

Senate Health and Social Services Committee Meeting

Official Minutes 150th General Assembly First Session

**Wednesday April 17th, 2019
2:30pm
Senate Hearing Room**

Meeting Attendance

Committee Members:

Present:

Senator Bryan Townsend
Senator Brian Pettyjohn
Senator Stephanie Hansen
Senator Ernesto Lopez

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Absent:

Senator Nicole Poore

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Legislators Present:

Senator Tizzy Lockman
Representative Andria Bennett

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Staff:

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Maria Faiola

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Attendees

Lizzie Lewis
Rick Heong
Peggy Schultz
Christina Bryan
Wayne Smith
Chris Dipetro
Kevin Musto
Geoff Chrisi
Richard W. Henderson
Marilyn Williams
C.S. Kronetz
Meredith Seitz

Organizations

Hamilton Goodman Partners
DPH
LWV-DE
DHA
DHA
Epic Pharmacies
Atlantic Apothecary
DPR
MSD
Lyme Disease Association of Delmarva Inc.
DAA
DSCYF

Beverly Sisson	N/A
Amy Roe	N/A
Sarah Bucic	N/A
Krista Griffin	N/A
Mike Malkiewitz	N/A
Hon. Bill Torbert	Fm. Delaware State Senator
Judy Setting	N/A
Rebecca Benson	N/A
Lisa Torbert	N/A
Ilaina Meisler	N/A
Catherine Santes	N/A
Josh Rosen, MD	N/A

Agenda:

HB 12
 HB 24 w/HA 1
 HB 89
 SB 15

Senator Townsend brought the meeting to order at 2:31 p.m.

Senator Pettyjohn made a motion to approve the minutes.

Senator Lopez seconded the motion.

House Bill 24 w/HA 1 (Representative Bennett) - AN ACT TO AMEND TITLE 18 OF THE DELAWARE CODE RELATING TO COPAYMENT OR COINSURANCE FOR PRESCRIPTION DRUGS.

Original Synopsis: This Act would prohibit insurers and pharmacy benefit managers from engaging in the practice of "clawbacks". When the total cost of a prescription drug to an insurer or pharmacy benefits manager is less than a patient's co-pay, the insurer or pharmacy benefits manager keeps the difference in a practice known as a "clawback". According to a March 2018 report issued by the University of Southern California's Schaeffer Center for Health Policy & Economics based on the Center's analysis of 2013 data from a large commercial insurer combined with data on national average drug reimbursements, almost 25% of filled pharmacy prescriptions involved a patient co-payment that exceeded the average reimbursement paid by the insurer by more than \$2.00. The report further noted that overpayments were more likely to occur on claims for generic drugs than brand drugs and that the total overpayments in the Center's sample amounted to \$135 million.

Senator Townsend recognized Representative Andria L. Bennett to testify on House bill 24.

Representative Bennett talked about how HB24 will amend Title 17 of the Delaware Code relating to copayments and coinsurance of prescription drugs. Said it prohibits insurers and insurer pharmacy benefit managers from carrying out the practice of clawbacks. It is the companion bill to last year's bill that closed the loophole that prevented pharmacists from disclosing prices to patients. She said we assume when we get health insurance we are going to get the cheapest prices for prescriptions, but with clawbacks, when the total cost of prescription drugs for an insurer pharmacy benefit manager is less than a patient's copay, the insurer pharmacy benefit manager is able to keep the difference. Patients can be burdened by the copays under this clawback practice. According to an analysis done by the University of Southern California Shaffer Center of Health Policy and Economics, almost 25% of filled pharmacy prescriptions involved a patient copay that exceeded the average insurer reimbursement by more than two dollars with an average of eight dollars. The report also found that the total overpayments added to \$135 million and were more likely to occur in generic drugs. Said she had pharmacists with her to answer any specific questions.

Senator Townsend asked if there were any questions from the committee. Asked if those that signed up to testify were only there if called upon or if they still wanted to say something.

Representative Bennett said one of the pharmacists has a real example to illustrate it.

