

National Capital Lyme & Tick-Borne Disease Association

Addressing recent activity in the Maryland Legislature and discussion about it on the LymeNet ListServe

February 28, 2010

Since the recent hearings on Lyme legislation in the Maryland House of Delegates, the blogs and listserves have been buzzing with innuendo accusation, sarcasm and disinformation. Some have accused the National Capital Lyme & Tick-Borne Disease Association of having been behind some or all the legislative efforts, pushing bad bills, compromising our doctors, keeping bills and amended bills secret. We did not think it was necessary to respond to such accusations, but the time has now come when it is unavoidable that we place the facts on the table. Some will find this explanation useful. Others will find ways to use it for further accusations and attack. Either way, we have no desire to participate in a personal attack dialogue and will not continue to engage in this debate. We will continue to work for the betterment of our members and the doctors who treat them.

I. Who is NatCapLyme?

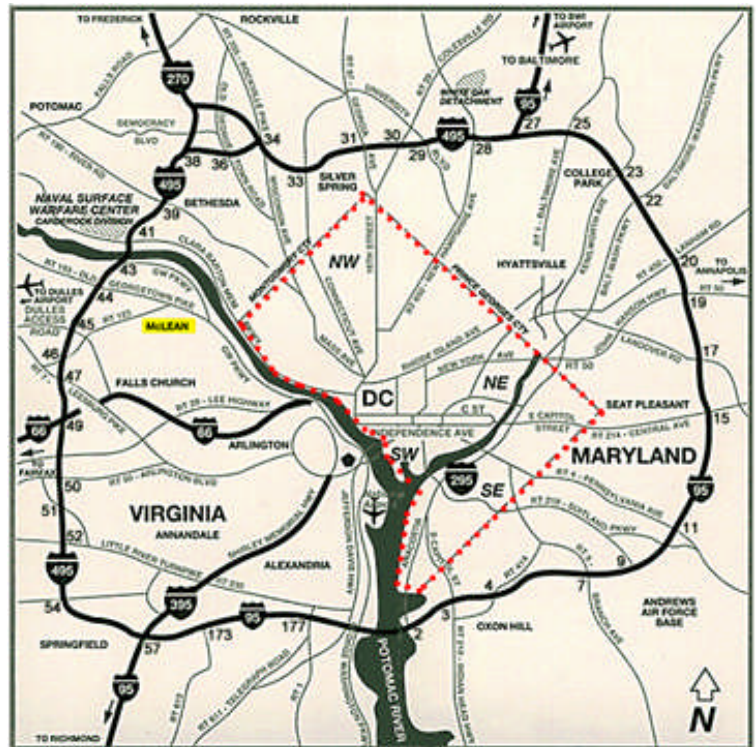
The National Capital Lyme & Tick-Borne Disease Association has been in existence since 2001 as a 501(c)(3) non-profit with a large membership comprised of patients from Maryland, Virginia & DC as well as from across the country.

NatCapLyme is based in the National Capital area. The area is a tri-state region. A local regional map reveals that all three jurisdictions have residents living inside the beltway. The majority of the land mass inside the DC Beltway, I-495, is Maryland and Virginia.

http://www.dt.navy.mil/div/images/dc_area.gif

NatCapLyme's Maryland members come from all over the state and we have chapters in Montgomery and Howard County. More than half of our 18 member Board comes from Maryland. We have worked in Maryland helping people with Lyme for many years. We have made many trips to Annapolis over a period of years, testified on bills and participated on the 2007 Maryland Lyme Task Force to help build strong diplomatic bridges within and beyond the Lyme community.

NatCapLyme was a principal partner with the Montgomery and Fairfax County Health Departments in creating educational programs to inform the public about this disease and its prevention. In large part, due to this kind of public outreach, performed daily by NatCapLyme volunteers, this disease is better understood today in our areas. Within a two day period last month, we reached over 85,000 people from all three jurisdictions, who attended the NBC Health



Expo at the Washington Convention Center. We educated those in attendance about Lyme & Tick-Borne Diseases. Many of the attendees were from Maryland.

II. Legislative Positions

Lyme protection and education bills are being initiated by well intended patients and advocates who want a doctor protection bill modeled after the recently enacted Connecticut Lyme bill to insure health care options in their state. They seek out their delegates armed with the Connecticut bill, the delegate agrees to support it and the bill is sent to a legislative drafting office lawyer. Modifications are made to fit the individual state drafting language and a new bill is born. The bill process is quite complicated. After the initial language is introduced, a bill will go through many stages including the committee process and amendments. Amendments can be made at anytime throughout the process. Delegates and their drafting offices need our input because they themselves are frequently not aware of the nuances of the disease and our needs. There are many points during the process when members and their staff can be educated, which may lead to favorable amendments.

