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SUFFOLK CLOSE UP

Public Health Scandal

By Karl Grossman

As terrible as Lyme disease is—and it is endemic in Suffolk County, elsewhere in the New York metropolitan area and, indeed, now in areas across the United States—equally awful is the refusal by health insurers to pay for long-term treatment of what is often a long-term disease. "The insurance companies are behind limiting the amount of treatment," stated Suffolk County Legislator Edward P. Romaine at a town hall meeting on Lyme disease that he chaired last month in Riverhead, organized with the help of the Empire State Lyme Disease Association. "The insurance companies have one goal, and that's to limit their exposure ... They're looking to treat at a minimal level because it's more costeffective." Thus, "we have literally thousands of people in Suffolk County who are not getting properly diagnosed or treated." The Lyme disease situation involves a public health scandal of the first order. At the town hall meeting was a pioneer in the treatment of Lyme disease, Dr. Joseph Burrascano, who, as a physician in East Hampton, first began treating it in 1981 in a place, he noted, "with the highest rate of Lyme disease in the world—the East End of Long Island." He found that although some people after being bitten by a tick and contracting the disease can be cured in three weeks or so through treatment with antibiotics, many could not be cured simply or quickly, and needed long-term care. By 1993, he was testifying before the U.S. Senate, emphasizing the need for long-term treatment for those with chronic cases of Lyme. That outraged health insurers and some doctors and scientists tightly connected with them. As a result, Dr. Burrascano was "forced," he recounted, to undergo hearings at the New York State Health Department that ultimately cleared him. "Obviously, I was the target. If the health insurers and their allies could 'knock me out,' they could better get away with not having chronic Lyme patients get the treatment they need," said Dr. Burrascano, author of a manual on Lyme treatment—now a standard, in its 15th edition—available for free on the internet under "Advanced Topics in Lyme Disease." In introducing Dr. Burrascano at the August 30 meeting, Eva Haughie, president of the Manorville based Empire State Lyme Disease Association, herself a long-term Lyme victim—she notes that she first contracted the disease in 1988—said he should receive the Nobel Prize. At the very least, Dr. Burrascano certainly merits the public health equivalent of a military medal: he has fought valiantly to help people against a powerful bloc in the United States, recently presented by Michael Moore, in his documentary "Sicko." State Assemblyman Fred W. Thiele Jr. of Sag Harbor, also in attendance at the meeting, spoke of how his bill to require that health insurers pay for long-term treatment of Lyme has been blocked. "It's a big battle because of the lobbying against this legislation. You have all the insurance companies [and] a lot of the business lobbies that don't want to have increased

costs," he explained. "You can't underestimate the influence of special interests on the legislative process in Albany," Mr. Thiele continued. "We need to take the influence of special interests out of the legislative process." Because of the "campaign contributions coming from insurance companies and big business ... a piece of common-sense legislation is not adopted as it should." The assemblyman added that "it's good to see a meeting like this" with people "speaking with one voice, because that's what it is going to take." People at the meeting gave heartwrenching testimony of undergoing enormous pain and suffering from Lyme. It was noted that it can be so painful and endless that suicide by Lyme sufferers is a significant problem. Diane Blanchard, president of Time for Lyme, who contracted the disease in 1987 while gardening at her home in Westhampton, told of having gone "from early morning runner to someone who could not get out of bed." As for the health insurers who won't compensate for long-term care, Ms. Blanchard said they "prefer to see a far less standard of care because it is less costly."

. insurers refuse to pay for long-term Lyme treatment, they must be mandated by government to do so. The Lyme disease treatment scandal underlines, moreover, why it is clearly time in the United States for universal health care based on medical need, not profit or the ridiculous fiats of bean-counters. On Saturday, October 20, a followup meeting will be held, starting at 11 a.m., at the Manorville firehouse on the "Children of Lyme." Organized by the Empire State Lyme Disease Association and the Manorville Taxpayers Association, youngsters with this dreadful malady will tell their stories.