

Translation of article in French Magazine “L’OBS”

<http://tempsreel.nouvelobs.com/sante/20160711.OBS4459/la-maladie-de-lyme-explose-c-est-un-scandale-sanitaire.html>

"Lyme disease is exploding, it is a health scandal"



Professor Christian Perronne has denounced for years the denial about chronic Lyme disease. For him, and for the hundreds of doctors who are launching an appeal in the "Obs" magazine to the Minister of Health, one must act. Quickly.

Professor Christian Perronne is department head of Infectious Diseases at the University Hospital Raymond Poincaré in Garches , and co-director of a working group on vaccination at the World Health Organization (WHO). He is one of the only hospital doctors in France, who for several years have denounced the lack of recognition of chronic Lyme disease.

Underdiagnosed, poorly supported by health authorities, this infection transmitted by ticks, can cause, if left untreated, paralysis and dementia. Now it is in full expansion. "There is an emergency," said Professor Perronne , who with a hundred other doctors, has launched in the " Obs " magazine an appeal to the Minister of Health . Interview.



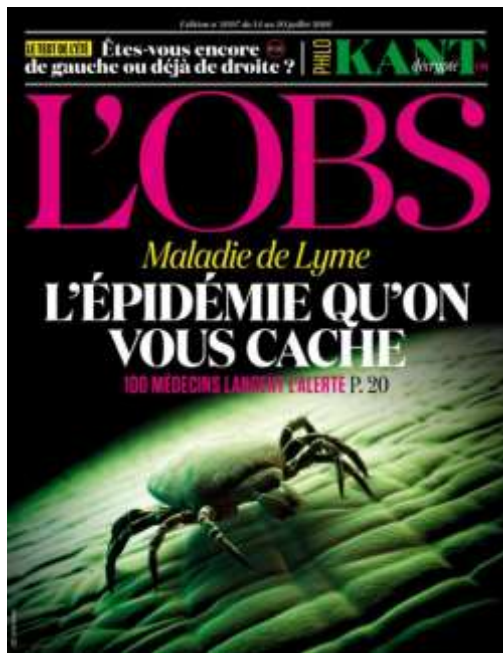
Christian Perronne

The government has announced a national action plan against Lyme disease. Is it good news?

This is a first small step. All these years, our interviews with the Ministry of Health have always resulted in a denial of the pathology. I hope this will not be the case this time.

How did you come to get interested in Lyme disease?

When I started working in Garches, in 1994, I've seen many patients arrive, bitten by ticks during their walks in the great forests of western Paris. Ticks can transmit what we call Lyme disease, caused by bacteria, the borrelie (Borrelia), itself often accompanied by other bacteria and parasites.



I treated these patients with three weeks of antibiotics, according to the official protocol, but many relapsed. I could see that it was not enough. The disease requires longer-term care. Which I have done. I discovered then that the medical profession did not at all want to hear about the chronic aspect of this disease. I was mocked, even in my own service.

If symptoms – joints, cardiological, neurological - come back it is no longer considered Lyme, they say it is "post-Lyme" and sent people to psychiatry. This is flabbergasting! It is like if one was saying after a fortnight of tuberculosis: "You do not have tuberculosis any longer, if you have signs, maybe you suffer from depression."

Why do you think that the tests supposed detect the disease are not effective?

In addition to the borrelia responsible for Lyme disease, there are about another twenty other Borrelia species. The Elisa test, mandatory step for French doctors, is only detecting three more of these, with a high proportion of cases where the test remains negative despite the disease. And yet, if it is negative, the French doctors do not have the right to continue their exploration, to complete it with a more specific test such as the Western blot. Even if their patient has significant clinical signs. Doctors may be prosecuted by the Assurance-Maladie (French NHS) if they do!

The reference center of borreliosis in Strasbourg still says today that this test is 100% accurate, while all publications show the opposite! How can we maintain such an aberration? Especially since it has been proven since long ago - it was published in most prestigious scientific journals - that serology may be negative despite the presence of the bacterium Borrelia.

In the United States, not only are physicians free to prescribe the Western Blot despite a negative Elisa, but he even has a duty to tell his patient that a negative test, whatever it is, is not a proof that he is not infected!

The issue divides the medical community. How do you respond to infectious disease specialists who say Lyme is a catch-all disease?

I agree. One should not, by the way, say "Lyme" but "tick-borne illnesses." The Lyme and associated diseases give very different clinical signs, which, additionally, can appear only years later. Hence the complexity of diagnosis. And specifically the need to improve the tests!

Today, patients with tick-borne illnesses are referred from one service to another, treated for conditions that they do not have: fibromyalgia, multiple sclerosis, dementia ... I see that all over the place, misdiagnosis! And during this time, their symptoms worsen. These are terrible stories. Some end up committing suicide. I have pulled people out of psychiatric asylums or from their stretcher with prolonged antibiotic treatment. They had arrived at that point because their pathology had been denied. It is a health scandal.

... which Professor Luc Montagnier, discoverer of HIV, compares to the contaminated blood [scandal]. You raise this as an outright "epidemic"?

Yes, the disease is exploding. Ticks have always existed, *Borrelia* has been found in a human mummy frozen for over five thousand years. But ticks are increasingly numerous and they are more and more infected. The latest US figures are very worrying: within a few years in the Northeast states, there was an increase of approximately 300% in the number of heavily infested counties.

In Europe, data published in *Eurosurveillance* (2011) show up to 350 cases per 100,000 people, depending on the countries: most affected are Slovenia, Germany, Austria and some Nordic countries. Another ongoing study based on the number of infected ticks and migrant show that a million more people are affected each year. And despite this, France says 27,000 new cases per year! It's ridiculous.

How do you explain this denial?

The reasons are numerous, I do not want to talk about what's out of my field of expertise as a doctor. What I can say is that, besides the complexity of diagnosis and treatment, it is a classic phenomenon: in cases of infectious epidemic, the authorities are reluctant to acknowledge the extent of the damage and their responsibility. Generally, they resist until patients force them to reverse their position. This was the case for HIV.

Is this what is happening with Lyme? Patients file complaints against laboratories, another one does a hunger strike and, hey presto, the government hurriedly announces a plan ...

The government will have to carry this out with patient associations, broadening the usual circle of medical experts. Otherwise, nothing will happen! Furthermore, it is fine to propose to review the recommendations on the treatment of advanced forms of the disease, by involving the High Authority for Health (HAS), but it is a very long process and insufficient: it is urgent to take more rapid measures.

What kind of measures?

The ones we describe in our call to action; implement reliable diagnostic tests; provide effective medical cover to those that are sick and stop legally pursuing the doctors who treat

them, create specialized hospital units for Lyme, and fund research: until today, I never managed to get one single euro of grant for this sector!

Interview by Emmanuelle Anizon