New Jersey Lyme Assn.

Charlene Paulsworth
S.New Jersey Lyme Assn.

John Bleiweiss,M.D.
L.D.Coalition

LYME DISEASE COALITION OF NEW JERSEY

The Lyme Disease Coalition of New Jersey was formed out of a common desire to share information about Lyme disease, to provide a united voice in promoting Lyme disease legislation, and to support each other in our efforts to fight this persistent affliction - through education, fund-raising, and personal support.

The groups and individuals involved currently are:

New Jersey Lyme Disease Support Group

Lyme Disease Assoc. of Northern New Jersey

Sussex County Lyme Support Group

Morris-Essex-Warren Co. Support Group

Lyme Disease Assoc. of Central Jersey

Southern New Jersey Lyme Disease Assoc.

Individual physicians and patient advocates

We are currently involved in the design and support of five bills before the State Assembly and five companion bills before the State Senate. The next major fund-raiser which we are supporting is a dinner-dance to be held at the Cameo in Garfield, NJ, complete with music, silent auction, a major prize (trip to Hawaii), and participation by opera stars and television personalities. This will be held on November 2, 1990. Inquiries to Peggi Sturmfels, at (908) 657-2190 (Central and South) or Sallie Timpone, at (201) 288-5249 (North).

Please direct inquiries about the Lyme Disease Coalition of New Jersey to:

Dr. Emilia Eiras, M.D.
20 W. County Line Rd.
Jackson, NJ 08527
(908) 905-9630

PERSONAL  PROTECTION

- **Check yourself frequently and thoroughly for ticks**
- **Check yourself frequently and thoroughly for ticks**
- **Avoid tick habitat(woods,brush,high grass) and walk in the middle of wooded trails**
- **Wear light-colored clothing**
- **Wear long pants with cuffs tucked into socks**
- **Use Permanone(permethrin) sprayed on your clothes per manuf. instructions(lasts 3 - 5 washings)**
- **Use Deep Woods Off(DEET) sprayed on exposed skin per manuf. instructions. Not >30% DEET.**

GOOD NEWS: Once the tick is on you, it may crawl around for several hours before biting. Transmission of the spirochete may take hours as well. In short - don't panic. You have time to find the tick - as long as you make it a habit to **look for them on a routine basis.**

All product names are used as examples only. Lyme Disease Coalition offers no warranty for any specific product. Consumers must rely upon manufacturer's instructions and warranties

HOME  PROTECTION

- Cut back brush around the yard.
- Keep grass cut short - eliminate weeds.
- May 1-15 - Granular diazinon, sevin(carbaryl), or dursban against nymphs. If a sensitive area, liquid permethrin(4-Week Tick Killer) may be good.
- Jul.31 - Damminix against larvae and nymphs. Will help control ticks & infection rate next year.
- Aug.01-21 - Like May 15. Against larvae and nymphs.
- Nov.01-30 -Liquid permethrin or liquid/granular diazinon, sevin, or dursban against adults.
- Whenever you use liquid sprays, apply after 10:00 or 11:00 a.m. This will expose the most "questing" ticks. Avoid windy days.

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COMMUNITY  PROTECTION

- Maintain parks - keep grass short.
- Examine walking trails and cut back brush along edges.
- Distribute Lyme disease information at all common areas
- Send public health, public works, and parks employees to training on:
  - Assessment of tick habitat
  - Design of a tick control program
- Use limited, targeted application of pesticides per the recommendations under "Home Protection". (Large-scale spraying would be prohibitively expensive, and would have very limited success.)
- Provide products such as Permanone and Deep Woods Off for public works and parks employees
- Require developers to provide protection to newly-developed property in endemic areas

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LYME DISEASE FACT SHEET

1. Lyme disease is caused by a spirochete, a bacteria similar to that which causes syphilis. Most cases are transmitted by the bite of a tick, although there are other possible vectors.

2. The disease has been present in New Jersey since at least 1978.

3. The reported cases are probably 10 % of the actual incidence.

4. All 21 counties are affected, with the greatest number of cases in Central New Jersey.

5. The current case definition from the Centers for Disease Control probably eliminates the majority of cases as reportable. Most primary care physicians familiar with Lyme agree that the criteria for reportable cases should be modified.

6. Since the Lyme bacteria can invade every organ of the body, the resulting symptoms can be myriad and capable of mimicking dozens of other diseases.

