

REPORT TO THE LYME COMMUNITY
ON THE MARCH 28, 2009 LYME LEGISLATIVE FORUM
George Mason University, Arlington, Virginia

The National Capital Lyme and Tick-borne Disease Association (NatCapLyme) thanks the 160 members of the Lyme community who attended the recent legislative forum as well as others who offered their generous support and valuable information. In an effort to inform the Lyme community about what the forum accomplished, and for the sake of the many Lyme patients and their families who could not attend, we are offering this summary of the day's events.

The forum began with opening comments by facilitator Dr. Wallace Warfield followed by a welcoming address by Dr. Gary L. Kreps, Dean of the George Mason University Center for Health and Risk Communications. Congressman Frank Wolf, a 15-term member of Congress from the 10th District of Virginia, delivered the keynote speech and answered audience questions. This was followed by two presentations and question and answer sessions about the legislative process given by Mr. Mark B. Harkins and Mr. John K. Mashburn of the Washington, D.C. law firm Womble, Carlyle, Sandridge, and Rice, PLLC.

Open discussion periods throughout the day focused on a variety of subjects, including:

- what are our goals and what do we need from the government;
- what problems does the Lyme community need to address, especially regarding shortcomings in the prevention, diagnosis, and treatment of Lyme disease;
- substantive issues in Lyme legislation, such as what should legislation accomplish and how can this be achieved through contacts with members and staff of Congress and through possible legislative, oversight, and investigatory hearings;
- strategies to use other government mechanisms in addition to passing legislation;
- an informative and neutral review of the current bill in Congress, H.R. 1179, was conducted by Mr. Les Meyer, a NatCapLyme Board Member;
- sharing ideas about advocacy on the state and local level by accomplished advocates from across the country; and
- the identification of areas of common ground and broad agreement among Lyme patients;

The day concluded with a unanimous vote in favor of forming a Lyme "coalition" of advocacy groups to better represent the needs of the Lyme community to the government.

Keynote Address by Congressman Wolf

Congressman Wolf is a strong supporter of Lyme patients and has many victims in his district. He is a co-sponsor of H.R. 1179, and will work with Congressman

Christopher Smith (NJ – 4th district) in an effort to get the bill out of the Committee on Commerce and Energy, whose Health Subcommittee is chaired by Representative Frank Pallone (NJ – 6th district). Rep. Wolf encouraged the Lyme community to contact members of Rep. Pallone’s Health Subcommittee in support of H.R. 1179. Alternatively, if no action is taken on H.R. 1179, Rep. Wolf will move to have Lyme provisions attached to a future appropriations bill, as he belongs to the House Appropriations Committee.

Congressman Wolf encouraged the Lyme community to help educate the members of both Congressional committees on the need for legislation to advance the interests of tick-borne disease patients. He will support hearings on this subject but notes that as a minority member it may be difficult for him to initiate an official hearing on his own. He has been contacted by medical personnel who are opposed to the current bill.

Womble Carlyle Legislative Experts

Mr. Harkins and Mr. Mashburn stated that personal visits to a Congressperson and his staff both in Washington and in local home offices are very important and effective. Members of Congress want to please their constituents, and they are more likely to take action when a problem is defined clearly and succinctly. It is important for persons contacting Congress to be well-informed on the subject matter, but written material given to Congressional staffers should be no more than one or two pages long. The Congressperson’s staff should be contacted first to make sure they have a full understanding of what the problem is and what the constituents want done. In general, Congressional staff will research and address an issue with as much fervor as the constituent writing to them about it, making personal letters more powerful than form letters.

Mr. Harkins and Mr. Mashburn advised that the best approach is for two or three persons from a member’s district to visit their representative’s office. More than this number can be counterproductive, as it overwhelms the representative’s staff. Similarly, a small number of constituents, who can vote for the member, will be more effective than numerous contacts from a national group. It is very effective to identify any family members, friends, or acquaintances of the representative who are suffering from Lyme who can make a personal appeal.

