

Part 22:
Turning point in Lyme wars

Science journalist Pamela Weintraub wrote that the battle about the seriousness of the epidemic escalated qualitatively in the summer of 1993, "when the U.S. Senate Committee on Labor and Human Resources, chaired by Ted Kennedy, scheduled a hearing on Lyme disease.

"To the horror of the patients, the sole expert witness was to be Allen Steere."

Weintraub explained, "Over the next week, patients bombarded Kennedy's office with thousands of faxes and calls and the upshot was inclusion, at the zero hour, of additional testimony from some chronic patients and the first Lyme warrior, Joe Burrascano himself.

"And so it was that on August 5, 1993," Weintraub continued, "Joseph J. Burrascano Jr., M.D., stood before the Senate committee as hundreds of Lyme patients looked on. Donning green ribbons to show solidarity with the cause, the patients there that day were poised for battle, but few had expected Burrascano's words to raise the ante so high."

David Grann, at the time the senior editor of the New Republic, emphasized the importance of the Senate Labor and Human Resources Committee meeting: "At stake was the direction of millions of federal dollars in research, the legal guidelines for patient treatment and, in the eyes of a growing number of patients, their very survival." (New York Times, June 17, 2001)

Grann described: "When Steere arrived, the gallery was already packed with spectators, many of them wearing green ribbons to indicate their solidarity with Lyme patients. Their attention seemed to be centered on a little-known practitioner from Long Island named Joseph Burrascano Jr. Unlike Steere, he had never done scientific research, but he informed the committee that he had seen over 1,000 Lyme patients and that his protocol had been translated into three languages.

"As Steere looked on, the young doctor began a tirade against the medical establishment. He warned that many researchers were deliberately playing down the severity of chronic Lyme disease."

Burrascano's testimony is quoted in full online. The following is from Weintraub's book "Cure Unknown." (St. Martin's Griffin: New York):

Burrascano stated: "There is a core group of university-based Lyme disease researchers and physicians whose opinions carry a great deal of weight. Unfortunately, many of them act unscientifically and unethically. ... They adhere to outdated, self-serving views and

attempt to personally discredit those whose opinions differ from their own.

“They exert strong, ethically questionable influence on medical journals, which enables them to publish and promote articles that are badly flawed. They work with government agencies to bias the agenda of consensus meetings, and have worked to exclude from those meetings and scientific seminars those with alternate opinions.

“They behave this way for reasons of personal or professional gain, and are involved in obvious conflicts of interest. ... Some of them are known to have received large consulting fees from insurance companies to advise them to curtail coverage for any antibiotic therapy ... even if the patient will suffer.”

At one point during the Senate proceedings, Dr. Burrascano, “pulled out a blown-up photograph of a spirochete, positively identified as *Borrelia burgdorferi* [Lyme] by the NIH’s Rocky Mountain Labs. ‘It comes from a patient treated with antibiotics for thirteen months,’ Burrascano declared.” (Weintraub, p. 223)

Grann noted in his New York Times account that after Burrascano had finished his opening statement, a young boy came forward in a wheelchair, aided by his mother. She explained that her son wore headphones because neurological damage from the Lyme spirochete painfully amplified sounds.

Grann reported, “As his mother tried to interpret his gestures, the boy leaned forward and whispered into the microphone, ‘We can’t think. We can’t sleep. We need you.’”

Grann described, “The room was aghast. Steere later told a reporter that in his 17 years of research he had never seen a Lyme case like the boy’s. During the Senate discussion, he tried to explain why there was so much misdiagnosis in general, but the gallery began to shout: ‘He’s wrong! He’s wrong!’” (June 17, 2001)

Grann’s report in the Times, however, left out the most damning part of Burrascano’s statement: “Long-term studies on patients who are undertreated or untreated demonstrated the occurrence of severe illness more than a decade later, reminiscent of the findings of the notorious Tuskegee Study, in which intentionally untreated syphilis patients were allowed to suffer permanent and in some cases fatal sequelae.” (Weintraub, pp. 221-222)

Burrascano was referring to the infamous historical crime carried out by the U.S. Public Health Service, referred to as the “Tuskegee experiment,” which involved another related spirochete--syphilis. From 1932 to 1972, 600 impoverished sharecroppers of African descent who had contracted the spirochete were told they were receiving free health care as treatment for "bad blood." When a cure was discovered, that fact was hidden from the Black men. The Tuskegee study was a racist massacre carried out in slow motion over four decades. (en.wikipedia.org)

Months after Burrascano's testimony, Karen Forschner of the Lyme Disease Foundation

reported that at a Jan. 1994 National Institutes of Health meeting on chronic Lyme, "Dr. John LaMontagne, a director of the National Institute of Allergy and Infectious Diseases, said to me, 'Someone should sue Joe Burrascano for his testimony.'" (Weintraub, p. 223)

No one sued Dr. Burrascano for slander. But years later, he and Lyme activists had to defend him from an attempt to strip him of his medical license.

Next: 'Medical McCarthyism'