





THE DUTCH LYME MONITOR 2019

The Dutch Lyme Disease Association (Lymevereniging) initiated this 2019 Dutch Lyme Monitor: for the first time, the situation of chronic Lyme disease sufferers has been properly mapped out. The result is shocking: the health, healthcare, treatment and quality of life of chronic Lyme disease patients is abysmal.

APPROACH

The Dutch Lyme Monitor's questionnaire was developed based on three group interviews, conducted with a total of 24 chronic Lyme disease sufferers. One group interview, for patients who were too sick to travel, was conducted on Skype. 1,657 chronic Lyme patients filled in the extensive online questionnaire over the course of twelve days (27 February to 10 March 2019): 1,600 adults and an additional 57 parents of minors suffering from Lyme disease. Besides these Lyme patients, 180 parents and 216 partners of Lyme patients participated. Participants were recruited via the Dutch Lyme Disease Association's digital newsletter, website and social media.

DUTCH EXPERTISE CENTRE FOR LYME DISEASE

Five years ago, the Dutch Lower House unanimously adopted the Van Gerven cum suis motion that called on the government to promote the establishment of a Lyme disease research and treatment centre. The Dutch Expertise Centre for Lyme Disease, set up two years ago, has in practice not improved anything for chronic Lyme disease sufferers. The expertise centre's annual research budget, less than half a million, is inadequate. International cooperation – aimed at advancing knowledge about the causes and progression of the disease, developing reliable tests and effective treatments – presents enormous scientific challenges. A much greater government effort is an urgent necessity for the tens of thousands of chronic Lyme patients in the Netherlands. Lyme disease is the first disease to be associated with climate change; therefore, this number of cases is likely to increase sharply in the coming years.

LYME FOUNDATION

The Dutch Lyme Disease Association plans to intensify its own contribution. The Dutch Lyme Disease Association has initiated the setting up of the Dutch Lyme Foundation. Following the example of the Lung Foundation and the Diabetes Foundation, this foundation plans to run campaigns to raise awareness of the disease. The Lyme foundation aims to raise funds for research into the disease, testing and treatments, to name but a few. The Lyme Foundation's Board of Directors is currently being assembled. The ambassadors for the Lyme Foundation are Hollywood star Yolanda Hadid, born and raised in the Netherlands, and politician Emile Roemer, who was incapacitated by Lyme disease for a year preceding his entrance to national politics.





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LYME DELTA PLAN

THE RESULTS OF THE 2019 DUTCH LYME MONITOR LEAD TO 10 URGENT RECOMMENDATIONS:



Chronic Lyme disease patients gave an average score of 4.5 out of 10 to the state of their health over the preceding four weeks.

This score from the Lyme Monitor confirms conclusions from scientific research that the quality of life of chronic Lyme patients is very poor. Half of them rarely leave the house. 1 in 6 spend much of their time in a darkened room.

Over 1,600 patients participated in the Lyme Monitor. They give the state of their own health a low score, yet healthcare for Lyme disease in the Netherlands scores even lower: the average score being 2.3 out of 10. Only 5% of patients gave Dutch healthcare a pass. The explanation given by participants suggests that the healthcare system leaves many chronic Lyme patients without care; worse, they are being stigmatized. Almost all Lyme patients indicated that at least one doctor had not taken them seriously. Many Lyme patients find that doctors simply do not believe they are ill, and are not interested in their serious health problems.

People are forced to turn to doctors abroad, or to integrative doctors who combine conventional and alternative treatments. Half of them have spent over €5,000 of their own money on tests, healthcare and treatments. For financial reasons, 7 out of 10 cannot get the treatment they would like. Almost half of the participants in the Lyme Monitor have no healthcare provider for Lyme disease.

Much more research into the causes and progression of the disease, and into effective treatments, needs to be carried out in an international context.



