

LYME DISEASE ASSOCIATION

SUMMARY OF 2009-2010 LYME-RELATED LEGISLATION

Connecticut

- HB 6200 - signed into law by Governor Jodi Rell June 21, 2009
- CT Medical Society supported the bill; Department of Health did not
- "It says the scientific community can have that debate, but we're not going to let anybody else go without treatment."
- See attachments below.

New Hampshire

- HB 1326 Doctor protection (Gary Daniels)
- 5 hour hearing on bill
- NH Medical Society against bill
- February 17, 2010
 - New Hampshire Lyme bill passes the NH House as amended
 - <http://www.gencourt.state.nh.us/legislation/2010/HB1326.html>
- SENATE EXECUTIVE DEPARTMENTS AND ADMINISTRATION: Bill was in fight to amend. Died. (Advocates did not want amendment – see below letter from House Bill Sponsor, Rep. Gary Daniels)

Massachusetts

- **Bill Number: HB 1148 (Hargraves)**
 - To allow physicians to prescribe, administer or dispense long-term antibiotics for therapeutic purposes to patients clinically diagnosed with Lyme disease.
 - Introduced (05/20/2009);
 - Referred to the HOUSE RULES (06/03/2009);
 - Reported, referred to the JOINT RULES, reported, rules and suspended and referred to the JOINT COMMITTEE ON PUBLIC HEALTH (06/22/2009);
 - Senate Concurred (06/24/2009);
 - Reported favorably by the Joint Committee on Public Health (02/09/2010)
 - Bill was amended (not requested by advocates) but original version was then appended to budget and passed by both houses. **Awaiting governor's signature.**
- **Bill Number: House Bill 4480**
 - An Act relative to tick borne illnesses
 - Would establish a special commission for the purpose of investigating and studying the incidence and impacts of Lyme disease and its associated co-infections in the commonwealth.
 - Status: New draft of HB 1148 and HB 3592 (02/08/2010);
 - referred to the Joint Committee on Health Care Financing (02/08/2010).

Minnesota

- SF 1631/ (Marty, Vanderveer)
 - Passed out of Senate Committee after hearing
- HF2597 (Ward)
 - Hearing and tabled
- In place of the bill, an agreement was reached and the MN Medical Board passed a 5 year moratorium providing doctor protection while the science evolves.

Pennsylvania

- SB 1199 (Greenleaf)
 - Task Force on TBDs – prevention and education

- Doctor Protection of Clinical Judgement and Patient Informed Consent
 - Insurance coverage for Physician prescribed treatment
- Referred to Senate Banking & Insurance
- Upcoming hearing June 22, 2010
- Awaiting amendment to be introduced by Senator Greenleaf from the bill listed on the PA House website.

New Jersey

- **Neuroendocrine immune disorders**
- **AR 122/SR133**
 - **Initiated by chronic fatigue advocates**
 - **Asked NJ legislature to memorialize formation of NEI Center that includes Gulf War Syndrome, multiple chemical sensitivity, chronic fatigue syndrome, & Lyme disease**
 - **LDA and most other Lyme groups opposed the Resolution**
 - **REASON: Lyme is not autoimmune disease but has a specific bacterial cause**
 - **Motion did not come up for vote in Senate**
 - **Failed**
- **Motion reintroduced w/o the words “Lyme disease” in it.**

Rhode Island

- **RI currently has proposed Lyme disease curriculum bill**
 - **LDA proposed new language changes (removing word treatment)**
 - **Sponsor proposed an amendment to only provide materials**
 - **Awaiting action**
- **Rhode Island Diagnosis & Treatment Act**

Doctor Protection Legislation Adopted

CHAPTER 159, 2002-H 7996A. Enacted 06/25/2002. Introduced By: Representatives Rabideau, and Ginaitt. **Rhode Island, June 10, 2004**

On June 8, Governor Donald Carcieri signed [S2939/H7240](#) into law, removing the sunset provision from the 2003 Lyme insurance law. This signing makes Rhode Island the only state in the nation with mandatory coverage for long-term antibiotics for treatment of Lyme disease when ordered by a treating physician who determines it is medically necessary after a thorough review of a patient’s medical history and condition.