7. Current approved diagnostic tests are incapable of definitively diagnosing early disease and can be inconclusive in late disease. Lyme disease is essentially a diagnosis made by the physician based upon the patient's symptoms, which may be supported by laboratory evidence, but in no way ruled out by the lack of conclusive tests.

8. There is no test for cure currently available.

9. Antibiotics are currently the cornerstone of treatment. There is no concurrence as to what is the optimal drug or length of treatment. Tetracycline is currently the drug of choice for early Lyme disease. In animal studies it has been shown that the Lyme bacteria can enter the central nervous system within hours of infection. Tetracycline does not achieve therapeutic levels in the central nervous system. This may account for development of late Lyme symptoms in patients "appropriately treated" early in the course of the disease. In late Lyme disease antibiotic treatment usually does not eliminate all symptoms. Persistence of these symptoms may be due to failure to eradicate the infection, or a "post-Lyme auto-immune process". There is ample evidence in the medical literature that the Lyme bacteria can survive despite lengthy courses of high-dose intravenous antibiotics. This may explain persisting symptoms in some patients. Our collective experience with several thousand patients with late Lyme disease has led us to conclude that chronic infection with the Lyme bacteria is responsible for ongoing suffering in the majority of

patients - despite prolonged antibiotic treatment. These patients do not suffer from hysteria, chronic fatigue syndrome, or major depression as primary diagnoses.

10. Current medical research in New Jersey does not address chronic Lyme disease as a chronic infection.

Emilia Eiras, M.D. John Drulle, M.D. Charles Weber, M.D.

John Bleiweiss, M.D. Susan Dick, M.D. Mori Schwartzberg, M.D.

Dorothy Pietrucha, M.D. Frank Alario, M.D. Joseph Bogdan, M.D.

LYME DISEASE PUBLICATIONS

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Division of Epidemiology and Communicable Disease Control

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LYME DISEASE COALITION OF NEW JERSEY

The Lyme Disease Coalition of New Jersey was formed out of a common desire to share information about Lyme disease, to provide a united voice in promoting Lyme disease legislation, and to support each other in our efforts to fight this persistent affliction - through education, fund-raising, and personal support.

The groups and individuals involved currently are:

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Lyme Disease Assoc. of Northern New Jersey

Sussex County Lyme Support Group

Morris-Essex-Warren Co. Support Group

Lyme Disease Assoc. of Central Jersey

Southern New Jersey Lyme Disease Assoc.

Individual physicians and patient advocates

We are currently involved in the design and support of five bills before the State Assembly and five companion bills before the State Senate. The next major fund-raiser which we are supporting is a dinner-dance to be held at the Cameo in Garfield, NJ, complete with music, silent auction, a major prize (trip to Hawaii), and participation by opera stars and television personalities. This will be held on November 2, 1990. Inquiries to Peggi Sturmfels, at (908) 657-2190 (Central and South) or Sallie Timpone, at (201) 288-5249 (North).

Please direct inquiries about the Lyme Disease Coalition of New Jersey to:

Dr. Emilia Eiras, M.D.
20 W. County Line Rd.
Jackson, NJ 08527
(908) 905-9630

TESTIMONY

The Impact of Lyme Disease in New Jersey and Measures to Address This Problem

to

Assembly Health and Human Services Committee
Jackson Township Municipal Building
November 2, 1990

by

William E. Parkin, DVM, DrPH
Assistant Commissioner
Epidemiology and Disease Control
New Jersey Department of Health

Frances J. Dunston, M.D., M.P.H.
State Commissioner of Health

22X

LYME DISEASE IN NEW JERSEY

Lyme disease is a tick mediated, spirochete induced multi-systemic illness that has been reportable in New Jersey since 1980. Since identification of the index case in 1978, the number of Lyme disease cases has increased dramatically from a handful each year during the late 1970's to nearly 1,000 cases through 10 months of 1990, despite a more restrictive case definition adopted in 1988. Several informal surveys suggest that there is a 5- to 10- fold degree of underreporting. New Jersey ranked third in the nation with respect to the number of confirmed Lyme disease cases reported to Centers for Disease Control.

The etiological agent Borrelia burgdorferi is transmitted primarily by the nymph and adult stages of the northern deer tick, Ixodes dammini. In New Jersey, the lone star tick, Amblyomma americanum serves as a secondary tick vector. In hyperendemic areas of New Jersey, 40-50% of deer ticks are infected with B. burgdorferi.