NatCapLyme hosted a Legislative Forum last year. Some of the listserv spinmeisters spun and criticized that the Forum would be about tearing down the Federal Lyme Bill H.R.1179 while encouraging people not to attend. The forum was billed as an opportunity for empowerment and a learning experience to understand the process by which a bill becomes a law, and to discuss the House and Senate rule structures and the legislative strategies that are employed by the members of Congress and their staff. That's what the NatCapLyme Legislative Forum provided. With a few exceptions, and there are always a few, those who attended thought it was a great Forum and left feeling they had learned something useful and empowering.

In Virginia, NatCapLyme did not initiate HB 520 with its sponsor; one of his constituents did. The bill was drafted before it was shown to NatCapLyme. Congressman Frank Wolf endorsed the efforts of the bill's sponsor. Once asked to participate, NatCapLyme decided to work together with the sponsor to improve the bill and seek its adoption so that we had input into this bill that was going forward with or without our suggestions.

In Maryland the situation was a bit different. There are several bills in Maryland, each sponsored by a different delegate. All of the bills were initiated without NatCapLyme's prior knowledge, and our help was not requested until after the bills had been drafted. It appears that Lucy Barnes/Tincup/Afterthebite knew about at least two of these bills before NatCapLyme did. We did not receive any notification on these bills from her or anyone else in the community. Delegate Peña-Melnyk's bill was initiated by her constituents. The delegate contacted NatCapLyme to ask for our support. Due to problems with this bill we could not endorse it as it was written.

We all know it is not unusual for a member of a legislature to introduce a bill to satisfy a promise to a constituent, with the expectation that the important changes will occur by redrafting, amendment or committee markup to produce the final bill. Sometimes these changes will occur before the bills first hearing, sometimes during, and sometimes at the hearing itself. While certainly desirable, it is not always possible to widely circulate each change, each step along the way. Such was the case with the Virginia bill, where amendments were submitted as the first item of committee business as well as with the New Hampshire bill and we believe the Minnesota bill. This was also the case in Maryland with HB 290, Delegate Peña-Melnyk's bill,

which was amended twice before it was introduced. In its final form it was an acceptable version of the Connecticut bill. None of us got to see it before it was brought up for hearing, but we were told that these amendments were being made just the evening before the hearing. Lucy Barnes/Tincup/Afterthebite, unknown to anybody and without checking with Delegate Peña-Melnyk's office or NatCapLyme, sent one of the unacceptable versions to Maryland doctors and the ILADS Board. Unfortunately, a statement of strong opposition was submitted by ILADS to the committee members where the bill was being introduced. This statement was issued without ever having contacted the delegate's office or advocates known to be working in Maryland to verify the legislative version or to inquire about extenuating circumstances. This action reinforced the already negative characterization of Lyme advocates in Maryland and effectively killed a Maryland version of the Connecticut Doctor Protection bill.

Clearly, the delegate made a mistake by not seeking input from experienced Lyme advocacy groups in Maryland that could have helped her create an initial draft without the problems she later corrected. Delegate Pena-Melnyk's spirited defense of her bill and reports of her active and well-prepared cross examination of physicians testifying against the bill demonstrated her commitment. However, once a bad bill was initially incorrectly publicized the spin was out of control and the paranoia took hold. With active Lyme Community involvement earlier on it may have ended in our favor.

The Task Force Bill, HB 798 was introduced by Delegate Susan Lee. NatCapLyme decided to reserve its endorsement based on the removal of mandatory recommendations on treatment and diagnosis from the task force assignments, and the necessary inclusion and participation of ILADS on the task force. Delegate Lee did not contact NatCapLyme when initially drafting her bill. We did not find out about the bill until later in the process. Delegate Lee has shown herself to be most gracious and cooperative in accepting suggestions and changes. NatCapLyme was included on the Maryland 2007 Lyme Task Force. That task force proceeded with many reported difficulties. Despite problems, the 2007 Interagency Subcommittee Task Force report included the views of both sides. It was a beginning.

We wish to make this point crystal clear. NatCapLyme testified at the hearing on HB798 at the request of Delegate Susan Lee, but made it clear to her and in our testimony that NatCapLyme was not endorsing the bill, and that to obtain its endorsement the final language of the bill would have to be provided, that it would have to provide for the full and equal participation of ILADS and the Lyme patient community. We have not yet received a copy of the amended bill nor have we provided the organization's endorsement.

