


Back in January, several of us at LymeDisease.org took the plunge and volunteered to serve on subcommittees of the Tick-Borne Disease Working Group, which was established by Congress as part of the 21st Century Cures Act. I personally put together my first résumé in decades and filled out the requisite paperwork. We also encouraged a number of other people we knew would support patient interests to apply for subcommittees. A month later, with a newly appointed Health and Human Services (HHS) secretary, we were notified that we had made the cut. Shortly after that, the real work began—with weekly conference calls, drafts, discussions, arguments, votes, and rewrites. Oh, yes, and minority reports.

A Seat At The Table – Federal Lyme Disease Program

Patients have a lot riding on the success of this effort. It's the first time we've had a seat at the table as the federal Lyme disease program is being discussed. We've already had positive examples of what can happen when enough patients get involved with government—doctor protection laws and mandatory insurance coverage are just two examples. This time the task is broader:

The Working Group will provide expertise and review all efforts within the Department of Health and Human Services related to all tick-borne diseases, to help ensure interagency coordination and minimize overlap, and to examine research priorities.



When we started, the program was already a full year into its two-year process, meaning deadlines would loom with alarming frequency. We had a huge amount of work to do in a short time. There was a learning curve just for the elaborate HHS-defined process of proposals and voting.



But we definitely had some of the top people on our side and they were willing to put in the

midnight hours alongside their regular work. Dan Sonenshine, professor emeritus and author of many books and several hundred scholarly papers on tick biology, chaired my subcommittee. His output was extraordinary.

This issue of the *Lyme Times* brings together articles that highlight the patient experience. Before the Working Group even met, LymeDisease.org led a successful effort to replace Gary Wormser on the panel, due to financial conflicts of interest. More than 10,000 people signed our petition in just four days and HHS subsequently announced that Wormser had declined the invitation to serve. Once the online meetings began, Lonnie Marcum and I live-tweeted the proceedings. Our Twitter followers amplified our message by re-tweeting our posts widely. LymeDisease.org CEO Lorraine Johnson was invited to speak with several subcommittees, and entomologist Robert Lane talked to the Surveillance Subcommittee about tick-borne diseases on the West Coast—an important point to understand because the majority of current researchers are East Coasters. Through her public testimony, we met the awesome Nicole Malachowski, a decorated female Air Force pilot who is now “unfit for duty” because of Lyme disease. I really wish you could have been there to hear the compelling testimony of Lyme Disease Association president Pat Smith, who went to bat for patients over the new vaccine, which seemed like a foregone conclusion at first—but now, perhaps not. Please watch the related videos on the Working Group’s website.

Patients also called attention to the way the CDC surveillance case definition is used for diagnosis, which delays care for thousands. The CDC could fix this problem in a day, but it has not—yet. LymeDisease.org has submitted written public comment on this and other important topics.

These are exciting times. Patients are coming together, and together, they are powerful. Inform yourself, ask questions, speak up, and have hope. Better times are coming.

For further reading and to keep up to date on the Working Group, visit <https://www.hhs.gov/ash/advisory-committees/tickbornedisease/index.html>.

Webcasts of the December and February meetings are available online. Click on Meetings and select a date.



In 1989, Phyllis Mervine established the Lyme Disease Resource Center, later re-named LymeDisease.org. She also founded The Lyme Times and serves as its editor-in-chief. In an effort to help Lyme patients join together for mutual support and

political action, she set up LymeDisease.org’s network of online state support groups. She has collaborated with researchers studying ticks, animal reservoirs, and human infection in northern California. She has served on numerous advisory committees both locally and nationally, and is a former member of the National Institute of Health’s Advisory Panel for Studies on Chronic Lyme Disease. She has had several letters and one article published in peer-reviewed medical journals, and her posters have been displayed at international Lyme conferences. Her special interests are networking and community-building, improving patient access to accurate information, and educating, mentoring, encouraging and supporting the next generation of Lyme disease advocates.

About MyLymeData: *MyLymeData is the third-largest national patient registry in the United States, with nearly 10,000 people either personally affected or parents of children with tick-borne diseases. It is a patient-driven big data project that tracks patients’ progress over time. Additional information can be found at: www.lymedisease.org/mylymedata/.*

About LymeDisease.org: *Since 1989, LymeDisease.org has advocated nationally for quality accessible healthcare for patients with Lyme and other tick-borne diseases. LymeDisease.org is committed to shaping healthcare policy through science-based advocacy.*

Editor’s note: Any medical information included is based on a personal experience. For questions or concerns regarding health, please consult a doctor or medical professional.

