Statement from Enid Haller, MSW, PhD for the Lyme Working Group Washington DC, December 11 & 12, 2017

For the last 11 years I have lived on Martha's Vineyard and have been trying to educate everyone on the Island about Chronic Lyme Disease. I started the Martha's Vineyard Lyme Support Group 9 years ago and the Lyme Center of Martha's Vineyard 5 years ago. During that time I have only received help and support from alternative practitioners including Physical Therapists, Naturopathic Doctors, Chiropractors, Massage Therapists and Accupuncture Therapists.

The Martha's Vineyard Boards of Health, the Island's Community Services, the local doctors and healthcare providers in the walk-in clinics and Martha's Vineyard Hospital have been of no help to our Chronic Lyme sufferers over the past 30 years. Most people I know who have Chronic Lyme on the Island -- including myself and my family -- have never tested positive for Chronic Lyme using the two-tier testing model, the ELISA and Western Blot.

It was not until I suggested to Island patients that we use the iGeneX Lab's Western Blot (a better version of the Western Blot test which also tests against more than one strain of Borrelia Burgdorferi), that we all finally began getting the correct diagnoses. Confusion in the medical community has been compounded by the actions of insurance companies who have both denied patients important care as well as pro-actively threatened and revoked the licenses of doctors who engage Chronic Lyme patients seriously. This has created fear among the mainstream doctors and has increased the rate at which normal, easily treatable acute cases of Lyme Disease have gone Chronic – meaning that cases have progressed with likely irreversible neurological damage that leads to mis-diagnoses of ALS, dimentia, Alzheimers, Multiple-Sclerosis and worse.

Just my Martha's Vineyard Lyme Support Group alone has 859 names on the mailing list. And we are not alone: there are thousands of Lyme Support Groups across this country and the world that provide support at this scale.

The number of people on Martha's Vineyard who carry Chronic Lyme Disease and the common co-infections boggles the mind. The Lyme-stricken patient travels from one specialist to another -- and another -- until their patience and their budget strains to the breaking point. Or they just suffer in denial and silence. The treatment of choice then becomes self-medication through alcohol and pain-killers, which are typically opiates. It follows that the local addiction rate on the Island is OFF THE CHARTS! The hidden personal cost of our inability to systematically cope with this growing disease is staggering. And the most common visible costs of bankruptcy and divorce are always rationalized away.
For 10 years, I have been directing Chronic Lyme sufferers to ILADS (International Lyme and Associated Diseases Society) or, in other words Lyme-Literate Doctors. Most people with Lyme cannot afford to travel and see these specialized Lyme doctors, who have to charge out-of-pocket due to the lack of insurance coverage for Chronic Lyme Disease. Finally, we are at a tipping point and the Island medical community is slowly beginning to acknowledge the depth of the problem. There are just too many people who are sick there, and we can't be ignored any longer.

Martha's Vineyard is known as “Ground Zero” for Chronic Lyme Disease because its towns are at the top of the Massachusetts Department of Public Health's ranking of the 50 towns with the highest concentration of reported Lyme Disease. Chilmark is #1, Tisbury #2, Aquinnah #3, Edgartown #9, and West Tisbury #10.

The Lyme fiasco is an injustice and a growing financial catastrophe for our families and an economic catastrophe already in full bloom across this Land. Insurance companies would save money if they would allow ILADS and Lyme-Literate Doctors to share their knowledge and be accepted into the systems. Our mainstream doctors need to be helped and educated about how to diagnose and treat Chronic Lyme and prevent acute Lyme from going Chronic.

This is a treatable disease and the situation can be turned around. With the proper incentives and honest medicine, millions of people can get their lives back and an equal number can be prevented from suffering so badly.

Thank you,

Enid Haller, MSW, PhD

*Lyme Center of Martha's Vineyard* and
*Martha's Vineyard Lyme Support Group*