¹ Berende A, ter Hofstede H. J., Vos F. J., van Middendorp H., Vogelaar M.L., Tromp M., et al. (2016) Randomized Trial of Longer-Term Therapy for Symptoms Attributed to Lyme Disease. *New England Journal of Medicine*. 2016;374(13):1209–20. pmid:27028911 <https://www.nejm.org/doi/full/10.1056/NEJMoa1505425>

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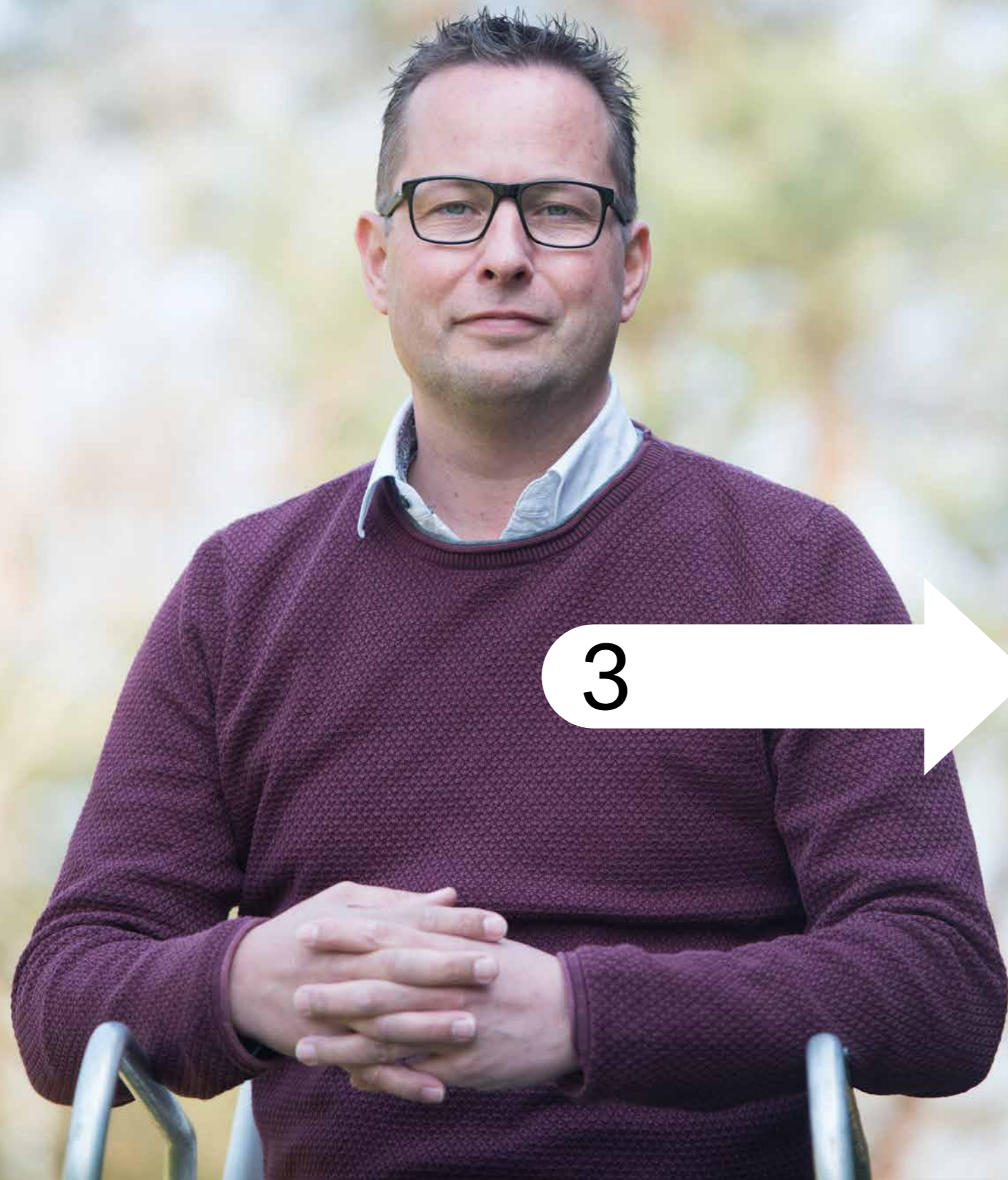
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In comparison: 8.3% of the adult Dutch population have considered suicide at some time in their life. 9 out of 10 patients find it hard to live with Lyme disease. 6 out of 10 feel isolated.

Every chronic Lyme disease patient should have easy access to formal care in the form of supervision by a nurse and/or social worker, and informal care by a Buddy (a professionally trained volunteer).



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Based on signals the Dutch Lyme Association receives on a daily basis, we get the impression that over three quarters of Lyme patients whose family doctor has referred them to one of the two academic hospitals that specialize in Lyme disease, are told they cannot be accepted due to insufficient capacity. For the patients who are accepted, the waiting list is often several months, which has a detrimental effect on the prospects for recovery. Or, following a single course of antibiotics, they are told they are no longer eligible for further treatment, whereas their symptoms often have not improved. On the contrary, they get worse or return some time later.

