

# AN

# INVISIBLE MONSTER

*A 'smart' bacteria - it hides, mutates and deceives. It is spreading throughout the world and damaging the quality of life of those it infects. It is the cause of Lyme disease and this is how it attacks its victims.*

BY NATALIA ROLDAN RUEDA



ILUSTRACIONES ISTOCK

## SYMPTOMS AND SUFFERING

*Every inch of my skin hurts. My fever is reaching 40°C. I start to shiver. The fatigue and nausea take over and stop me from moving. Maybe it's malaria. My eyes cannot focus. It seems like something inside me is slowly tearing my organs out. I beg the doctor to administer an antibiotic injection. He isn't convinced, but he goes through with it. 20 minutes later I can feel myself fading away, my brain is no longer in tune with my body. I can't talk, I can't breathe. I'm leaving. So, I say my goodbyes. Suddenly, the medicine starts working. I'm back. The bacteria inside me revolt, the injection is their bane. They don't want the party to be over. Maybe it's malaria.*

*Five days of peace for me. Five days for this monster to recharge itself. It's back. The vertigo persists. I can't sum up one plus one, I don't know what day it is, let alone the time. My memory isn't working. My left arm and leg are not responding. At times, my hands remain open and I can't close them. My brain forms a sentence but that's where it stays, I can't pronounce all words. I'm tired, so tired. My soul feels like a ball of lead.*

Paola Ribadeneira had Lyme disease but she didn't know it. Before she managed to find out what was killing her, she visited more than thirty doctors over a period of four and a half years. Like her,

thousands of people around the world suffer due to an “smart” bacteria which is known as the “great imitator” within the medical community. It hides, it mutates and it confuses. Sometimes it presents itself as Chronic Fatigue Syndrome. Sometimes it mimics fibromyalgia, lupus, encephalitis, meningitis or Multiple Sclerosis, just to name a few. It can also mimic as depression, Alzheimer's, Attention Deficit Disorder or anxiety. It can be everything and nothing at once. It can disappear for months and come back later with the force of a thousand armies.



**It is recommended to use tick repellent and to check the body from head to toes before going to bed. A baby tick can be the size of a sugar grain.**

Although it is an underdiagnosed illness, it is calculated that at least 300 000 people are newly diagnosed each year in the United States alone. In Europe Lyme diagnoses make up 100 patients for each 100 000 inhabitants. Even though it has been common in these areas; climate change, globalization, unplanned urbanization and transport of goods have contributed to the spread of the illness in regions like Latin America where it was non-existent in the past. “According to risk zones prediction mapping, it is not ‘crazy’ to think that it will turn into a pandemic” Almudena Cervantes explains to Cromos magazine. She is a Mexican doctor who is among the experts in this region. Reports of patients in Colombia, Argentina and Brazil exist. In 2014 the World Health Organization alerted the world about vector-borne disease given that 50% of the population are at risk of being infected of dengue, zika, leishmaniasis and Lyme, among others”.



## HELPLESSNESS

It all started in 2013. Paola is Colombian but she was living between the UK and Ghana when a tick bit her without even realizing it. She had few days in which she felt unwell and fatigued but medical tests did not show anything to be worried about. She was in a post-partum period, so “it’s normal” she was told. Later her symptoms worsened and unfortunately her mysterious disease crossed paths with other illnesses that drove attention away from it. The first distraction was a mastectomy, followed by a hysterectomy. And most recently, she overcame malaria.

Once she got rid of all those conditions, she could finally *hear* her body and *follow her intuition*. There should be an explanation for that torturous headache that lasted for seven months, along with tingling sensations all over her body, numbness of one side of her face, depression and irritability. She suffered from attacks, so during all these years she studied herself and collected information, and then concluded having Lyme disease. She just needed to run the specialized tests to confirm it..

The vaccine is now undergoing phase II, but the US has urged the researchers to accelerate the process given that it represents the sixth most common disease in the country and thus it can be of high cost for the health system.

By then, she was living in Ghana and as her husband is Italian, she decided to travel to Italy where she could probably do the tests she needed. *I find a laboratory in Bologna. My mother-in-law is with me. It’s an ‘odyssey’.* She has her age and yet she had to carry my circa 200-page clinical history folder. *I walk for three minutes and I must sit, my heart is unable to pump enough blood. I feel as if I’m going to faint. Finally, I got my blood samples taken but they need to be sent to Germany for analysis. The results will take few weeks to come back.*

*In the meantime, I suffer another serious episode and end up again in the ER. They wanted to send me for a psychiatric evaluation so I desperately told them “When a doctor doesn’t have a clue, we [the patients] are sent to be assessed by a psychiatrist.*



*What I need is a good internist!" I'm not heard so I'm sent off frustrated and even without having removed the cannula off me. My only option is to keep waiting for the results that eventually arrived. So, I have borrelia burgdorferi, borrelia miyamotoi, ehrlichia, anaplasma, chlamydia pneumoniae, yersinia, coxsackie virus. In other words, I have Lyme disease.*

## BACKGROUND TO LYME

Lyme disease was discovered in 1977 by Dr. Willy Burgdorfer after more than 50 patients in Connecticut were suffering of a strange

rash and joint pain. Burgdorfer started researching the cause and he found out that it originates from ticks. Even though Lyme disease cases started to be reported at that time, there are journal articles in Europe that describe similar symptoms since 1883. A tick is like a tiny vampire. It hooks up to the skin and sucks blood until it is full. Its mouth secretes a kind of anesthetic-like substance so that the host cannot feel its presence. During the time it is attached, it transfers its stomach's bacterial load to the host, thus the victim becomes

infected with Lyme disease (and other coinfections, therefore Paola had such an extended diagnosis).