In 2004, patients have already received reimbursement under the original law passed in 2003; however, the 2003 law contained a sunset provision that would have terminated the law at the end of 2003, depriving patients of much needed treatment. Recently, the RI legislature overwhelmingly passed the new law eliminating that sunset provision — no expiration, so patients can continue to receive coverage.

Maryland

- **Three Lyme-related bills have passed through the Maryland legislative process so far this session (2010)**
- **LDA & most other Lyme groups were not favorable to 2 of these bills which we felt would have caused problems for docs and patients**
 - **HB 290- Doctor Protection- Voted Unfavorable in Committee and Withdrawn.**
 - **HB 798- Task Force- Voted Unfavorable in Committee and Withdrawn**
- **HB 2- Reporting Cases- Voted Unfavorable in Committee and Withdrawn**

- Purpose of this bill was unclear, favored reporting yet reporting was already done.

**New Jersey Department of Education Adopted
NJ Core Curriculum Content Gr 6**

“Diseases & Health Conditions

- **3. Compare and contrast diseases and health conditions prevalent in adolescents, including asthma, obesity, diabetes, Lyme disease, STDs, and HIV/AIDS.”**
- **SE: 191-195, 200-201**
- ***Applying Health Skills* 201**
- **TWE: MA 200”**

**Core Curriculum Content Standards for
Comprehensive Health and Physical Education
Grade 6 Teen Health Course 1 © 2005**

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California

Connecticut Lyme bill – HB 6200 – May 2009

Source: http://www.connpost.com/ci_12267343

The Connecticut Lyme bill received unanimous approval in that State's House of Representatives today. The bill is designed to protect doctors who treat Lyme disease and, in particular, Chronic Lyme disease. Introduced by State Representatives Kimberly Fawcett and Jason Bartlett, the bill also received unanimous support from the State's Joint Committee on Public Health in an earlier vote.

The bill has the support of the Connecticut State Medical Society, although not from its Department of Public Health.

Today's vote in the House of Representatives brings the bill one important step closer to becoming law. Connecticut may soon join the ranks of New York and Rhode Island, which already have Lyme doctor protection laws in place. The bill now moves on to the Senate.

"I had no idea what last July was going to present to me when my husband was diagnosed with a life threatening case of Lyme disease," said Rep. Fawcett.

State Representative Jason Bartlett has made this his cause because his mother has Chronic Lyme disease.

From The Connecticut Post: "[The bill] comes down on the side of people who suffer from Lyme in this big debate," said state Rep. William Tong, D-Stamford, a bill co-sponsor. "It says the scientific community can have that debate, but we're not going to let anybody else go without treatment. The state House of Representatives took a strong stand on the issue. **In a 137-0 vote, members passed legislation to reassure doctors they will not face retaliation if they choose to diagnose chronic Lyme disease and treat it with long-term antibiotics.**

Newtown, CT, JUNE 21, 2009 – Patient groups across Connecticut and the nation are elated by the June 21 announcement by Connecticut Governor Jodi Rell that she has signed the Lyme disease doctor protection bill, following its recent unanimous passage in both houses of the Connecticut General Assembly.

HB 6200 contains language that will protect Connecticut licensed Lyme treating physicians from prosecution by the State of Connecticut Medical Examining Board solely on the basis of a clinical diagnosis and /or for treatment of long-term Lyme disease. The bill provides the definition for Lyme disease which includes "the presence in a patient of signs and symptoms compatible with acute infection with *Borrelia burgdorferi*; or with late stage or persistent or chronic infection with *Borrelia burgdorferi*, or with complications related to such an infection." It also defines clinical diagnosis as determined by a physician "...that is based on knowledge obtained through the medical history and physical examination alone, or in conjunction with the testing that provides supportive data for such clinical diagnosis." In addition, it provides for updating the Lyme disease definition if other strains are found to cause Lyme disease.

This law resulted from months of negotiations between Legislative Leaders, the Connecticut Department of Public Health and the undersigned patient Groups. According to Maggie Shaw, Newtown Lyme Disease Task Force, who has been a leader in the Connecticut effort, "This law will be a relief to the families in CT who will finally be able to receive care in their own communities and their own state. One of the burdens of Lyme disease, finding treatment, will be lifted from their shoulders, as this law offers hope to residents that more physicians who are knowledgeable about Lyme disease will be encouraged to practice within the State of Connecticut."

