

The All-Decisive First Impression

by Fred Verdult

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For seventeen years, Fred Verdult has been living with HIV, the virus that can cause AIDS, and for five years, he has been living with Lyme disease. He has a thorough knowledge of the HIV movement and he shares his reflections: in 1982 the borreliae bacteria that causes Lyme was discovered and in 1983 the HIV virus, that can cause AIDS. The war on AIDS resulted in a great medical success story. That is a stark contrast to the war *about* Lyme. The authoritative British Medical Journal recently wrote: ‘We cannot allow ourselves to repeat past mistakes at our patients’ expense.’ Could that contrast be caused by the difference in the first impression that the world got of these two diseases?

When you apply for a job, put your house on sale or have a first date, you know that often the first impression is all-decisive. You Never Get a Second Chance to Make a First Impression. Is the first impression that the world gets of a new disease decisive for how the world handles that disease? One would hope not, but I’m afraid it is.

Breaking news

The appearance of HIV and AIDS in the early eighties was breaking news: the world trembled in fear for an epidemic. After being sick for months AIDS patients died a horrible death. And there was a huge uncertainty: How was this disease transmitted? Could one catch it by touching a person, by a kiss or by mosquitoes?

The war on AIDS

This worldwide panic led to enormous efforts, somewhat comparable to the action against the Zika virus nowadays. The quick discovery of the HIV virus as the cause of AIDS was an important step in a medical success story: the war on HIV and AIDS. One year later, HIV tests were introduced that were very effective in diagnosing whether or not someone had HIV. In the nineties a test appeared that could measure how much HIV virus was present in somebody’s blood. That is crucial in the development of new drugs, because with this test their effects can very easily be determined, and also when treating an individual patient, because the doctor can check whether or not the patient’s HIV is being suppressed properly.

The war about Lyme

The appearance of Lyme into this world never made headlines. The world reacted with resignation, because according to the initial reports it was hard to catch Lyme disease, there was a simple way to diagnose it and the disease could easily be cured. Soon some doctors stated that things were different and that Lyme disease could terrorize your health in the long run, but the tone was set: Lyme disease was ‘hard to catch and easy to cure’. And it’s almost impossible to fight against a first impression like that. If after the discovery of borreliae energy had not been wasted on the war about the existence of chronic Lyme, but had been focused on the war *against* Lyme, the treatment of Lyme disease might by now well have been as successful as that of HIV.



Arguments with the doctor: a matter of life and death

In the eighties doctors faced patients that were dying of AIDS. All they could do, was alleviate certain symptoms. In the western world many AIDS patients were highly educated gay men, who often were more knowledgeable than their doctors. In the late eighties the first HIV drug was introduced. Finally, internists could do something. Many people living with HIV that then meekly followed their doctors, have now passed away. They took their one daily HIV drug and their virus became resistant to it. But the people who had made a study of their disease, who argued with their doctor and who could afford to wait taking meds, started using the combination therapy in 1996: by using three or more HIV meds daily, nowadays ever more combined in one pill, you can suppress the virus for as long as you live. Many of them are still alive and kicking today.

Effective response

Since the world disposes of an effective response to HIV, people living with HIV study treatment options to a much less extent, and they hardly care for alternative treatment options anymore. Life expectancy and overall health of those starting to take medication in time, are practically normal. Yet the horrific first impression that the world got of HIV and AIDS continue to have their effect: when you tell someone that you're HIV positive, you often get a shocked reaction. And people still are afraid to catch the disease in situations that, as we know now, are completely safe. In 2016, HIV still leads to upheaval at the dentist's and in the kindergarten. The disease's first impression is all-decisive.

Expensive HIV treatment

HIV treatment is completely reimbursed by the health care insurance system. In the Netherlands HIV drugs cost about one thousand euros a month. That is an huge amount of money for, in most cases, thirty pills. This high price does however contribute to a situation in which:

- A state institution keeps a database of anonymous data of all HIV patients in the Netherlands, to monitor closely the effectiveness and side effects of any HIV treatment option;
- These treatments can only be prescribed by a limited number of specialised internists that each treat a sufficient number of patients;
- Pharmaceutical companies organise activities to keep HIV on the political agenda;
- Hundreds of scientists all over the world study options to cure HIV. As one important reason to finance this research, it is often mentioned that a cure of HIV would save a lot of money spent on HIV drugs.

