

**Part 25:**  
**'Growing army of patients and support groups'**

The New York Times recognized that it was a turning point in 1993 when the Lyme wars erupted in the U.S. Senate gallery--in defense of a physician dissenting from the ruling medical Lyme establishment. (June 17, 2001)

Journalist David Grann, making reference to Polly Murray--the parent who first reported a Lyme outbreak among Connecticut children to scientists in 1975--stressed the role of those who were ill in the Senate gallery: "It was the most telling sign that there was something happening outside the ordinary circles of medicine, that in frustration a parallel universe was being created—a universe in which there were now hundreds of Polly Murrays, self-taught medical experts armed with their own doctors and research."

The article pointed out, "Even Polly Murray turned against Steere, saying he was doing to other patients what the medical community had once done to her. 'I don't know why he's doing it,'" she told Grann. "I've tried to talk to him, but he won't discuss it."

Grann wrote that Steere liked to insist, "In the scientific community there is no controversy." But Grann added, "Burrascano wielded a growing army of patients and their support groups.

"In the past," Grann recalled, "such groups typically tried to help patients get better treatment, lobbying for more research funds and sometimes, as in the AIDS movement, leading demonstrations and protests against the establishment."

Grann contrasted, "But because the Lyme movement considered itself a victim of a corrupt scientific establishment rather than political bias, it seemed to go even further, trying to discredit the existing research and come up with its own.

"The most powerful of these organizations, the Lyme Disease Foundation, created its own scientific publication, the Journal of Spirochetal and Tick-Borne Diseases; organized its own scientific conferences; financed its own research; and trumpeted its own medical experts with their own treatments."

Grann stated that several weeks after his interview with Dr. Burrascano in June 2001: "[S]cores of Burrascano's patients and supporters spilled into the corridors of the New York State Capitol to lobby politicians to stop the state's investigation. Denouncing Steere, they carried signs that read 'Ticked Off' and 'Leave Our Doctors Alone.' Some sat in wheelchairs; others leaned on canes."

Grann wrote that when Lyme/+ activists discovered he was a reporter, "[T]hey began to give me their testimony, one after the other, on how [Steere] had refused to treat them,

how they were going broke because the insurance companies heeded his guidelines and wouldn't foot their bills, how most doctors, with the exception of Burrascano and other doctors on his side, had ridiculed them and dismissed them and called them nuts."

One patient appealed to Grann: "Please help us. We are dying."

*Next: The rich get best care: George Bush and Lyme*