

More than 65,000 signatures for the Dutch Lyme Association's petition

The Dutch Lyme Association (NVLP) has collected more than 65,000 signatures, requesting attention for Lyme disease in The Hague, the country's political centre. In the petition, the NVLP advocates the establishment of a national Lyme Expertise Centre, for better diagnostic analyses, to exchange and combine experiences in treating chronic patients, to conduct research on the *Borrelia* bacteria and to develop better tests and treatments.

Sybe de Lint, chair of the NVLP: "We are very happy with this result. It is a signal that the unsolved issues concerning Lyme disease are being noticed. Official counts show that since 1997 three times as many people are being diagnosed with Lyme on the basis of an *Erythema migrans*, the circular red rash. It is urgent that the Lyme issue in the Netherlands is acknowledged and something is done to address the often distressing situation of Lyme patients".

On January 1st, 2009 the NVLP started a citizen's initiative to call the Dutch government's attention to Lyme disease. At the moment the initiative is being assessed by the Committee for Petitions and Citizen's Initiatives. The NVLP hopes to be able to submit the petition to the Committee for Public Health, Welfare and Sports in the Tweede Kamer (comparable to the House of Commons in the UK) in April.

The petition can still be signed on www.lymevereniging.nl (for Dutch citizens).

The petition

To the Ministry of Public Health, Welfare and Sport (VWS), the Ministry of Agriculture, Nature and Nutritional Quality (LNV), the Ministry of Public Housing, Regional Planning and Environment (VROM).

LYME: A PAINFUL AND LINGERING DISEASE IN SOCIETY

In the Netherlands an estimated 250,000 to 500,000 people suffer of Lyme disease. Every year several tens of thousands more are infected, both because the amount of infected ticks is rising and because there are practical problems in diagnosing and treating Lyme, causing many patients to go undiagnosed and untreated. Many patients visit several specialists before even being tested for Lyme, while late diagnosis reduces the success of short antibiotic treatment and strongly increases the chance of chronic, difficult to treat symptoms.

The diagnosis of Lyme disease in the Netherlands is normally done by testing for the presence or absence of antibodies for the *Borrelia* bacteria in the blood. The tests that are used, however, are unreliable, there is no general standard, and the results thus vary depending on which laboratory is consulted. In Europe there are at least five various *Borrelia* species, but most of the tests are made on the basis of only one species. Also, the *Borrelia* bacteria can elude and suppress the immune system, in which case the test will not show the presence of any antibodies but active infection still is present. According to some scientific studies false-negative test results like this cover 50% of the negative test results. In this way, patients go undiagnosed and untreated and are not recorded in the official Dutch statistics, and the necessity for strong measures is not made clear!

Many Lyme patients who receive late and/or inadequate treatment become partially or completely unable to work and have to depend on governmental disablement benefits.

The disease can be fatal. Often, Lyme patients searching for help visit physicians and research centres both in the Netherlands and abroad which are not covered by their health insurance. All of this causes unnecessary suffering, loss of productivity and unnecessary costs for patients as well as for society.

At the moment, the CBO guidelines for treatment of Lyme disease are being revised. In addition to this we, the signatories of this public letter, ask the above mentioned Ministries to support the following:

- The institution of the duty to report any case of Lyme disease.
- To adjust basic medical education at universities, and educate practising physicians about the *Borrelia* bacteria, the development of Lyme disease, and most of all, about how to offer a quick clinical diagnosis of Lyme disease;
- The development of good standard tests, which includes taking account of various species of *Borrelia* and the complex microbiology of Lyme.
- The institution of a Lyme Expertise Centre in the Netherlands, which must coordinate research on the *Borrelia* bacteria, the development of Lyme disease, and various treatments.
- More research on and attention for the diagnosis and individual treatment of chronic Lyme borreliosis with longer, higher and/or combined doses of antibiotics.
- More research on and attention for the treatment of coinfections caused by tick bites, which can complicate diagnosis and treatment and worsen the illness of the patient.
- More education of the general public about ticks, the danger of tick bites, and the possible consequences; issue a warning to nature lovers.
- The insistence on European level to develop a vaccine.

Lyme disease is a real danger for anyone working or taking leisure in nature. The consequences are unnecessary and unjust. Therefore, we call on all institutions that play an important role to commit themselves to enable rapid improvement in diagnosing and treating Lyme disease.