The healthcare capacity at Radboud University Medical Centre (Radboudumc) and Amsterdam University Medical Centre (Amsterdam UMC) location AMC must be vastly increased in the short term, so that every patient with a referral, who suffers from this infectious disease can be seen by a specialist within two weeks. Every Lyme patient with persisting symptoms should have a quarterly consultation, focused on treatment of the disease.



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Furthermore, almost half of them point out that natural treatments with antimicrobial properties for example, played a major role. Long-term antibiotic use is often not reimbursed by health insurers.

Government and politicians should ensure that long-term use of antibiotics to treat Lyme disease, and other tick-borne infections, is included in the standard health insurance package.



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On average, it takes chronic Lyme sufferers 4.4 years to be diagnosed, and during that period they have had to see 6 different doctors to arrive at the Lyme diagnosis. Despite the fact that the National Institute for Public Health and the Environment (RIVM) clearly states that a Lyme disease diagnosis is a clinical diagnosis, and doctors should not solely rely on lab tests, many patients experience doctors to have blind faith in these tests. Antibodies fail to show up in the current Lyme tests in at least a quarter of the diagnoses, even in people who contracted Lyme disease months or years ago, and the Dutch Lyme Association suspects the percentage is much higher. A test to determine whether the Lyme infection is still active does not exist.

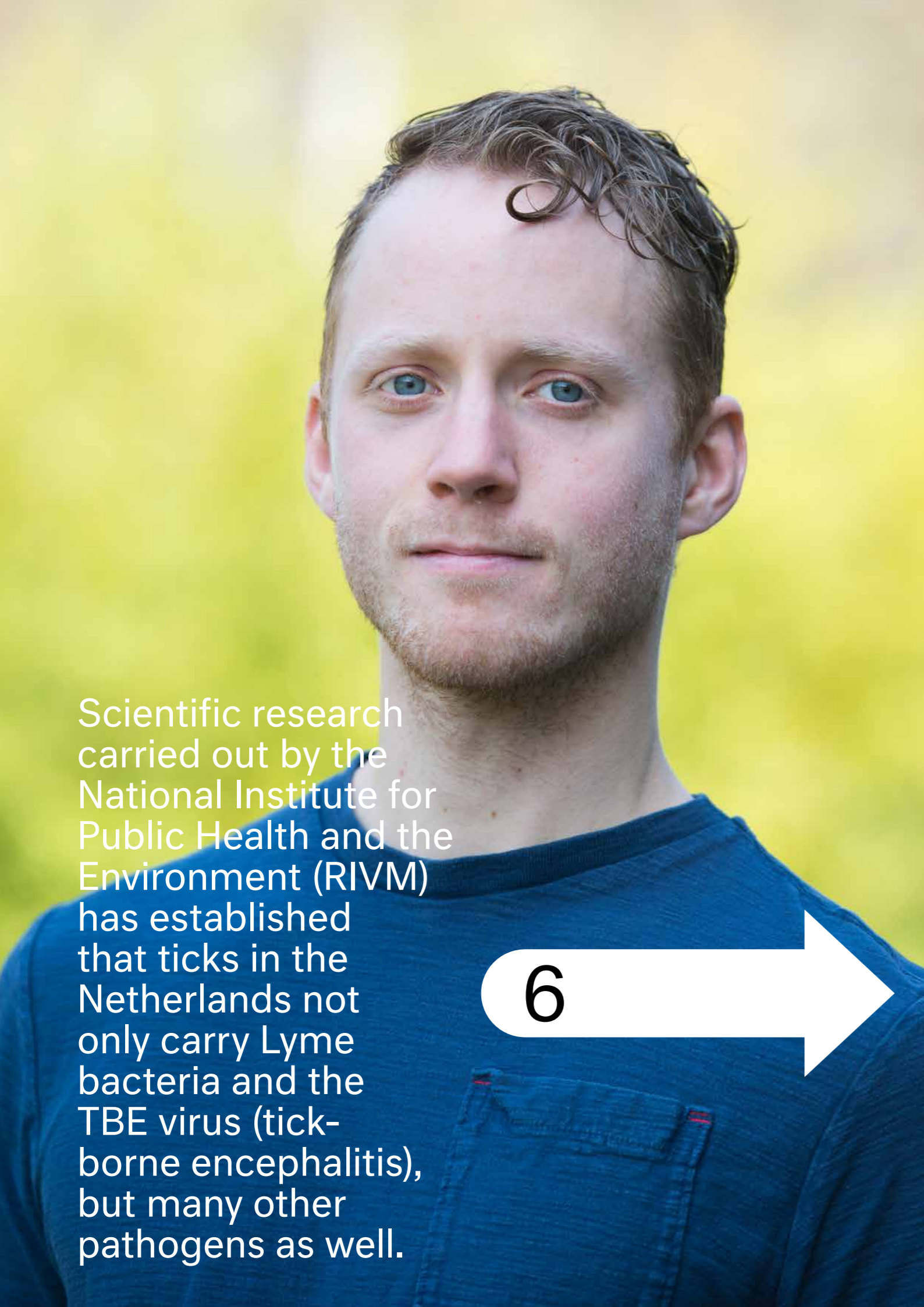
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Better Lyme tests that can reliably determine whether someone has an active Lyme infection should be developed internationally.