Pat Smith, president of the national Lyme Disease Association, who has been working and meeting with legislators in Hartford to secure passage, commented on the new law: "Justice has been served. Human health has finally triumphed over vested interest in the Lyme capital of the world. Lyme patients and treating physicians in Connecticut can breathe a collective sigh of relief. For years, they have not only been battling the disease but also battling the politics which have prevented patients from getting treatment and physicians from treating. Governor Rell and the Legislature have come down on the side of the people."

The Groups extend their gratitude to Governor Jodi Rell and the General Assembly, and in particular, Representatives Jason Bartlett, Kim Fawcett, Chris Lyddy, and Peggy Reeves, and Senator Jonathan Harris and Representative Betsy Ritter, Co-Chairs of the Joint Public Health Committee. The support of patients, families, members of the Lyme community, the Connecticut Medical Society, Association of American Physicians and Surgeons, and the International Lyme & Associated Diseases Society was invaluable.

Connecticut becomes the third state in the nation to have a law that protects physicians who treat Lyme disease long term.

For wording on the bill, please go to <http://www.cga.ct.gov/> **HB6200 (File # 903)**.

New Hampshire Representative Gary Daniels, bill sponsor

Dear Lyme Community,

HB1326 died on Wednesday in what can only be described as a bizarre and shameful Committee of Conference on the bill. The Committee of Conference was established because the versions of HB1326 passed by the House and Senate were different.

Bill History: In the House

In January a public hearing on the bill was held by the House Health and Human Services Committee (HHSC), which voted 18-1 to recommend to the full House that the bill be put in study, essentially delaying any relief for Lyme victims for at least a year. Rep. John Cebrowski was the only member to vote against Interim Study and in favor of passage, and our thanks go to him for his steadfast support. The full House subsequently overturned the HHSC recommendation and voted 300-56 to pass the bill.

Bill History: In the Senate

In April HB1326 went to the Senate, where a public hearing was held in the Senate Executive Department and Administration (ED&A) Committee. In May, with one (Sen. Martha Fuller Clark) of the five members absent, the ED&A Committee voted 2-2 on a motion to pass HB1326 without amendment.

Senators Betsi DeVries and Michael Downing supported passage of the bill and our thanks go to them also for their support. The motion was opposed by Senators Sharon Carson and Jackie Cilley, who both supported gutting the bill and setting up a study committee. The proposed amendments were created without any attempt to solicit feedback from the sponsor of the bill or the Lyme Legislation Committee whether or not the proposed amendments would be helpful or harmful to the Lyme community. (Note: Once the Lyme Legislation Committee got a look at the amendment, it felt that the amendment was so badly drafted and flawed that the Lyme community would be better off with no bill than the amendment proposed by Senators Cilley and Carson.) Parliamentary procedure states that a motion fails on a tie vote, so the bill when to the full Senate with an Inexpedient to Legislate recommendation (kill the bill).

Senators Cilley and Carson proposed their study amendment before the full Senate and managed to pass the amendment by one vote, 13-11 (a 12-12 vote would have killed the amendment). The vote was taken by voice, not roll call, so there is not a record of how each senator voted (though you can call your senator and ask!) If only one person who voted for study voted instead to pass the bill, the bill would be before the Governor now for signature.

Bill History: To Committee of Conference

Instead, HB1326 went to a Committee of Conference this week, and that's when things started getting strange. The Committee of Conference normally consists of four members from the House committee that held the public hearing on the bill, and three from the Senate committee that held the public hearing on the bill. All conferees must have supported the position passed by their respective chambers. The Lyme Legislation Committee was well aware that there were numerous obstacles to overcome with a Committee of Conference:

1. In the House the bill would go back to the HHSC, chaired by Rep. Cindy Rosenwald, who had told her committee even before the House public hearing in January that HB1326 was a bad bill that needed to be killed. Rep. Rosenwald, who voted against the bill when it was before the full House, would select the House conferees, those selections being further OK'd by House Speaker Terie Norelli. The sponsor of the bill expressed his concerns to Speaker Norelli on this issue, and

further requested to be appointed to the Committee of Conference. He was told by the Speaker to discuss this with Rep. Rosenwald, who told the sponsor that normally the conferees would come from the HHSC. The question remained: Who would be appointed?

