

## What Balance Really Means for the Tick-Borne Disease Working Group

Toward the end of the Tick-Borne Diseases Working Group meeting on June 21, 2018, there was some discussion about including patient stories in panel's upcoming report to Congress. Working Group member Robert Smith, MD, noted that most of the stories that had been chosen for inclusion depict people suffering and waiting years for diagnosis, failing the two-tier testing criteria, having treatment cut off, and having bad outcomes.



Smith stated that most of his Lyme patients have responded well to treatment and he felt that the report's patient stories should reflect that reality. Working Group Chairman John Aucott then agreed that the report should be "balanced." The question of how to include a series of horror stories while still comporting with the goal of balance remained unanswered.

Both Smith and Aucott are misreading the Working Group's charter. Congress intended for panel members to represent diverse scientific disciplines and views. *This* is balance, and this is why the Working Group includes representatives from all stakeholder groups: government and non-government, patients and advocates, as well as scientists, researchers, and doctors with a range of views.

That’s why Dr. Smith was included — he is a member of the Infectious Diseases Society of America (IDSA) and supports that society’s practice guidelines. Richard Horowitz represents the other end of the diagnostic and treatment spectrum as a member of the International Lyme and Associated Disease Society (ILADS), which published the first Lyme guidelines to follow the rigorous Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) evidence assessment protocol recommended by the Institute of Medicine. *That* is balance.

## Balanced Lyme Disease Stories

The charter makes no mention of “balanced” stories. Dr. Smith, whose interests veer towards running large vaccine trials, thinks those diagnosed and treated early who become well need an “equal” voice in the stories included in the report. But those people aren’t the ones struggling with illness. They don’t need a community to fight for healthcare or just to get through their day. And the people who got better are not the people who fought to pass the legislation creating the Working Group. They simply got on with their lives. They don’t need representation by anyone, including Dr. Smith, because they are well.



The purpose of the stories is to provide some human interest and incentivize Congress to act. People no doubt recall the PR campaign about the Zika virus in 2016. Media carried heart-rending stories and pictures of babies born with tiny heads (microcephaly). The world was horrified. This is how you encourage people to act, and it worked. Congress earmarked US\$1.1 billion to fight Zika virus.

This is the scale of effort we now need for tick-borne diseases, after decades of denial, neglect, and deferred maintenance. Dr. Smith's proposal to tell Congress that tick-borne diseases are easy to diagnose and cure will simply undercut the whole purpose of the Working Group. Why should our lawmakers act if there isn't a problem? So let's identify and illustrate the problem that the Working Group was established to address.



Let's tell the stories of the patients who have suffered without a voice — the stories about what happens when IDSA takes a restrictive surveillance case definition and wrongly insists that it should be used for clinical diagnosis, which results in disastrous consequences to patients. We need to hear about patients who are ridiculed and labeled as psychiatric cases or malingerers. Let's tell those stories.

One would expect Dr. Smith, a member of IDSA, to promote the IDSA view that “the vast majority” of patients recover with standard treatment. However, for patients who are diagnosed late — as far too many are — the success rate of treatments intended for acute illness is poor. Only about half recover.

## Late Stage Lyme Disease Diagnosis

LymeDisease.org's MyLymeData ([mylymedata.org](http://mylymedata.org)) shows that 70% of people with persistent Lyme were not diagnosed until a late stage. This is because they could not obtain a timely diagnosis. Many cases take three or more years to obtain an accurate diagnosis. Could we correct this? You bet! We could permit—or even encourage—clinical diagnosis of these patients, although they don't meet the restrictive CDC surveillance case definition. We could allow community physicians who treat them to do so without the threat of potentially losing their license from medical board actions, as is currently the case.





Most of these patients report being profoundly ill for 10 or more years. Most have had to quit their jobs, reduce their work hours, or modify the work they do because of their functional impairment. And only 10% of our survey participants elect to see infectious disease specialists. Why? Because the IDSA protocols—which assume acute disease that is diagnosed early—don’t work for those who are diagnosed late. Could we do something about this? Yes! That’s why more than 10,000 Lyme patients leaned in over one weekend to help pass the 21st Century Cures act that established the Working Group. These are the stories we need to tell.

To do these things, we need to tell the stories of the patients who are suffering *because* they were not diagnosed early and *because* of their lack of treatment options.

“The point of the Working Group report is to encourage Congress to *do* something about an epidemic that we recognize is growing and that has a huge human cost. There’s no point in letting our legislators think there isn’t really a problem.

Let’s give Congress charts showing how cases have continued to climb every year with no indication of a slowdown. Let’s tell them global climate change may even make the problem worse. Let’s show Congress how funding for Lyme is in the basement. And let’s run the bad stories—there are tons of them and they have been silenced for decades. We have to recognize the problem before we can address it. We should have done this years ago, but I’ll settle for today.

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.