Chris DiPietro identified himself as representing Epic Pharmacies, which is made up of independent pharmacies that work together to get cheaper drug prices. Said they are in support of the bill because it will help constituents save money. Said as pharmacists they often see that what they pay for the prescriptions and what patients pay is vastly different and it all goes back to insurers.

Kevin Musto identified himself as representing Atlantic Apothecary and the Delaware Pharmacists Association and said they support the bill. Talked about how yesterday a patient of his came in for a prescription that was going to cost \$60 with insurance but only costs the pharmacists \$10. He checked the network of other chains that sell prescriptions like Walmart and Rite-Aid and found their bottom line was \$40, even without insurance. This happens day after day. He said they want the bill to give patients affordable prescriptions.

Senator Townsend recognized Geoff Christ.

Geoff Christ identified himself as the executive director of the Delaware Board of Pharmacy. Said they had a meeting that morning and they wanted him to express their support of the bill.

Senator Townsend recognized Peggy Shultz.

Peggy Shultz identified herself from the Delaware League of Women Voters and said they support the bill vigorously because it benefits the consumers and pharmacies.

Senator Townsend asked if there were any others who wanted to testify. No one came forward. He thanked Representative Bennett and said they'd circulate the bill.

SB 24 w/HA 1 was circulated for signatures. It was released from committee with U:0, F:0, M:5.

House Bill 12 (Representative Kowalko) - AN ACT TO AMEND TITLE 31 OF THE DELAWARE CODE RELATING TO THE PROVIDER ADVISORY BOARD.

Original Synopsis: This Act strengthens the role and responsibilities of the Provider Advisory Board in regard to the implementation and enforcement of The Delaware Child Care Act.

Senator Townsend asked if anyone wanted to testify on HB 12. Seeing no one, said they would circulate the bill for signatures.

SB 24 w/HA 1 was circulated for signatures. It was released from committee with U:0, F:0, M:4

House Bill 89 (Representative Matthews) - AN ACT TO AMEND TITLE 16 OF THE DELAWARE CODE RELATING TO THE CHILDHOOD LEAD POISONING PREVENTION ACT.

Original Synopsis: This bill updates the members of the Childhood Lead Poisoning Advisory Committee to include additional stakeholders, and directs the Committee to report to the General Assembly on the effectiveness of the Act, ways to improve the Act, and other measures that should be taken by the State of Delaware to prevent lead poisoning in children.

Senator Townsend recognized Amy Roe and Sarah Bucic.

Amy Roe said she is from Newark and is here to ask the committee to support the bill. Talked about the role of the advisory committee since its enactment. She said between 2012 and 2016 when the committee was in place, over 1650 children in Delaware experienced elevated lead levels when they were tested. Showed map from the Department of Public Health and Delaware Health Statistics Center that tracks the spread of lead cases and it is all across the state. The highest concentration of cases are in Newcastle and Sussex. Said despite the cases of children with elevated blood lead levels, the advisory committee has not met since 2012. Said that by adding stakeholders to the committee they believe they could get the community expertise necessary for solutions that would best fit Delaware.

Sarah Bucic talked about what high blood lead levels do to children. Children with asymptomatic symptoms have lower IQ scores, language difficulties, attention problems, and behavioral disorders. Said medical research has found that lead causes neurological damages to children. It leads to lifelong health effects. There are no safe levels of lead exposure. There continues to be dangers of lead exposure in homes, schools, and parks around the state. Said lead poisoning can be prevented by having stakeholders assess how the advisory committee is

performing and develop recommendations for the General Assembly on ways to improve practices and policies.

Senator Townsend recognized Lizzie Lewis.

Lizzie Lewis identified herself with Hamilton, Goodman Partners, reading a testimony on behalf of Nemours. Nemours supports HB 89. Said despite progress, childhood lead poisoning remains a serious concern. The American Academy of Pediatrics finds that most existing lead standards fail to protect children from lead. Said the most effective way to stop lead poisoning is to identify and remediate the primary cause of contamination. Said Nemours sees the advisory committee as the most effective way to recommend and implement improvements to the current program. Adding stakeholders provides appropriate and necessary review of policies. HB 89 provides a way to assess where we have work to do. With additional expertise the committee will be well positioned to examine and adjust challenges with screenings and data collection. Said based on the committee's findings, it may be necessary to intensify outreach in the state to healthcare providers and improve surveillance to ensure that we identify children with elevated blood levels in their earlier years.