2. The committee from which House conferees were to come was the same committee that voted 18-1 to study the bill. Rep. Cebrowski was the only person who originally supported what would become the House position of Ought To Pass. With the Senate proposing to study the bill, would the chair select House conferees that upheld the House position, or the original HHSC recommendation to study the bill?

3. There were only three HHSC Democrats who, after Interim Study was overturned, supported passage of HB1326 (Reps. French, Merrick and Tilton) when it was voted on the House floor. All but one HHSC Republican also, ultimately, supported passage of the bill. Those appointed as House conferees were Reps. Barbara French, Evalyn Merrick, Frank Case and John Cebrowski. All had voted for final passage of the bill in the House, but three of the four originally supported studying the bill. Rep. French was appointed as Chair of the Committee of Conference. Would those selected as House conferees actually uphold the House position as they were obliged to do, or would they self-servingly side with the Senate to satisfy their own desire to study the bill?

4. The Senate appointed as their conferees Senators Peggy Gilmore, Molly Kelly and Michael Downing. All members appointed by the Senate were from the Senate HHSC, in spite of the fact that the Senate public hearing was held in the ED&A Committee. Only Senator Downing sat on both committees. How informed were the other two Senate conferees if they had not been involved in the process to date?

5. Senator Downing was a strong supporter of the bill as written, and had opposed passage of the Cilley/Carson amendment to study the issue. Why had he been appointed to the Committee of Conference, since conferees were supposed to have been selected from those supporting the Senate position (to study the bill)?

6. After deliberation of the Committee of Conference, it became clear that no Senate amendment was going to pass. The question remained: If the Senate amendment was rejected, would Senate conferees then support the House position rather than kill the bill?

7. Rep. French, as Chair, had the power to determine what motion would be made first. She correctly asked for a vote on the Senate amendment, to which she and the Senators Gilmore and Kelly raised their hand. Quickly realizing that she had exposed her true position, while also betraying her obligation to uphold the position of the House by supporting the Senate position while the House position was still an option, she said, "Oh, I meant to vote on the House position first," and negated the vote.

8. Not only was voting on the House position before the Senate amendment inappropriate, since the Senate version was the latest, but it also handed all the power to the Senators. The Senators now could hold their position and ultimately force the House to choose between the Senate amendment or nothing. This was disgraceful that Rep. French would willingly give all power that the House held to the Senate.

9. Even though objections were voiced by some House conferees members as to the inappropriateness of voting on the House position before the Senate amendment, Rep. French proceeded with the vote on the House version, this time voting with all other House conferees to support the House position. Senators Gilmore and Kelly opposed. Senator Downing was absent, participating in another Committee of Conference. The vote failed 4-2. It needed to be unanimous to pass.

10. Rep. French then went back to redo the original vote she had called for on the Senate amendment and voted with Senators Gilmore and Kelly to support the Senate-proposed study. All

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Press Releases

6/9/2004 **Rep. Gallison's Lyme disease bill now law**

STATE HOUSE -- The governor yesterday signed legislation sponsored by Rep. Raymond E. Gallison Jr. to permanently require health insurers in Rhode Island to cover antibiotics as a treatment for Lyme disease. The bill (2004-H 7240) is now law.

"Unfortunately, Rhode Island has one of the highest incidences of Lyme disease in the nation. Rhode Islanders need to have coverage for its treatment, particularly because the disease can become chronic and debilitating if left untreated," said Representative Gallison, a Democrat whose District 69 is in Bristol and Portsmouth. "Early detection and antibiotic treatment of Lyme disease saves victims from unnecessary pain, complications and costs."

The bill builds on legislation enacted last year, which was also sponsored by Representative Gallison. That law requires every individual or group hospital or medical insurance policy or individual or group hospital or medical service plan contract to provide for Lyme disease treatment. That treatment, under the law, includes not less than 30 days of intravenous antibiotic therapy, 60 days of oral antibiotic therapy, or both, and further treatment if recommended by a Rhode Island Medical Board certified rheumatologist, infectious disease specialist or neurologist.

The law is set to expire on December 31, 2004.

However, this year's bill removes that expiration date to make mandatory Lyme disease health insurance coverage a permanent requirement for Rhode Island insurers.

Representative Gallison said he has heard from people from all over the state who said they are grateful that they were able to get coverage for their treatment as a result of last year's bill, which was the first of its kind in the United States. The success of that bill, Representative Gallison said, warranted the removal of the expiration date.