Along these same lines, Dr. Laura Kwinn, who served Senator Edward Kennedy (MA) last year as an American Society for Microbiology Congressional Science Fellow in the office of the Senate Health, Education, Labor, and Pension Committee, contributed additional excellent comments as to how Congress works during the morning brainstorming session. She stated that it would be better if the Lyme community can act in unison in its approach to Congress. Dr. Kwinn suggested that many members of the Lyme community calling Congress with the same message is more productive than a few people calling repetitively. In addition, the message must truly be unified and consistent; having different Lyme groups call Congress with differing messages is wholly

counterproductive. Dr. Kwinn also said that Senate and House staff members are regularly contacted by parties seeking to influence them on health measures, including Lyme. She suggested that Lyme patients maintain cordial and regular contact through personal visits with Congressional staff members, during which pertinent information on Lyme is shared, including examples of questions they could ask persons lobbying about Lyme on behalf of other groups, such as the IDSA. Staff members have great influence over the representatives they serve and can be persuaded to raise an issue's priority in a Congressional office. For example, Dr. Kwinn noted that the film *Under Our Skin* was made available last year to the Senate Health Committee staff and interns, and this heightened their interest in addressing Lyme disease.

The Womble Carlyle speakers declared Congressional hearings, which can be for oversight or investigatory in nature, to be another effective way to educate Congress about our problems and the need for legislative solutions. Hearings may be full or mark-up in nature, and senators can offer amendments from the floor of the Senate.

Mr. Harkins and Mr. Mashburn did not feel that an executive order addressing Lyme was a wise idea, since use of an executive order would open the floodgates to requests for many more such orders.

Both speakers gave a good analysis of the authorization and appropriations procedures involved in passing laws. These procedures are also discussed in the attached paper, "The Legislative Process," which was distributed at the Forum.

Discussion of Community Goals and the Role of Government

Dr. Warfield opened the first moderated discussion by laying down the four outcomes of open communication: 1) All parties have equal opportunity to express their thoughts; 2) All privileged notions of truth are suspended; 3) Everyone participates equally; and 4) Opinions can be expressed without fear of retaliation or censure.

The discussion of goals and the role of government brought forth ideas such as the importance of creating an open, public Congressional record about Lyme from which all legislation and agency implementation would flow; the desire of ILADS to have representation on the scientific advisory committee proposed by H.R. 1179; the need to address the privatization of medical research enabled by the Bayh-Dole Act of 1980; the possibility of uniting voices and resources with other disease advocacy groups with similar symptoms, such as Chronic Fatigue Syndrome and fibromyalgia; the possible role of class action lawsuits; and the importance of asking elected officials questions about the marginalization of tick-borne diseases which they will have to research.

This morning discussion also highlighted some strategies for advancing scientific knowledge and awareness within the medical community. Researcher and author Pam Weintraub advocated a "middle out" approach to presenting scientific data about Lyme, in which neither the extreme of denying persistent Lyme nor the other polar extreme regarding diagnosis and treatment is tolerated. She reminded the audience of the

importance of studies focusing on the pathogenesis of the disease, which describe its genetic complexity and possible methods of survival, rather than treatment studies, which have proven highly controversial and easily debatable. Dr. Daniel Cameron, President of the International Lyme and Associated Diseases Society (ILADS), called for a treatment study in which patients' health improved, rather than ones in which a pre-determined length of treatment is imposed. Others suggested that finding common or "middle" ground with teachable physicians and moderate members of the IDSA is key to progress. Dr. Warfield also applied this "middle out" strategy to intra-coalition building and reconciliation within the Lyme community.

Attendees suggested that social workers, educators, and psychologists also need to be informed about Lyme's neuropsychiatric and cognitive complications. Opportunities to reach medical students early in their training should be identified and seized. Finally, Lyme patients and their families need assistance in establishing support groups, finding connections on-line, and securing insurance coverage for treatment.