Senator Townsend asked if anyone else wanted to testify. Moved onto Senate Bill 15.

SB 89 was circulated for signatures. It was released from committee with U:0, F:0, M:5.

Senate Bill 15 (Senator Lopez) - AN ACT TO AMEND TITLE 16 OF THE DELAWARE CODE RELATING TO THE PROVISION OF INFORMATION ABOUT LYME DISEASE.

Original Synopsis: This Act, modeled on similar laws in Virginia and Maryland, requires a health-care provider to provide notice to a patient at the time blood is drawn to perform a laboratory test for Lyme disease that explains the limitations of the test and instructs the patient to see their health-care provider if the patient continues to experience unexplained symptoms. This Act is consumer and patient friendly.

Senator Lopez gave an overview of his bill. Thanked all the guests and Senators. Said the act is to require healthcare providers to give notice to patients at the time blood is drawn for Lyme disease testing that there are limitations to the test. Said he never thought a one-page piece of legislation would gain so much interest. Said they can all acknowledge that Lyme disease brings a tremendous negative impact on a lot of people and many of his constituents are affected by it. Said it is a constituent driven bill and came out of concern from those in medical field and constituents. He said there isn't any bill he has brought up that has brought about so much conversation among members. Said there are 27 members of the Delaware General Assembly on the bill. Said he believes this bill is a step in the right direction, but wants to hear the concerns of others.

Senator Townsend asked if there were any questions from committee members.

Senator Hansen commented that she recently found a connection between Lyme disease and invasive species with her work with the Delaware Native Species Commission. Said she did not expect to find this connection. Said there is an ongoing study by the US Forestry and University of Delaware where they are looking at plots of forested areas in Delaware and nearby states. They found that most of these areas have non-native species and also large amounts of ticks that carry the pathogens for Lyme disease. Said this gives an even better reason to clear out these invasive species. Said we should think about when we send our kids outside to play in the woods.

Senator Townsend talked about how Lilliana is concerned about their son going outside to play and how the environment really affects us in ways we don't always acknowledge but need to do a better job. Recognized Christina Bryan.

Christina Bryan identified herself as the communications director of the Delaware Healthcare Association. Said they agree that Lyme disease is a serious concern and deserves more attention and education, but they oppose SB 15. Said the individual drawing the blood, a phlebotomist, is not the healthcare provider. Said the statement is also ambiguous and would lead to more questions and a phlebotomist would not be qualified to answer them. DHA is also concerned with the larger issue with legislating specific language regarding laboratory testing. Said treatment and testing is always changing, much quicker than any legislative process. Language like in SB 15 would likely become outdated. They also take seriously the patient and practitioner relationship. Said mandating specific wording is inconsistent with the relationship. Said that Virginia let a law with similar language expire because of similar concerns. They do not support the bill.

Senator Townsend asked for everyone to try to keep their testimonies to three minutes or less. Recognized Dr. Henderson.

Dr. Richard Henderson identified himself as the immediate past president of the Medical Society of Delaware. Said they represent Delaware physicians. Said they have concerns with SB 15. Said they have to recognize where we are in the state. Because of inaccuracies of Lyme disease testing twenty or thirty years ago, some patients were not diagnosed in a timely manner and now there is distrust over Lyme testing. With ongoing efforts, the tests have become more standardized, sensitive, and specific than earlier tests. Practitioners are more aware and able to diagnose patients from other context. Even as technology improves, skepticism remains around testing. The CDC recommends a two-step testing process for Lyme and is endorsed by various Lyme organizations and medical groups. Said practically every medical test can have false negatives, yet we do not, and should not legislate requirements of language. Said this interferes with the ongoing patient/physician relationship where there are informed steps for treatment. Senate Bill 15 will drive a wedge between patients and physicians, making patients doubt their doctors. This doubt may lead patients to request antibiotics for a condition that probably isn't Lyme disease if they get a negative test. Inappropriate use of antibiotics can lead to harm to

patients and the community through superbugs. Said other disease prospects may not be considered.

