

## July 13 Support Group Meeting Recap

At the July 13 meeting, legislative and outreach committee member Mari Maack-Magnusson and communications coordinator Monique Dubos talked about the renewed effort by MLASG to get the federal Lyme legislation enacted.

During the summer recess, our federal legislators are back in their hometowns. It is imperative that we contact them via email AND telephone, write letters to newspaper editors AND comment on Lyme-related articles online to keep the issues of Lyme disease in front of the public. While doing so, everyone must urge our federal representatives and senators to sign on to HR 1179 / S 1352.

### **This is a numbers game!**

Legislators need to hear from LOTS of people MANY TIMES before they begin to understand the importance of a particular issue.

*Be persistent.* Call back in a week to get an update about whether the legislator has had time to consider the bill. Offer to email or drop off information, or direct them to the mlasg.com website for peer-reviewed papers. It may help you to write your letter first, then use the letter as a guide when you call. Do whatever works!

### **Bill Summary**

- ***Establishes a Tick-Borne Diseases Advisory Committee.*** This committee would: (1) address tick-borne diseases with other Federal agencies and private organizations, including Lyme disease organizations; (2) advise government agencies on priorities concerning tick-borne diseases, and (3) ensure that a broad spectrum of scientific viewpoints is represented in public health policy decisions regarding both acute and chronic tick-borne diseases, and that information given to physicians and the public is balanced.
- ***Addresses The Problems of Inaccurate Testing and Underreporting*** by encouraging the Centers for Disease Control (CDC) to develop more accurate diagnostic testing for Lyme disease, and to improve the surveillance and reporting of Lyme and other tick-borne diseases (i.e., by looking for better ways to more accurately determine the presence of Lyme and other tick-borne diseases). The development of better diagnostic testing would be a research priority.
- ***Increases Lyme Disease Prevention Efforts.*** The bill would aid in the prevention of Lyme disease through community-based public education, the creation of a physician education program, and scientific conferences that would include the full spectrum of scientific research and clinical experience.
- ***Authorizes Appropriations of \$100 Million for Disease Prevention, Treatment Research, Improved Diagnostic Testing and Surveillance, and Balanced Education.*** Appropriations of \$20 million are authorized for each of 5 years. The money would support disease prevention efforts, fund important long-term treatment outcome research, help develop more accurate diagnostic testing, improve reporting and surveillance, and support balanced physician and public education.

### **List of MN Legislators:**

Sen. Klobuchar

Sen Franken – on the senate committee that will vote to send the bill forward to full senate floor

Rep Bachmann

Rep Ellison – cosponsor

Rep McCollum

Rep Oberstar – cosponsor

Rep Paulsen

Rep Peterson

Rep Peterson

Rep Kline

Rep Walz – cosponsor

## **Writing to your legislator:**

Try to keep it to one page, don't get overly emotional, and begin and end by stressing why we need this legislation.

## **Writing Letters to Newspaper Editors:**

- Be brief—no more than 200-250 words maximum.
- Keep it to one point. State your point clearly right away.
- Tie your story to the need for the legislation.
- No more than three paragraphs, with one to two short sentences per paragraph
- Avoid too much emotion—no ranting, raving or sarcastic remarks about the opposing side.
- End by asking readers to urge their legislators to cosponsor the bill.

## **Letter to Editor Example**

Dear Star Tribune Editor,

In July, the MN Dept. of Health receives the most Lyme disease reports, with roughly 1000 cases reported each year. But, because the standard Lyme blood tests are sensitive to only one form of Lyme disease – Lyme arthritis - they fail to detect many other forms of the disease, and hundreds are misdiagnosed and inappropriately treated for other ailments.

People who have neurologic Lyme, for example, spend many years and thousands of dollars in pursuit of a diagnosis and treatment of this debilitating illness. Without the appropriate medical care, the advancing disease makes it impossible to keep a job. Without work they have to depend on the state to feed and clothe them.

Representative Keith Ellison just signed on as a cosponsor to HR 1179, a bill that would provide funding to the CDC to develop more accurate Lyme disease tests; it would also support disease prevention efforts, fund long-term treatment outcome research, and support balanced physician and public education. I want to thank Rep. Ellison for his support of this important legislation, so vital to our Lyme-endemic state, and urge all MN legislators to do the same. Accurate testing is the first step in uncovering the hidden epidemic that is Lyme disease.

Monique Dubos  
Address  
Minneapolis, MN  
55418  
Phone number

## **Calling Your Legislator (you will probably be talking to an aide, not the actual representative)**

If they have co-sponsored the bill, please call to thank them. Otherwise, just talk about why the bill is important to you.

“I'm calling to talk about HR 1179 (or S 1352, if calling a senator).”

Tell your story as briefly as possible. Pick out one or two compelling points of your story. For example, if you

were once a productive worker and are now on disability, legislators will be interested to know that. Tell them how hard it was for you to find a doctor to diagnose and treat you. Finish by asking the legislator to cosponsor the bill, because all Minnesotans are at risk of getting Lyme, or will know someone who gets Lyme.

Give them our web address and let them know they can find lots of articles and peer-reviewed papers about Lyme disease prevention, treatment, etc.