

Legislative Advocacy Tips

STATE LEGISLATION IN THE LYMELIGHT

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Passing legislation to combat problems associated with Lyme disease can help correct some of the problems Lyme patients face, or it can exacerbate the very problems that it is intended to address. This article will provide you with a framework to think about legislative issues and will discuss some of the pitfalls you should avoid.

Educate Before You Legislate

Before you begin this whole process, it may be beneficial to ask for hearings on Lyme disease in your state. You can (and should) also have hearings in connection with an introduced bill, but often they are necessary before the birth of legislation itself to make lawmakers understand the need for legislation. These hearings are valuable tools which can educate legislators about Lyme disease itself and also the problems facing patients. If done in an organized fashion, they can have a positive influence on the legislative and policy-making process.

Have facts prepared to support your case, and have reliable, intelligent witnesses prepared to testify. Be selective about witnesses, who can turn legislators against the cause if they are unduly strident or antagonistic. It is good to include a mix of both patients, physicians, and possibly other experts. If you have access to favorable testimony from vector control districts or department of health officials, this should be included. Witnesses should have prepared testimony. It is important to coordinate witness testimony so that all important points are covered without unnecessary duplication given the time constraints.

To date, significant hearings have been held in New York, Rhode Island, Texas, Michigan, Connecticut, and California. Some of these hearings were legislative; others were public entities such as advisory committees, the attorney general's office, and the state department of health.

Beyond legislative hearings, patients can meet individually with their

representatives at their local offices or participate in state lobby days. To prepare for these activities, patients should educate themselves about Lyme disease and be prepared to be factual and not emotional. Lobby days are a great way to bring focus on an issue and rally the troops. Lyme advocates can arrange a day to meet at the capital and visit legislative offices in small groups. Patients can also arrange a meeting with a legislator they or a friend personally know, or one who has Lyme disease in his/her family, or who has been sympathetic to health issues. These one-on-one meetings add a personal touch that helps turn individual legislators to your cause.

Strength in Numbers and Coalitions

Maximize your numbers by coordinating with other Lyme groups including national ones and other groups outside of Lyme with a similar agenda. In New York, for example, the Lyme community was able to work with the Foundation for the Advancement of Innovative Medicine (FAIM). Its agenda coincided with that of Lyme patients: namely, the need to reform the Office of Professional Medical Conduct (OPMC). LDA has worked with many state groups and individuals and helped provide an orderly process for grassroots support in their states.

LDA has also been invited by many state legislators to educate and to provide input into legislation. Remember also that 501(c)(3) organizations are limited in the amount of lobbying they can do, so check with your accountant or attorney on this issue.

Initial Considerations for Legislation

Legislation should never be developed in a vacuum; it is complicated. No one has all the answers because the variables are many, and they change constantly. Legislators often are election rather than issue-oriented. That may be an advantage if you can muster up the numbers to persuade them, or it may be a disadvantage if your numbers are small. Be proactive. Take time to understand the politics in your state before you begin. Who is introducing your bill? Do they really support it or are they giving you "lip service" on the issue and introducing it knowing it will never move? Selecting a legislator to sponsor your bill may determine whether your bill will be successful or not. Do they have the support of their party? Do they need bipartisan (2 party) support, and do they have it? Is the support only in one house or both houses of the legislature? Generally speaking, it is easier to get a bill introduced and passed in the house/assembly than in the senate.

Decide what points you want in the bill. Look to other states that have successfully passed legislation, since legislators do usually not like to be "first." If you borrow a bill from another state, make sure that you check how its provisions apply in your state. It may be different. You may be asking for doctors to be notified of a complaint in 30 days when your state regulations already say 10 days. If your bill is to be part of or replace chapter 10, find out what chapter 10 is and how your bill fits there.

Advocates in different states have used a number of legislative approaches, including those listed below:

- the reformation of medical board practices to provide increased levels of due process to physicians,
- doctor protection against actions by medical boards,
- mandatory insurance coverage for long-term Lyme disease treatment,
- informed consent for those who are using treatments considered non-standard,
- Lyme in public education reforms (state-adopted Lyme curriculum, mandatory teacher in-service for educators with students with Lyme disease in NJ),
- establishment of Lyme advisory councils, commissions (to advise governors, health departments, legislators: CA, DE, NJ, MA),
- Lyme awareness resolutions, and
- support of federal Lyme research initiatives.

What is contained in your bill usually determines in which legislative committee(s) it must be heard. Check with the sponsor to determine if there is a way to keep it out of a committee if you know that committee chair or a member is vehemently opposed or if the committee poses a particular problem because of budgetary constraints on your state. For example, sometimes insurance or budget committees are obstacles to success. Check out legislator credentials online for clues to position, or ask the legislator who is helping you.

Deadly Combinations

Controversial areas where powerful lobbies will play a major role, such as mandatory insurance, are best handled as a separate bill. If you combine it with doctor protection, for example, it is likely that both issues will be derailed, and it will usually be harder next time. For example, in Pennsylvania a house bill was introduced combining doctor protection for those who treat long-term and mandatory

insurance coverage for patients. Insurance companies fought against it, although it passed the house. The bill was never considered in the senate. The physician protection portion of the bill probably would have had a better chance had the mandatory insurance coverage been handled in a separate bill. Insurance companies will be prepared to fight, and they often contribute to legislative campaigns, especially senate campaigns. Campaign financing records are public in most states, and some are even on the internet. Find out who your obstacles may be and be prepared to educate them more vigorously. Have constituents from districts of suspected opposition legislators prepared to meet with and lobby those people.