Senator Townsend recognized Marilyn Williams.

Marilyn Williams identified herself as the executive director of the Lyme Disease Association of Delmarva. Said right now there are only indirect tests for Lyme disease where you look for the host's reaction to an organism. Only if this test comes back positive will someone get tested for another indirect test. PCR is a direct test, but is not always an accurate test because these are very mobile organisms and so a test might just not include the organism and come back as negative. It also takes time to develop antibodies so right after a bite the test will not come back as positive. Long-term symptom patients will also come back as negative because the body may have given up fighting the organism. Taking antibiotics may suppress the organism and cause tests to become negative. Said we are only testing for one strain of Lyme disease, so other strains will not come up on the tests we use. Said the same bill has worked in Maryland. A lot of medical practitioners learned for the first time that Lyme disease tests are inaccurate when they had to read the statement in Maryland. Said she was a victim of a false negative test for Lyme disease for 16 years. Lab Corps prints the statement on their test reports so no one has to have a conversation about it.

Senator Townsend introduced Fm. Senator William Torbert.

Senator Torbert said he thanked the Senators for all they do for the residents of Delaware. Said a lot of people don't know they've been bitten by a tick. Said people will get a test done and when they get a negative result they just say they'll take care of themselves and then it gets more serious. He said he was here because his son-in-law died last year from a tick disease. Said his grandson had Lyme disease when he was young and his daughter had it. Said it is a terrible disease to die from. Thanked the Senators for what they are doing.

Senator Townsend thanked him for his service. Recognized Judy Setting.

Judy Setting thanked all the Senators for having the hearing. Said it is a gift to her to see the possibility of this bill after ten years of struggling from Lyme disease. Said it was a journey she wouldn't wish on anyone. Had cardiac issues, thyroid issues and often was in a wheelchair. She originally got a negative test result. She said she was lucky to have doctors tell her that negative tests do not always mean negative. Said the bill could potentially prevent so much suffering. Said Delawareans should be told there is a possibility that they have Lyme disease when they have a negative result. Asked the committee to consider supporting this bill to save so many people from suffering.

Senator Townsend recognized Rebecca Benson.

Rebecca Benson identified herself as a psychiatric nurse in practice for thirty years and is now a teacher. Said she has had multiple patients come in with diagnoses of bipolar disorder, somatic disorder, but in fact they had Lyme disease. Talked about a lady who came into her practice with clear clinical Lyme disease symptoms, but her test results were not positive enough according to the CDC guidelines. Talked about a boy who was four-year olds who went on a trip with his cousins who got Lyme disease and his pediatrician said his test came up negative. The boy wound up in a wheelchair and that since the test came back negative it must be a genetic or psychiatric issue. He eventually got treatment out of state. Pointed out a few studies that were given to the committee members. Said multiple studies found that there are no confirmatory tests available for practitioners for Lyme disease. ITSA supports the CDC, but said the test has many limitations and we need more testing. The Federal Tick-borne disease working group found that Lyme disease tests have limitations. Said we need to be able to advise that Lyme disease is not reliable. Said we do this for mammograms too. Most practitioners do not know that there are limitations to the tests.

Senator Townsend introduced Lisa Torbert.

Lisa Torbert identified herself as a business owner in Delaware and has published books about Lyme disease and cancers. She provided many statistics for the committee members. Said there is a lot of Lyme disease around the state and there is more of it than statistics acknowledge. Delaware is #6 per capita of Lyme disease in the United States. We are missing 29-40% of people that are tested too early and do not get a positive result for Lyme disease even if they have it. Said some doctors may feel that the bill dictates how they practice medicine, but this will not affect their time and effort since the statement will be given at testing facilities. Said Lyme disease is multi-layered and Lyme disease can cause a variety of diseases. Talked about how her husband died last year at the age of 54. He suffered from Lyme disease and eight other infections. She said a year after they moved to an area where deer passed through their yard she had multiple infections with no mention of Lyme disease. Chronic Lyme disease affects her whole body and it is a daily struggle. Said we have a chance to save lives through education to stop the spread of Lyme disease by being the example for other states.