According to information provided by the National Centers for Disease Control and Prevention, Rhode Island has consistently had one of the highest annual numbers of reported Lyme disease cases as a percentage of population in the United States.

With tick season now in full swing, Representative Gallison said this is a particularly appropriate time to call attention to the dangers of Lyme disease and the necessity to detect and treat it as soon as possible.

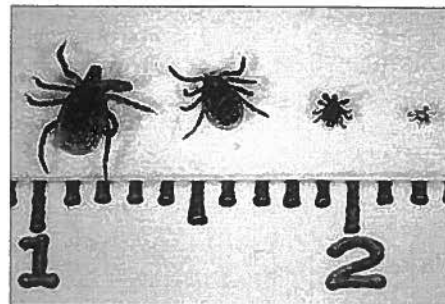
For information about Lyme disease and how to protect yourself from it, visit the Rhode Island Department of Health's Lyme disease information Web site at www.health.ri.gov/disease/communicable/lyme/home.htm.

The bill is cosponsored by Rep. Joanne M. Giannini (D-Dist. 7) of Providence, Rep. Thomas Winfield (D-Dist. 53) of Smithfield and Glocester, Rep. Fausto C. Anguilla (D-Dist. 68) of Bristol and Warren and Rep. William Enos (D-Dist. 71) of Tiverton, Little Compton and Portsmouth.

Identical Senate legislation sponsored by Sen. Michael J. Damiani was also signed by the governor yesterday.

For more information, contact:
Meredyth R. Waterman, Publicist
State House Room 20

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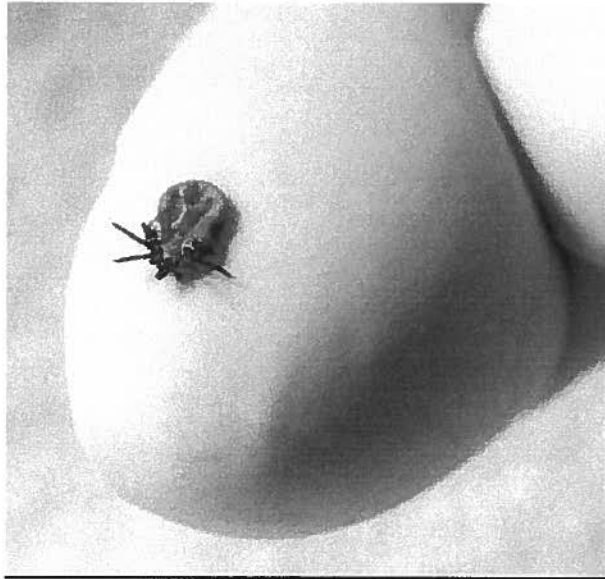
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Chronic Lyme disease treatment could face insurance battle

By Brian Lockhart
Staff Writer

Posted: 06/13/2009 10:08:27 PM EDT

Updated: 06/14/2009 10:12:08 AM EDT



Insurance companies could possibly refuse to pay for longer-term antibiotic treatments for chronic Lyme disease. A bill approved by the General Assembly and awaiting Gov. M. Jodi Rell's approval would allow physicians to diagnose chronic Lyme disease without fear of censure by peers of state health officials. (File Photo)

Many Lyme disease patients rejoiced last month when the General Assembly unanimously passed a

bill specifying that physicians could diagnose the controversial chronic Lyme disease and prescribe equally contentious long-term antibiotics to treat the tick-borne illness without fear of reprisal.

But the bill, which needs to be signed by Republican Gov. M. Jodi Rell, did not address another issue: Must insurance companies cover the extended treatments when various health organizations do not recognize the existence of chronic Lyme and warn against overuse of antibiotics?

"Even if the governor signs our law and the doctors will be technically allowed to prescribe (long-term) antibiotics, the insurance companies only have to pay for so much," said state Rep. Kim Fawcett, D-Fairfield, who helped spearhead the bill.

Many, including Fawcett's husband, believe they suffer from chronic Lyme disease. But various groups, from the state-based American Lyme Disease Foundation to the Infectious Diseases Society of America, dismiss its existence and caution against prescribing more than 28 days of antibiotic treatment.

Connecticut's chronic Lyme bill is intended to let physicians who wish to diagnose and treat the disease know they will not face recrimination from peers or health officials.