Initial investigations conducted in the early 1980's indicated that the geographical range of vector tick populations was limited to the southern two-thirds of the State. By the late 1980's, this geographical range had expanded to the New Jersey/New York border. Today, although Monmouth, Ocean, and Atlantic Counties continue to account for 60% of all cases each year and demonstrate a confirmed case rate (unadjusted for degree of underreporting) as high as 48/100,000, Lyme disease has been

reported from every county in the State. In certain municipalities, case rates exceeding 500/100,000 have been reported. Therefore, the entire State is now considered endemic for Lyme disease.

Despite the absence of a formal Lyme Disease Program and dedicated resources, the New Jersey State Department of Health (Department) has been quite active regarding Lyme disease. The Department's activities have and continue to stress education, surveillance, and research.

Educational activities include:

1. community outreach (distribution of pamphlet Lyme Disease in New Jersey, numerous presentations to the general public and support groups, and telephone consultations); and

2. education of the medical/professional communities (annual distribution of Health Bulletin on Lyme disease, presentations to physicians/professional groups, training of local health officers, preparation of several videotapes, publishing results of research in the scientific/medical literature, and active participation in the first three International Conferences on Lyme Disease and Related Disorders).

Surveillance activities include:

1. establishment of fee-for-service serological testing, tick testing, and tick identification; and

2. maintenance of a passive surveillance program for this reportable disease.

Research activities have led to the publication of over 20 papers in the scientific literature (list attached) on subjects including

the clinical aspects of early and late stage Lyme disease;

geographical distribution of Lyme disease cases and the distribution and behavior of vector tick populations;

This research has been conducted in cooperation with local health departments (Freehold Township), other state agencies (NJDEP), other state departments of health (New York at Stony Brook), and federal agencies (U.S. Army/Ft. Monmouth and U.S. Navy/NWS Earle).

The Department of Health anticipates continued concern about Lyme disease and intends to pursue examination of the case definition and how it is used by third party payers. We are also making an informational telephone line available during working hours so that the public can call and receive information and referrals to appropriate services.

Conclusion

I appreciate this time to speak before you. The Department of Health will be interested in hearing the testimony of others and the results of your own deliberations.

45 Jackson Road
Medford, New Jersey
08055

October 31, 1990

David Price, Committee Aide
New Jersey State Legislature
Assembly Health and Human
Services Committee
State House Annex, CN-068
Trenton, New Jersey 08625-0068

Dear Mr. Price:

As a nurse and mother of three adolescent daughters, I am addressing my concerns about Lyme disease in adolescents, its increase in incidence statewide, and measures we can take to help prevent this disease.

The June 25, 1988 Philadelphia Inquirer printed that 217 cases of Lyme disease in New Jersey were reported to the Center for Disease Control for 1986. The New Jersey State Health Department reports that in a survey of Lyme disease cases from 1978-1987, 43% of cases were in children, 18% of those cases were in adolescents 10-19 years of age. In 1988, 551 cases of Lyme disease were reported in New Jersey, 33 of these cases occurred in Burlington County, where I reside with my family. Last year, as of June, 1989 there were already 33 cases of Lyme disease in my county, and this was only the beginning of the season.

As you know in our area, the Jersey Pinelands, there appear to be the following three species of ticks that transmit Lyme disease to humans and animals: Lone Star, American Dog, and Deer ticks. Because adolescents spend alot of time outdoors with their friends hiking, biking, and partying in woodsy areas, they are at high risk to be bitten by ticks and be infected with the borreliosis spirochete bacteria that cause Lyme disease.

In August 1989 I graduated as a Pediatric Nurse Practitioner with a Masters in Nursing from the University of Pennsylvania. On the afternoon of July 1, 1989 I saw a 15 year old girl who had a primary rash called erythema chronicum migrans as well as secondary satellite lesions, a history of a tick bite three weeks previously, and an interest in outdoor-type activities. There was laboratory confirmation of Lyme disease, and the patient was placed on appropriate antibiotic therapy. I educated the entire extended family concerning what is presently known about Lyme disease and its prevention.

We must therefore, support bills as the Moynihan-Hochbrueckner bill that proposed the authorization of $7.5 million over three years for National Institute of Health research grants and $3 million for public education concerning Lyme disease.

Thank you.

Sandra Frame M.S.N., CPNP, B.S.N., RN

Dear Ms. Price,

This was a letter I wrote to Senator Bradley last year which never received a response but I would like this read in the hearings also.