Discussion of Advocacy on the State and Local Level

A diverse cross-section of Lyme advocates from across the country shared their advocacy successes and lessons learned from advocacy experiences on the state and local level. Several themes emerged, including the importance of a unified message about the severity of Lyme and the need to cure and prevent chronic Lyme disease and the need for unity and collegiality among Lyme organizations and advocates.

Lisa Torrey of the Landford Foundation (LifeLyme, Inc.) commended the Lyme Disease Association for hiring a professional public relations firm and encouraged all Lyme advocates to improve the public image of Lyme and its advocates. She also issued a call to put aside past divisions within the Lyme community and move ahead with a greater sense of cooperation and mutual respect, supporting and promoting each other's work. Ms. Torrey and others suggested engaging local community groups, including unions and civic groups, in the Lyme awareness efforts.

Other attendees shared their successes in securing screenings of the documentary *Under Our Skin* or presentations about Lyme in public and private schools; renting billboard space along busy highways; conducting smaller, regional conferences that offer continuing medical education credits for medical professionals; and fundraising through walkathons and other means. Meeting with state and local epidemiologists have proved fruitful in some areas. Some reported that attending community functions is a good way to meet elected officials and engage them about Lyme. Finally, the possibility of funding private medical research was raised.

Pam Andrews of the Lyme Disease Association of the Eastern Shore of Maryland discussed potential pitfalls associated with legislation, such as the corruption of well-intended legislation by special interests late in the legislative process. She described a bill in Maryland which the Lyme community first supported and then opposed because of this kind of interference. On a positive note, she mentioned the benefits of allowing

Lyme community members with special skills to employ their talents to expand the reach and efficiency of Lyme organizations.

Section-by-Section Analysis and Discussion of H.R. 1179

The afternoon session included a section-by-section analysis and group discussion of the proposed Lyme disease legislation, H.R. 1179, the Lyme and Tick-Borne Diseases Prevention, Education, and Research Act of 2009. Les Meyer, a member of NatCapLyme's Board of Directors, led this discussion, which was joined by a number of forum attendees.

The discussion highlighted that the main anticipated effect of H.R. 1179 would be to give the Department of Health and Human Services a federal workscope over matters pertaining to tick-borne infections. Some attendees raised the idea of involving the Department of Defense (DoD) more actively, as the DoD is believed to have information on the incidence, severity, and treatment of military personnel with Lyme and the possible role of Lyme as a biological weapon. One way to involve the DoD would be to suggest the addition of a Defense Department representative as an ex-officio member of the Tick-Borne Diseases Advisory Committee.

The other ex-officio members of the proposed advisory committee, while officially not having a vote, are considered powerful nonetheless because they represent agencies which must implement the policies recommended by the committee. Concerns about H.R. 1179 primarily related to the composition of the voting members of this committee: whether all regions of the country will be represented equally, whether the presence of patient advocates truly balances the number of credentialed scientists present, whether the number of ex-officio officers outnumbers voting members, and whether there will be true diversity of thought about chronic Lyme among the scientists serving on the panel. As one of the Womble Carlyle lawyers shared earlier in the day, the Lyme community should identify those whom it wants to have seated on such a committee long before one is formed. One proposed solution to this problem would be to expressly allow that a minority report from this committee be drafted and released, so that dissenting members can express their concerns to Congress.

A second area of concern about H.R. 1179 is the funding of clinical outcomes research, which would produce studies involving currently available treatments, rather than pathophysiology studies which might unlock ideas for better treatments. At least one attendee suggested that the important factor will be the scientists to whom the money is granted, not the amount of money or the composition of the advisory panel. If even a handful of quality studies by open-minded researchers are funded, that could be considered a victory, even if other studies do not produce promising results. Some suggested that the legislation is genuinely well-intended and something around which Lyme patients should all unite, even if some suggest amendments to it.

A show of hands revealed a genuine split of opinion regarding H.R. 1179. However, a point of common ground is that as many Lyme organizations, informed minds, and voices should be included in the formation of Lyme-related legislation as early as possible to avoid obscure pitfalls and complications.