Senator Townsend recognized Joseph Setting.

Joseph Setting identified himself as a company manager of Setting Properties and a minor owner of the Blue Rocks. Said this was one of the first time he missed Rocky being at Legislative Hall because it was the first time in ten years his wife was healthy enough to travel. He said his wife was sick for ten years and they were fortunate enough to be able to look at a lot of different options for her. He also said it was similar to laws in Maryland and Virginia. Asked for support for the bill.

Senator Townsend recognized Dr. Krista Griffin.

Dr. Krista Griffin identified herself as a practicing chiropractor. She wanted to talk to the physician side of the issue. When a physician orders a test they want to rule in or out a diagnosis. No test is 100% effective, but we can see with the Lyme disease that there is between 50 to 100% sensitivity. Having a patient be educated at the lab empowers them to know they can go back to their physician if they are still having symptoms. Said that for people to be afraid that patients will be confused is insulting. She said she believes that there is a partnership between patients and physicians and this bill strengthens that partnership.

Senator Townsend recognized Mike Malkiewitz.

Mike Malkiewitz identified himself as being from the Delaware Trial Lawyers Association. Said he is here to help legislatures understand a scenario that could happen with the bills current language. He said hypothetically if he was a defense lawyer for a lab group that didn't give the information out, he could tell the lab group that they have nothing to worry about because as the bill stands is toothless. Said the Board of Nursing can reprimand people not doing something in law or the Board of Medical Discipline but they are not mentioned in the bill. These are administrative procedures. Says that sections b and c do not give anyone authority to tell people consequences if they don't give out the statement. Recommends that sections b and c are removed to give it teeth.

Senator Townsend asked for guests to stick to three minutes because of the executive meeting afterwards. Recognized Beverly Sisson.

Beverly Sisson identified herself as working with the Lyme Disease Association and is representing herself. She has lived through the disease. Talked about her experience with symptoms she felt from Lyme disease. Has had a lot of joint issues that she believes it is possible it is from the Lyme disease. Had severe symptoms at various times. Said she was lucky to have a relative that knew a doctor that was very familiar with Lyme disease in Maryland and he diagnosed her and treated her. Said she needed a knee replacement that was possibly related to the disease. She said she went to get the procedure done, and when fluid was extracted from her knee the fluid was green. The doctor asked if she had been bitten by a tick, but when the fluid was tested the results came back negative. Said this bill was designed to help people and avoid confusion and she said doctors would be glad to be able to inform patients.

Senator Townsend recognized Dr. Rick Heong.

Dr. Rick Heong identified himself as the medical director for the Division of Public Health. Said it sounds like everyone is in agreement that education is necessary and we need to empower patients. He said he questions whether the bill will meet the desired outcomes. Said they are here to advocate for individual practices. He said having the person who draws blood make the statement is a lost opportunity because they are not the person talking about the risks of labs. This person also cannot answer questions if a patient has them. He pointed out that in MD where this bill is implemented the Department of Health has authority over it. In VA the bill was

sunsetting in 2018 with a unanimous vote. Said the division of health will be a partner with the disease awareness education regardless of what happens with the bill.

Senator Townsend asked the sponsor to speak on the bill and left for executive meeting.

Senator Lopez said there were beautiful testimonies given and thanked everyone for coming and sharing. Thanked all his colleagues on the committee for their support of the bill.

Senator Hansen said we definitely need to get the word out about the testing not being reliable. She talked about how her father died in 2005 from Lou Gehrig's disease they thought, but he was tested for Lyme disease and even though it came back negative maybe he did have Lyme disease. She said it sounds like the medical community is saying they don't want legislatures telling them what to say to their patients. Advocates are saying we want someone to tell us about the testing.

Senator Lopez adjourned the meeting at 3:33

SB 15 was circulated for signatures. It was released from committee with U:0, F:2, M:2.