²<https://www.rivm.nl/nieuws/labtest-alleen-niet-doorslaggevend-bij-diagnose-lyme>

³<https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-016-1468-4>





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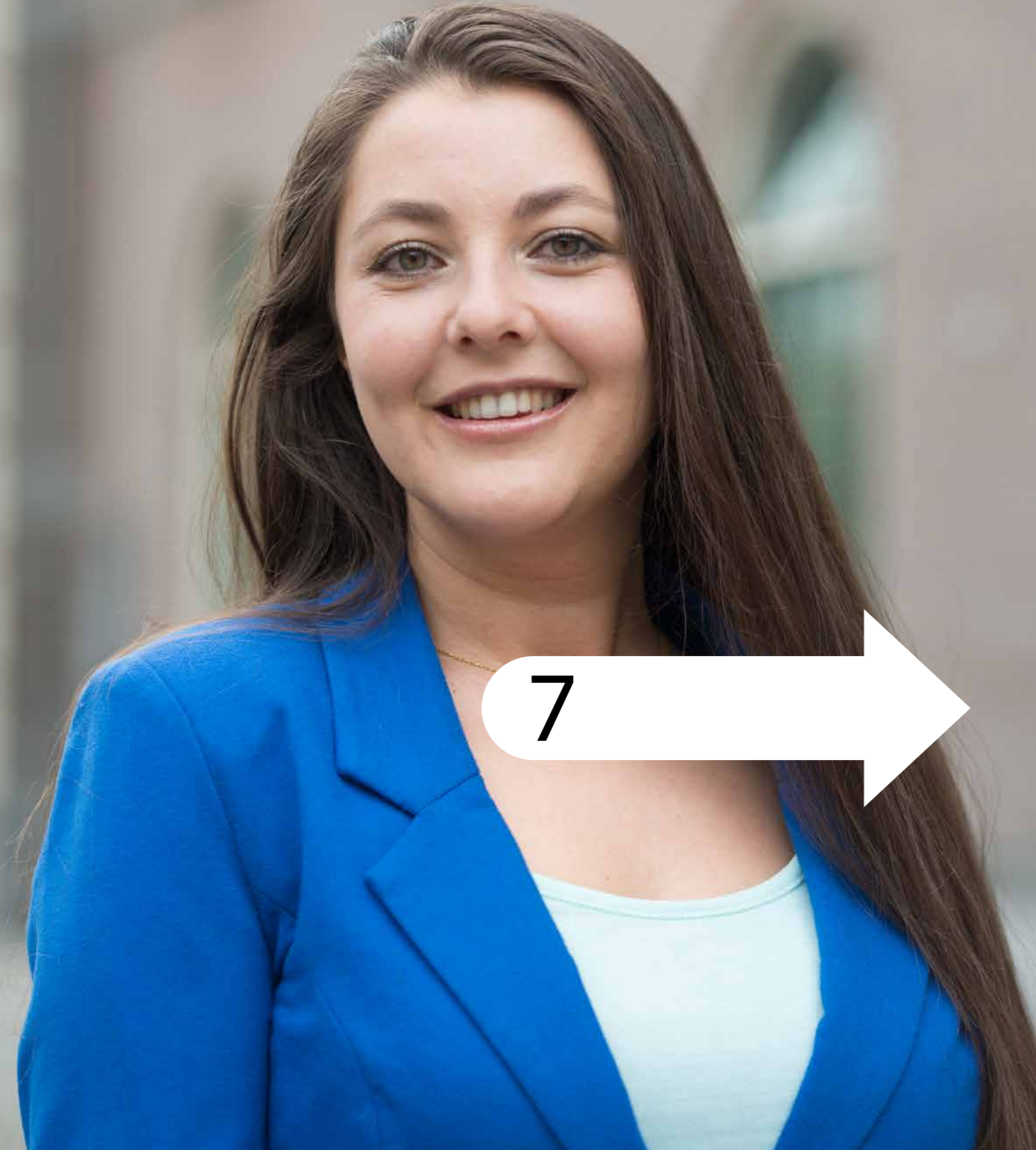
Family doctors and specialists in the Netherlands do not test patients for these other pathogens and show no interest in doing so. The Dutch Lyme Monitor shows the following: when foreign doctors or integrative doctors do test Lyme patients for other tick-borne infections, at least eight out of ten patients test positive for co-infections and are treated accordingly.