In Rhode Island, the LDA RIC was successful in having two separate bills passed, although there were behind the scenes machinations which almost derailed the legislation. Fortunately, they had very committed legislators who withstood a lot of pressure and stuck with the bill. The Rhode Island Lyme Commission, created to study the problem in the state, heard two nights of testimony. The LDA contacted each of the testifying doctors to ensure that all the issues were thoroughly covered by professionals and that testimony was not unnecessarily repetitious. Patients testified at one of the hearings. Patients were cautioned not to reveal treating doctor names either in written or spoken communications for protection of the physicians.

First, the doctor protection bill was passed, which provides that doctors cannot be brought up on charges by the medical board strictly for providing long-term treatment. Next, the governor's office was able to reach an agreement with Blue Cross/BlueShield requiring medical treatment for Lyme patients. The insurance company began to undermine that agreement almost immediately. A bill was then introduced and passed requiring treatment. To placate the insurance lobby, the bill had a sunset provision so that it expired at year's end. The rationale was to try it for a year. The next year, after extensive debate and lobbying against it by the insurance company, the sunset provision was removed. To date, patients have been able to get coverage under the law.

Bills that Hurt

"Any bill is better than no bill at all" is not a good philosophy with legislation. Passing legislation is difficult. Repealing a law after you have discovered it has hurt you may be impossible. Be prepared to kill your bill through grass roots efforts or through the sponsor (some states give this power to the sponsor, others

do not) if something goes wrong. For example, New Jersey had a mandatory insurance bill introduced in 1993. Unfortunately, the sponsor "turned" after his election was over, and amended the bill to favor the insurance industry. Instead of providing mandatory coverage for physician prescribed treatment, the bill was amended to provide that after 56 days of antibiotic treatment, further insurance coverage was subject to a second opinion by a panel of doctors, regulated by the department of health. The proposed second opinion panels probably would have routinely ruled against extended treatment unless they were populated with Lyme literate physicians, and Lyme literate physicians were not comfortable applying for panel membership, because the environment in New Jersey had been hostile to Lyme treatment for years. The medical board of New Jersey was the first to press charges against doctors for Lyme disease treatment, and insurance companies had been harassing doctors for providing treatment. Moreover, the doctor panel would be under the Department of Health, which was not known to be Lyme friendly.

In essence, the 56 day period would have become de facto treatment guidelines and would have worked against patients who were denied further treatment and whose only recourse was court. The courts would have viewed the 56 days as the treatment guidelines. Ultimately, the bill had to be sacrificed because of the sponsor's after-election alterations, although it had passed in both houses, albeit in different form. The next year, the sponsor said his bill or no bill at all, and sadly, we had to choose no bill, since other legislators were not willing to buck his influence.

A similar situation occurred in Connecticut. There, a bill was passed that provides for 30 days of IV and 60 days of oral medication and then requires a second opinion from a neurologist, rheumatologist, or infectious disease specialist. Doctors in those specialties who are willing to concur with long-term treatment are few, and pediatric ones are almost non-existent. Thus, this bill, which was intended to help Lyme patients, has made it more difficult to obtain extended treatment. It was introduced without those provisions, but was amended in response to pressure by the insurance industry. Those supporting the bill were probably unaware of the negative impact these changes would have upon patients, but the insurance lobby was not. Attorney General Blumenthal is using this new law to ensure patients rights to extended treatment instead of allowing insurance companies to use it as a restrictive guideline, which is how the insurance companies have attempted to interpret this law. The ongoing concern is the difficulty in finding the authorized

second opinion.

The Governor Holds the Ultimate Power

You must try to educate the governor to the need for the legislation also. In New York, the OPMC reform bill was vetoed by the governor due to outside group opposition, although the bill was not a Lyme bill per se. You may be able to get what you want tacked onto another bill, or the most important provisions put into another related popular bill less likely to be opposed.

Conclusion

Be proactive, not reactive, and remember that legislation may solve some of your problems or it may add to them. Be cautious, move slowly, and choose your allies carefully. Legislation frequently depends on relationships developed over time. Even when you do not have a legislative agenda for the year, taking the time to educate with one-on-one meetings and state lobbying days help set the groundwork for the future. Legislation is one of the most powerful advocacy tools available to the Lyme community. The educational learning curve in Lyme disease is steep. Only legislation and judicial action afford patients the opportunity of a full airing of the issues. However, legislation is cheaper, less time consuming, more likely to be effective, and offers greater maneuverability if the tide turns against you. Make sure you and your sponsor have a contingency plan to abandon or actively lobby against the bill if it becomes patient unfriendly, and be prepared to use it.

Note: History of political activity in different states and at the federal level can be found in the Lyme Disease Association's Lyme Disease Update: Science, Policy, & Law which can be ordered on www.LymeDiseaseAssociation.org.

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