Connecticut, where Lyme disease was first identified, has had a unique law since 2000 mandating a minimum amount of long-term antibiotic treatment -- "not less than" 30 days of intravenous therapy, 60 days of oral therapy or both, with the possibility of longer treatments.

But observers such as Fawcett said they recognize that the law does not guarantee unlimited coverage for chronic sufferers.

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"The science is at best unclear. It was done in response to overwhelming pressure on legislators from people who clearly were suffering from something, although it's not at all clear necessarily it was or is Lyme disease," said Keith Stover, a lobbyist for the Connecticut Association of Health Plans.

"It's a heart-wrenching thing. There's no question if you attend hearings or speak to people they're suffering. (But) it is a very dangerous thing, we believe ... to be establishing particular courses of treatment in statute as mandates."

The 2000 antibiotic mandate is expected to garner far more attention if more physicians begin stepping forward to treat chronic Lyme.

Stover said the health plan association did not oppose this year's chronic Lyme bill. The group is instead relying on the existing process insurance companies use to determine "medical necessity" and patients' and doctors' ability to seek a third-party review of coverage decisions to grapple with the use of long-term antibiotics.

Fawcett said she has heard of insurance companies declining to cover continuous long-term antibiotic treatment beyond the 90-day minimum outlined in the 2000 law. She and state Rep. Betsy Ritter, D-Quaker Hill, chairman of the legislature's public health committee, said some chronic Lyme sufferers allege that doctors have been pressured for years by large insurers not to diagnose or treat the disease to hold down claims.

"There was some feeling ... insurance companies were getting claims and didn't want to pay," Ritter said. "But we didn't have opposition from insurance companies (to the chronic Lyme bill). It seemed to me it would follow this should not be an issue. If they start denying coverage, we'll find out."

Problems with antibiotic coverage could be dealt with in the future by the General Assembly, but Ritter said lawmakers have to be careful not to go too far.

"(Insurance companies) are often in terrible positions where publicly they're just vilified in cases where there actually is real abuse in the system. I understand that," Ritter said. "Insurance mandates can be a problem because often all that does is create a more fertile ground for more abuse."

Sarah Yeager, spokeswoman for Anthem Blue Cross and Blue Shield of Connecticut, wrote in an e-mail that the company follows Connecticut's 2000 Lyme treatment law, which also states insurers "shall provide further treatment if recommended by a board-certified rheumatologist, infectious disease specialist or neurologist licensed in accordance with (Connecticut) general statutes."

Robert McDonough, medical director for Aetna's clinical policy unit, said that the insurer follows the 2000 guidelines. But McDonough also said Aetna recognizes Lyme disease policies established by the Infectious Diseases Society and other evidence "that concludes there really is no reliable scientific evidence to support the need for very prolonged courses of antibiotics for Lyme."

"It's not merely there's a lack of evidence, but these treatments can have serious and even fatal adverse effects," McDonough said. "Highly virulent resistant organisms can take hold, or other adverse effects can occur. It's not an innocuous treatment." "It's more of a question of whether we would say at some point to stop it."

Kevin Lembo, who, as the state's health care advocate, assists residents denied coverage by insurers, said his office has dealt with Lyme disease issues, but he was uncertain whether any involved the use of long-term antibiotic treatments.

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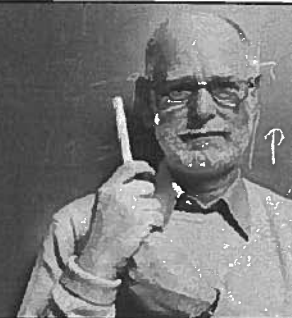


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Lembo said he suspects that will change if Reil passes the chronic Lyme bill and more doctors feel free to diagnose and treat the controversial illness.

"Whenever we make a case for trying to get a treatment for a patient considered investigational by the plan, we pull the academic research and clinical research together and get doctors not actively treating the patient to weigh in," Lembo said. "It will be interesting to see what happens when and if we get one of these cases. "Folks are very, very passionate about this issue."

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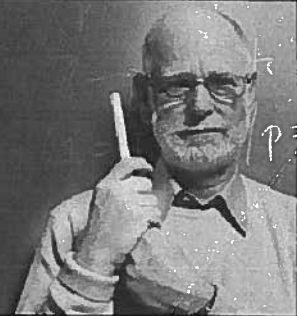
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