There is an urgent need for thorough research into the role of tick-borne co-infections in chronic Lyme patients, and into treatment of these infections.



⁵<https://www.rivm.nl/nieuws/twee-promoties-tal-van-tekenbeetziekten>

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About half of chronic Lyme patients are (practically) unable to study or work due to the state of their health. These people have had to deal with occupational health physicians and UWV. The decision by occupational health physicians and UWV medical examiners as to whether a person is fit for work, and the decisions made with regard to social assistance benefits, appear to be a completely arbitrary affair, depending on the doctor or civil servant on the case. The average score for how occupational health physicians deal with occupational impairments related to Lyme disease is 4.8. The average score for how UWV deals with these occupational impairments is 4.5, and the score for the course of action regarding social assistance benefits is 4.6. In all three cases, approximately half consistently say the way they have been treated is below par, with 1, 2 and 3 the most common scores. In contrast, the other half say the way their case has been handled is adequate, with mostly 6, 7 and 8.

It is understandable that occupational health physicians and medical examiners have difficulty determining fitness for work and establishing whether Lyme is the cause of disability. Lyme tests are unreliable, no tests exist to diagnose active infection, and the symptoms of chronic Lyme sufferers vary from patient to patient, and over time.

Government and politicians should initiate pilot projects with occupational health physicians and medical examiners specialized in Lyme disease. In collaboration with the Dutch Lyme Association, they would receive additional training in this field and these specialized doctors would gain experience by working with Lyme patients more closely.



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However, Dutch health authorities say that this mode of transmission is highly unlikely: 'Because there is no study which proves the opposite, we cannot say that it is one hundred percent certain that it is not possible.' However, a large number of case studies describe transmission from mother to child with adverse birth outcomes. A meta-analysis of nine studies showed more favourable outcomes in women treated for Lyme disease during pregnancy. Rapid diagnosis and treatment of Lyme disease during pregnancy is recommended.⁷

There is an urgent need for thorough research into Lyme transmission from mother to child, and for a strategy to prevent this transfer.



⁵ <https://eenvandaag.avrotros.nl/item/lyme-overdragen-via-zwangerschap-kan-maar-is-onwaarschijnlijk/>

⁶ A systematic review on the impact of gestational Lyme disease in humans on the fetus and newborn <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0207067>



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Many schools and Safe at Home (Veilig Thuis) do not treat families whose children suffer from chronic Lyme disease well.

More than 1 in 3 parents with a child suffering from chronic Lyme disease say the school fails to deal with the child's illness adequately. Over half of these parents give Veilig Thuis a score of 1 out of 10. The parents are often accused of causing or perpetuating the child's illness. It is often claimed that an infectious disease is not present, and that the child and/or parents suffer from psychological problems. Children are erroneously placed under supervision orders, and are threatened with out-of-home placement. Sometimes out-of-home placement actually takes place. This is incredibly stressful for families who are already at the end of their tether because their child is seriously ill, and doctors have no effective treatment.

The Dutch Lyme Association requests the Ombudsman for Children to conduct research into the way in which schools and Veilig Thuis deal with families whose child suffers from chronic Lyme disease.



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Chronic Lyme disease is very stressful for both the patient and his or her partner and parents. Adult patients are often dependent on care from their parents. 6 in 10 parents and 5 in 10 partners indicate that Lyme has a huge impact on their lives. Lyme disease accounts for half of the cases where a patient breaks up with their partner.

The Dutch Lyme Association plans to offer more information and to organize contact options to share experiences for both partners and parents.

Chronic Lyme patients often display no visible symptoms. It is often difficult for outsiders to realize how ill you are.

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