It should be noted that the criticism that the Lyme patients on this new task force are outnumbered 6 to 16 is no different, and actually a better percentage than the structure of the Federal Bill HR 1179 Tick Borne Advisory Committee. In fact, the Federal bill is subject to the same criticism made of the Maryland state bill. The federal bill offers no safeguards that a fresh \$200 million dollars won't end up going back to the same people that it has always gone to, funding research that will only make the mountain before us so much higher to climb. It is odd that the same people who are willing to promote the Federal bill are strongly negative about a bill that offers much less risk. The criticism is also based in an assumption that wherever possible a member of the task force would be chosen who is sympathetic to the IDSA guidelines.

III. Maryland's Past

Regarding Maryland, it is noteworthy to revisit the controversy over a delegate that has gone on since 2007. A Lyme advocate intimates that this delegate is against the Lyme community and that she kept patients from testifying at the hearing of her bill in 2007. One might ask, why would a delegate who wants better Lyme and Tick-borne disease reporting and has tried in the past to protect Lyme treating doctors behave that way, if in fact she has? What most of you don't know is that this delegate reported to us that the Lyme advocate became abusive toward her, allegedly shouting at her and threatening her with bodily harm over her Maryland Education and Prevention bill. That was followed by an anonymous denial of service attack on the bill sponsors fax machines that went on for days. If you were a state legislator faced with that experience and trying to accomplish something positive for the Lyme community, would you be motivated to welcome them in your office or have them testify on your bill? NatCapLyme representatives recently had occasion to ask the delegate whether she had intended to reference the IDSA Guidelines by the phrase "the Latest Consensus Guidelines" and whether she was amenable to removing that provision. Her answer was an unqualified yes to removing it, but it never came to that because of the contentious communication and threats, the delegate viewed as coming from the "Lyme Community". Moreover, she stated this to Lyme advocates when they called her office three years ago.

IV. Hurtful Distracting Discourse

There has been an incredible amount of misinformation and allegations on LymeNet directed toward NatCapLyme following the recent hearings. Many of these allegations are hurtful, condescending and uninformed. There are those in the Lyme community blogosphere who have made attacking others a hallmark of their discussions, tearing down anyone who disagrees with them, spinning events out-of-control without checking facts and then censoring dialogue. A syllogism is only as good as the major premise, and these people seldom have that part right. Moreover, they are guilty of the very "crimes" they accuse others to have committed. We choose to disregard such melodrama. We at NatCapLyme attempt to reserve time and energy on building bridges and the actual work that is involved in education and healthy dialogue within and outside the patient community.

V. Conclusion

It would be naïve to hope that this message will bring an end to the bickering and personal attacks. We do not believe that those who have chosen to be our adversaries have it in them to cooperate. We don't think they will share information, work cooperatively or create useful dialogue. We would welcome that, but cannot waste our energy waiting for what may never come. I think it is necessary to give you at least one example of what I am referring too. The 2008 Capitol Hill Legislative Luncheon was publicized for many months and planned with support of patients from across the country. Another Lyme group associated with Lucy Barnes/Tincup/Afterthebite held a surprise briefing one week before NatCapLyme's. They even tried secretly to secure the same physician speaker NatCapLyme had engaged. Numerous private emails were sent to many groups around the country advising them not to support this effort and calls were made to Hill offices advising them not to attend the briefing by this group. The idea of doing two Lyme briefings on the Hill a week apart in a *Lame Duck* session usually leads to only one being well attended and it is usually the first one scheduled. Lyme patients sacrificed to buy *Under our Skin* DVD's & Pam Weintraub's book *Cure Unknown* so they could

be a part of the process of educating their legislators and were almost undermined by this group. Despite all these destructive efforts on the part of this Lyme group, over one hundred Capitol Hill members and their staff attended NatCap's briefing including Congressman Frank Wolf. Congressman Wolf was so inspired after attending the briefing that he went to the House floor and delivered his famous speech and stated his dedication to do something about the plight of Lyme patients. All 535 Senators and Congressman received a copy of *Under Our Skin* DVD & a copy of the book *Cure Unknown* and the briefing got national coverage by the press for many weeks after. One has to wonder what else positive could have happened for our community if this group hadn't tried so hard to undermine this project. This is just one example.

NatCapLyme is not about the money, is not about demeaning people and not about attributing motives to people to make ourselves look better. We are about building bridges, reaching out and extending a hand not a fist, creating dialogue and looking for common ground and building alliances.

We seek to involve all who will work together constructively and avoid those who would destroy the work of others. We invite all who have any further questions about the Maryland bills to attend our next meeting this Sunday at Sibley Memorial Hospital in Washington DC. We will be addressing the issue of the Maryland bills from 1:30-2:00. All questions will be taken.