Thank you,
Cindy Brame

45 Jackson Road
Medford, New Jersey
08055

June 27, 1989

Senator Bill Bradley
1 Greentree Center
Marlton, New Jersey
08053

Honorable Senator Bradley:

As a nurse, wife of a veterinarian, mother, and a New Jerseyite, I am addressing my concerns about Lyme disease, its increase in incidence statewide, and measures we can take to help prevent this disease.

The Journal of the American Medical Associaton, in May of 1984, stated that there was a total of 117 cases of recognized Lyme disease in New Jersey during the years of 1978 to 1982. The June 25, 1988 Philadelphia Inquirer printed that 217 cases of Lyme disease in New Jersey were reported to the Centers for Disease Control for 1986. Last year, 551 cases were reported in New Jersey, as stated by the May 28, 1989 Philadelphia Inquirer, and 33 of these cases occurred in Burlington County, where I reside with my family. The May 18, 1989 Central Record of Medford, New Jersey stated that this year, there are already 33 cases of reported Lyme disease in my county, and this is the just the beginning of the season!

As you know, in our area, the Jersey Pinelands, there appear to be the following three species of ticks parasitic to humans: the Lone Star tick, the American dog tick, and the deer tick. All three are known to transmit Lyme Disease, and the Lone Star and American dog ticks may also harbor Rocky Mountain Spotted Fever. Ticks require multiple animal hosts to complete their life cycle. The adult tick prefers to feed on a deer. The adult females, after a bloodmeal, drop off and lay eggs in the early summer, and these by July or August hatch into six-legged larvae, which feed on infected rodents as the white-footed mouse or other small mammals. The borreliosis bacteria are sucked up as well as their bloodmeal. The infected larvae drop off the host and emerge as eight-legged nymphs during the spring. These are about the size of a pinhead, and they require another bloodmeal before they can molt into adults. They climb up small shrubs or tall grasses and await a warm-blooded host as a bird, dog, cat, white-tailed deer or a person.

The greatest threat to man and animals is the nymph stage of the tick. The engorged nymph is gray and the size of a sesame seed and, therefore, difficult to see. It is also possible to contract a tick-borne disease by ingesting their feces, as when hands are not washed after handling wild animals or ticks or

after petting your dog.

My husband, a practicing veterinarian in New Jersey's Burlington County, last week had four canines with positive titers for Lyme disease. We anxiously await the canine test kit and vaccine which will, hopefully, be available in the late fall.

As a pediatric nurse practitioner student and an August, 1989 Masters candidate at the University of Pennsylvania, I have been questioned by mothers at my clinical site at a pediatric practice about their Lyme positive dogs. What is the danger of transmission in the household? How long after treatment is a dog still infectious? Neither pediatricians nor veterinarians have the answers.

As a former school nurse, I have worked with children still recovering from handicapping Lyme arthritis symptoms. In researching Lyme disease and pregnancy, there are documented case studies revealing that stillbirth, miscarriage, and other adverse outcomes are more frequent in pregnant women who contract this disease.

Lyme disease recognizes no socioeconomic barriers. I was sorry to hear that former U.S. representative Bedell of Iowa, who contracted Lyme disease possibly on a fishing trip to Virginia four years ago, was forced to retire from his House seat because of continuing symptomatology. The same fate befell former House member Kenneth Gray.

Prevention, education, and research will help fight Lyme disease. Please support the Moynihan-Hochbrueckner bill which proposes the authorization of $7.5 million over three years for National Insitute of Health research grants and $3 million for public education concerning Lyme disease.

Federal subsidies are also needed for Damminex, the biodegradable eight-inch tubes filed with insecticide-soaked cotton, which mice as hosts, bring back to their nests and kill the ticks and not the mice. The New Jersey counties of Atlantic, Burlington, Mercer, Monmouth, and Ocean, which have the highest incidence of Lyme disease, have a total of 1.7 million acres. However, only areas with tall grasses, woods, and shrubs need to be treated. Each acre is treated with 50 Damminex tubes twice per year, at a cost of $195 per acre per application. The New Jersey Mosquito Commission's budget for 1989 was $909,204; with federal monies, the Commission's program may be expanded to include Damminex treatment for areas highly infested with ticks.

Thank you.

Sandra Frame
1989 Masters in Nursing Candidate
University of Pennsylvania

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