Lyme research

As it seems, research into better ways to treat Lyme is not so much about the quest for a new drug, that can be patented by a company, as about the skilful, patient and tailored application of existing drugs that are very cheap in comparison to HIV drugs. In present-day society such an approach seems difficult to finance.

Funding

There are a great number of patient initiatives with regard to Lyme disease, and of course that is very valuable. My impression however is that many of these initiatives are hardly connected to each other. The 'Citizens' Lyme Initiative' was unanimously supported by the Dutch parliament, but is being followed up antagonizingly slow. For HIV and AIDS there is a special trust, the AIDS Fund. This fund had an income of no less than 25 million euros in 2014. Part of that was invested in the patient movement. The AIDS Fund strives for one strong patient association that represents all people living with HIV and AIDS. Sometimes that is quite a hassle, but it has resulted in a patient movement with a clear and loud voice.

Society's interest

Another difference between HIV and Lyme: in the case of HIV it is in society's interest that the disease be treated. When somebody has been treated for some time, he or she can no

longer transmit the virus. In the case of Lyme, however, it is often regarded as being in society's interest not to prescribe antibiotics too often or too long, because that could lead to resistant bacteria.

Persistence under treatment

I also see an important similarity between HIV and Lyme: an obstacle to cure is persistence under treatment: the germ, the virus or the bacterium, hides itself in the body, so that the drugs can not exterminate it to the last copy. With respect to HIV, the solution is the lifelong use of medication. HIV meds nowadays are so safe that for the patient's long-term health all that counts is whether treatment was started early enough.

HIV cure

I made an inquiry: as far as I know not a single researcher has studied persistence in Lyme disease in order to learn lessons in regard to curing HIV. That knowledge is much too controversial, any HIV researcher knows better than that. Researchers into HIV cure do study highly prestigious cancer treatments, of which I could not explain the connection to HIV. I myself underwent so many treatments that aim to activate hiding borreliose, that I sometimes jest: It wouldn't surprise me if those treatments have by now also activated my hiding HIV virus, thus curing me from HIV without anyone knowing...

Resistance among doctors

Recently I interviewed a pain medicine specialist. She honestly seemed to do anything within her reach to have her patients suffer as little pain as possible. The nature of the conversation changed radically when we came to discuss medicinal cannabis as a pain medication. Many patients report to benefit by it, but this pain specialist had very serious doubts. She argued that there is too little scientific evidence for this effect. Which in itself is true. Only will the necessary scientific studies never be financed, because cannabis can not be patented. With regard to Lyme disease as well, it's the patients who take the initiatives, and it's scientific research that fails to give the answers that are needed. Does this cause resistance among doctors and researchers?

Little convincing evidence

My impression is that almost all the care providers and researchers that more often diagnose Lyme and that prescribe longer and more intensive treatments, have been confronted with Lyme in their own family. I took the time to read the ILADS-guidelines. It impressed me how thorough they are. At one point I thought I was reading an opposing point of view: the guidelines say that there is little convincing evidence that substantiates the Lyme treatment. Research results often are inconsistent. The guidelines state that ambiguous guidelines also exist for other diseases where little convincing evidence for treatment has been found. The fact that there is little or no evidence for a treatment, doesn't mean that the treatment doesn't work. Because the disease is so aggravating for Lyme patients, these guidelines recommend to give space to doctors to inform their patients thoroughly about a treatment's possible risks and advantages, in order to make a choice.

Past mistakes

In my professional contacts with doctors and researchers I observe that the judgement of a colleague often has much more effect than the voice of hundreds of patients. That is why I derive hope from an article about Lyme in the December 2015 issue of the authoritative British Medical Journal: 'Recently, the medical community has been collectively forced out of its comfort zone on Lyme disease by increasing evidence of the complexity of this multisystem disease. (...) We cannot allow ourselves to repeat past mistakes at our patients' expense. The suffering of many affected patients obliges us to learn more about this disease, and fast.' Will we, after all, be able to overcome that first impression that the world got of Lyme disease?