Discussion of Areas of Agreement and Common Purpose

In the late afternoon session, facilitator Sandra Cheldelin, Ed.D. summarized areas of agreement that emerged from the morning brainstorming, and then directed the forum attendees to break into discussion groups of 3-4 people. The objective of the small groups was to list other areas of agreement.

Dr. Cheldelin identified the following areas of agreement: 1) The priority of educating the public (including Congress) about Lyme disease; 2) The need to unify a message, strategy, and set of questions to ask the outside world about Lyme; 3) The importance of a unified organizational narrative to represent patients; 4) The necessity of a better public relations campaign for the Lyme community; 5) The importance of meeting with local elected officials; 6) The value of teaching from the “middle out” to people holding different scientific and political views about Lyme; 7) The imperative of effective advocates to keep up with the latest research about Lyme disease; 8) The usefulness of attending community functions to create awareness; 9) The urgent need for a definitive screening test other than the ELISA; and 10) The possibility of creating a forum where both sides of the Lyme debate could participate.

To this list, the small groups added the following: in addition to ideas repeated from earlier sessions: 1) The importance of reducing tick populations; 2) The possibility of a national advertising or public service announcement campaign; 3) The role of immunizations and integrative medicine; 4) The creation of a shared database 5) The role which hospitals could play in educating the public and providing better first-line medical treatment for Lyme.

The most common theme emerging from the small groups is the need to create an umbrella coalition of Lyme organizations to advance awareness, advocacy, and research goals. Approximately 52 voluntary organizations dedicated to Lyme exist throughout the United States, but a unified voice and coordinated action are lacking. One immediate and important product of a new coalition would be the production of more standardized materials to be used by all Lyme advocates, such as brochures, talking points, and a database to facilitate communication and learning. Other goals can include a national awareness campaign, fundraising to share expenses, funding a pilot research project to serve as a model for others, the posting of tick warning signs in national parks, the creation of speakers’ bureaus featuring the community’s best spokespeople, the reform of private disability insurance, providing enhanced protections for Lyme-treating doctors, and the passage of federal legislation. The “shared language” of Lyme organizations needs to be recorded and disseminated with the goal of “de-mystifying” Lyme in the minds of the public and even the medical profession.

Ways to establish this new umbrella organization were discussed. Specialization and experience distinguish some Lyme organizations from the others, so within the coalition some organizations might play a leading role in fundraising, while others might focus on education or lobbying depending upon their known and agreed strengths. Two or more representatives from each geographic region and/or five to ten representatives from several prominent groups could draft a charter and decide organizational issues regarding the coalition. Skype or video conferencing may be employed. Invitations to some of the largest Lyme organizations must be extended, and an existing Lyme organization may have to take the lead in the formation of this coalition. A conference closely related to the ILADS conference may be a good time and place to meet. In addition, another powerful way to promote unity and collaboration would be to allow representatives from the same state to meet and network within the context of a larger national conference. Common obstacles as well as goals must be discussed.

Conclusion

At the conclusion of the day, facilitator Sandra Cheldelin again noted the high level of consensus in the room, especially for forming a coalition type of organization based on regional representation. She called for a show of hands of those supporting the formation of an “umbrella” group, and ALL HANDS WENT UP. Attendees also expressed support for a spirit of full inclusiveness within the newly-proposed umbrella organization.

The March 28, 2009 legislative forum included representatives from 22 states: Arizona, California, Connecticut, Florida, Idaho, Iowa, Maryland, Massachusetts, Michigan, Minnesota, Nebraska, Nevada, New Jersey, New York, North Carolina, Oregon, Pennsylvania, Texas, Virginia, West Virginia, Washington State, Wisconsin. NatCapLyme thanks all participants for their willingness to travel and their great contributions. Thanks are also due to keynote speaker Representative Frank Wolf, attorneys Mark Harkins and John Mashburn, facilitators Dr. Wallace Warfield and Dr. Sandra Cheldelin, and the faculty and staff of George Mason University as well as the Turn the Corner Foundation who helped to make this event possible.