

LymeMD News

LYME DISEASE RESEARCH

FOUNDATION OF MARYLAND



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SLICE Study Update

The Study of Lyme Immunology and Clinical Events (SLICE) is celebrating its first birthday and ready to enter its second Lyme season. **SLICE** had a successful first year, enrolling 17 participants into the study. These acute Lyme patients have completed 5 rounds of study visits over the 6 months following their enrollment.

Patient participation has been excellent. In fact, our overall retention rate is 97%. Here's a small glimpse of how it works: at each study visit, a range of clinical information, questionnaires, and blood samples are gathered. A total of 83 sets of samples have been processed for immediate analysis of the immune system or for freezer storage for future analyses. This invaluable resource of biological samples has already attracted attention and interest from collaborators around the country.

The SLICE study was also designed to capture the presence and severity of symptoms at a single time point and over the 2-year follow-up period. The information we collect has the potential to reveal much about the time course of specific Lyme symptoms. Our SLICE study patients have exhibited a wide range of symptoms before and after treatment of their Lyme disease. This variability in symptoms is the key observation that we plan to describe.

Initial results show the immune response to early Lyme disease to be unpredictable: In our study of patients whose acute Lyme disease is a certainty (They have the rash!) only 29% tested positive for Lyme disease on their initial blood test. Patients

with negative Lyme tests were retested three weeks later, and still 29% of them failed to have a positive diagnostic test for Lyme disease. Our SLICE study is currently performing sophisticated research-based immune tests so we can identify better ways to use blood tests to diagnose early Lyme disease.

We have also begun analyses to connect specific markers of the immune response in the bloodstream with patients' symptoms and responses to therapy. Our hypothesis is that patients who develop persistent symptoms may have significant elevations in one of the immune markers that we are measuring.

In the coming year, we anticipate doubling the enrollment of Lyme cases. As a result, we also anticipate a sample size large enough to begin generating further ideas on how Lyme disease adversely affects the immune system and patients' health.

We are diligently laying the groundwork for unraveling the mysteries of Lyme disease. The SLICE study is creating a unique resource of patient samples that will form the foundation for the fundamental research needed to develop better diagnostic tests and ways to monitor patients' response to treatment. Only with this understanding can we help the thousands suffering from Lyme disease.



VOLUNTEER PROFILE—JOAN HIGDON

Volunteers make LymeMD succeed.

In this issue of the newsletter, we are happy to shine the spotlight on someone working in the background whose dedicated service should be celebrated and appreciated.

Joan Higdon has been involved since the inception of LymeMD, and her (literally) hundreds of hours of volunteer service as Administrative Coordinator have helped to form the foundation of our success. Because of Joan's

meticulous attention to detail behind-the-scenes, our organization is professionally run and well organized. LymeMD's taxes, financial reports, meeting minutes, project management, and more all come under Joan's skillful management.

So, thanks Joan for your expertise, dedication, and top-quality work. LymeMD is a success because of you and others like you who give so much!





A PATIENT'S STORY

Let me tell you what Lyme Disease has been like for me. This is my story, just mine...but sadly, too many others have similar tales.

Lyme forces its greedy hand into life in ways impossible to imagine...until it happens to you. In addition to all the physical symptoms, there is the stress caused by the lack of diagnosis and treatment. Even people close to you have a hard time giving you their support when you can't give a 'name' to what you have. You spend a lot of money and time searching for an answer. And with no 'medically approved excuse', there is still an expectation that you will go to work each day, socialize, meet your obligations to friends and family, live your life.

Lyme is anything but easy to live with.

It took more than 20 years for my Post-Lyme Syndrome to be correctly diagnosed. In that time, virtually every part of my body was attacked: my brain - making

me forget words and process thoughts incorrectly; my joints; even my nervous system, ears, and urinary tract! Nothing was spared.

A line from a song has come to have special meaning for me: "When all's well, my love is like cathedral bells." That's how I feel about my life with Post Lyme. The bad days are a blur, and there are far too many of them. But on a good day, the fog lifts, and my zest for life is as clear as a beautiful song and I remember once again what it means to be alive, loved, successful, interested. These are days to be treasured and savored.

All I want from LymeMD's research is the chance to have someone turn their ear to my music. To hear me. I want more days to revel in the melody—and listen to it with the awe and respect it deserves - which any life deserves.

V.A. Donley



PREVENTION!

Fastening seatbelts in the car and using sunscreen regularly have become things we do without even thinking. We practice these *preventive strategies* ourselves, and we take care to see that our children do so.

We need to add preventing Lyme Disease to our list of these 'automatic behaviors'. And, yes, it is possible to minimize risk and still take part in all of the outdoor activities we enjoy like hiking, gardening, biking, and riding. Practicing prevention doesn't mean sacrificing pleasure.

Here are a few tips:

- Walk, hike, or run only on established paths; stay out of the underbrush.
- Wear long pants and long-sleeved shirts; consider clothing that has been pre-treated with *permethrin* insecticide.
- Check your kids, your pets, and yourself for ticks every day.
- Learn to recognize the many shapes that a Lyme disease rash can take.

Visit www.LymeMD.org for more preventive tips.

POLITICS AND LYME DISEASE

Logic suggests that groups around the country committed to improving diagnostic tests, enhancing public health surveillance systems, and generating effective public education campaigns to prevent new cases of Lyme disease would band together to seek financial support for research and cooperate with one another to ensure that these funds are put to best use.

Logic, however, does not prevail; hence, we have the "**Chronic Lyme Controversy.**" This unfortunate situation is best illustrated by the ongoing battle over Federal legislation to increase research dollars for Lyme disease.

Any reasonable person should wonder why it's been so difficult to pass legislation that would authorize a \$100 million, five-year initiative to expand Lyme disease research and education. (www.house.gov/list/press/nj04_smith/lymeintro.html)

Ironically, the bill (*H.R. 741*) has again pitted patient advocacy groups against the ISDA, the Infectious Disease Society of America, the very groups that would benefit from increased research dollars. So why would the IDSA start a letter writing campaign to kill the legislation? The answer to this baffling question is all about the controversy and politics (*See IDSA Sends Letter Opposing Lyme Disease Legislation in House and Senate 3/21/2008 at <http://www.idsociety.org/lymedisease.htm>*). **It makes for fascinating, if frustrating reading!**

Our foundation, LymeMD, will participate in this public controversy only on a very limited basis. Our primary focus remains on discovering the knowledge needed for the accurate diagnosis and effective treatment of patients with persistent symptoms of Lyme disease.

Lyme MD

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Contributions are welcome and can be made directly on the website