

Local residents join New York Lyme disease protest *Gilchrest among congressmen questioning guidelines*

By STEVE NERY

Staff Writer for the Easton, MD Star Democrat

December 15, 2006

VALHALLA, N.Y. —

Nearly 400 people, including more than 40 from a bus that departed from Easton, protested the Infectious Disease Society of America's new Lyme disease diagnostic and treatment guidelines outside of a New York hospital on Nov. 30.

The IDSA released its new guidelines in October, and have since come under fire from patient-advocate groups such as the Lyme Disease Association and the International Lyme and Associated Diseases Society.

Unless a “bullseye rash” is visible, the group still recommends blood testing, which critics contend has been proven ineffective in studies.

Long-suffering Lyme disease patients also charge the new guidelines essentially deny that “chronic Lyme disease” even exists, and prevents them from being treated. Lyme disease is caused by the bacteria *Borrelia burgdorferi*, transmitted through tick bites.

Three of the guideline authors — lead author Gary Wormser, Raymond Dattwyler and Robert Nadelman — all work at the Westchester Medical Center, which the protesters picketed outside for three hours.



PHOTO BY LUCY BARNES

Ruth Ann Robinson, left, formerly from the Eastern Shore, stands with Jean F. Galbreath of Street, Md.

The crowd included people from Texas, Washington, California, Pennsylvania, Florida, Maryland and Delaware, said Lucy Barnes, director of the Lyme Disease Education and Support Groups of Maryland.

More than 40 of the protesters, many of them with Lyme disease-related disabilities, came on a bus originating in Easton and stopping in Centreville, Elkton, Claymont, Del., and by the New Jersey Turnpike.

The trip from Easton and back took 12 hours, Barnes said.

The group included children, elderly people, a Maryland doctor, several nurses, and Douglas W. Fearn, the author of “Lyme Disease and Associated Disease Basics,” Barnes said.

A Talbot County patient also called her at the last minute to get a ride, having just come from a doctor’s appointment and denied treatment because of the new [] guidelines, she noted.

President Pat Smith of the Lyme Disease Association and Dr. Joseph Burrascano Jr. of the international group spoke at the protest. The protesters created a 14-foot-long memorial with hundreds of names of people who died from Lyme disease, Barnes said.

Patients who could not come called the hospital from across the country all day long and told their Lyme stories and their dissatisfaction with the three doctors, Barnes said.

Lyme disease patients also received the support from a group of congressmen, including Rep. Wayne T. Gilchrest, R-Md.-1st, who last week sent a letter to the Centers of Disease Control questioning their implicit support of the IDSA guidelines.

The CDC posted a link to the IDSA guidelines on its Web site, but did not include information about the group’s guidelines, which address chronic Lyme disease.

In the letter, addressed to CDC Director Dr. Julie Louise Gerberding, the congressmen write, “We are concerned that these guidelines have the potential to effectively shut down all treatment for chronic Lyme disease.”

The authors critiqued the position of the international group that only the bullseye rash is enough for a clinical diagnosis.

“This seems a remarkably broad restriction since there is currently no commercially viable or available gold standard for the diagnosis of Lyme disease,” the letter reads.

Less than half of all infected people recall the tick bite, according to the international association, and more than half never develop the bullseye rash.

The new guidelines, the congressmen wrote, “appear to ensure that no physicians treat chronic Lyme disease and that many patients are denied access to care.”

The IDSA guidelines state that a few weeks of antibiotics produces a highly favorable outcome, and urges doctors not to administer alternative treatments. Lyme support groups favor treatment taken on a case-by-case basis.