With the bite, this parasite produces a lesion known as "bullseye-rash". It is characterized by a red ring followed by a white ring and then another inner red ring. This is the sign that should tell us that we should run to a doctor; however, between 40% and 60% of the patients do not recall having had such rash; it might be because it did not develop or because it developed in an area where it was not visible. Even though being infected by a tick bite is the most common form of transmission, there are also other possibilities: "The illness has been transmitted by other insects such as horseflies, spiders, fleas and head lice." Dr. Elena Frid explains to Cromos magazine. She is a

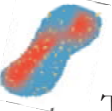
US neurologist who is an expert in infection-induced autoimmune disorders and one of the most prominent doctors in studying and treating this illness. She also states that "It [Lyme] can also be transmitted in the uterus from mother to child and there is some speculation about the possibility of sexual transmission, however there is no scientific proof".

The bacteria that causes the illness has a spiral shape which allows it to cross through viscous areas as if it were a screw. Once there, it protects itself from being attacked by the antibiotics and sometimes they will take weeks or even months to reach the bacteria. During that time, the bacteria can already affect the nervous system or even the immune system. No system remains free from the bacteria effects.



## DIAGNOSIS

How can we find out about this ‘*great imitator*’? “We have to raise a red flag when a patient has atypical symptoms of common illnesses” explains Frid “or when a patient doesn’t improve with a conventional treatment and he or she has been seen by multiple specialists for a number of issues and still there is no specific diagnosis. In such cases I suggest looking into the possibility of a vector-borne infection. It can even affect the brain”.



There are different genospecies of this bacteria and this complicates the diagnosis even further.

“Depending of the strain, the clinical manifestations can be different” says Cervantes. “In the US for example, the symptoms are more about joints pain specially in knees and hands; in Europe patients present more

neurological symptoms such as bell’s palsy or brain fog. There is no test that is 100% reliable. A traveler from Canada goes to Europe and comes back sick. The patient is told that it might be Lyme. In the US they run the tests but the result is negative because that strain of bacteria is not studied in America. But it might be positive if the test is run in Europe”.

Although this disease has been studied for four decades, there isn’t much known about it and more importantly there is no appropriate diagnosis. Usually the first test that is done is the Elisa (the same that detects HIV), but this test should be complemented with another one known as Western Blot, which is usually not done in countries where the disease isn’t endemic like Colombia. Here, a patient that suspects suffering this infection

## — LYME DISEASE HAS BEEN REPORTED COUNTRYWIDE IN THE US AND IN OTHER 80 COUNTRIES

needs to send the samples to the US or Germany for testing and still there is a risk for the bacteria not to be detected.

“These tests can fail to identify the infection in 88 out of 200 patients” adds Frid.



## SKEPTICISM

*Today I take at least 50 pills a day. Maximum 56. This illness is also very expensive: one jar of pills can even cost me 90 USD and I need six a month [of such kind]. When you get to such a critical state without having had a diagnosis, your health condition becomes a snow ball that grows and grows. It’s an infection that causes a chronic inflammation and it starts affecting other functions of your body. There can be mitochondrial damage and you won’t produce enough energy. That’s why I take so many pills so that I can help my body to detox, metabolize and I can support my immune system. I take*

*antibiotics for each infection, homeopathic medicines, vitamins, probiotics to maintain the gut flora and I do drips. I also need to eat well. No sugar, no alcohol, no dairy, no gluten, and no carbs.* Because of this ‘*smart monster*’, Paola is now self-treating. She now lives in Egypt and she has not managed to find a specialist that understands the disease.

There is still disbelief and a huge lack of understanding of the illness in the medical community, therefore, many patients are being labelled as hypochondriacs or they end up diagnosing themselves.

“For us as Latin American doctors it is difficult to believe that such an illness has crossed borders because ticks do not fly” explains Cervantes. “The other day I saw a patient with facial paralysis and he told me that back in December he was selling Canadian Christmas trees. He told me that while opening the shipment he found tarantulas, snakes and racoons. Isn’t it possible that there were also ticks? We — as doctors — should be more open to other possibilities, we must be willing to seek answers and to research. We have to stop telling the patients that they have psychological problems when they keep presenting symptoms. We have to believe them until we have looked into all possible options”

It has been proven that the illness evolves dramatically. If a case of Lyme is discovered on time, it can be treated with

oral antibiotics in a period between 14 and 21 days (only between 20% and 25% of the cases in the US are diagnosed early). If the condition goes undiagnosed for more than six months, the treatment is done with intravenous antibiotics and they should be administered for at least one and a half months; however, at that point in time, it is possible that the infection has spread enough, having aggravating effects in the body, for example it can spark an autoimmune disease that might require life-treatment.



**2008, A STUDY REPORTED THAT [TO A PATIENT] THIS ILLNESS CAN COST BETWEEN 100 USD AND 2000 USD PER MONTH. PAOLA SPENDS 1100 USD EVERY THIRTY DAYS.**



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Mery Zambrano seems to have reached an early diagnosis. She got infected during a trip to Europe. Once back in Colombia, her symptoms — that during the trip seemed to be ‘just a cold’ — started worsening. She had burning sensations in one leg and that leg was covered in a rash with little pink dots; her hands were sometimes becoming blue and her hair started falling in an unusual way. She also felt crawling sensations in the skin and mild electric-like shocks in her fingertips. She also suffered from headaches, sweats and tachycardia. She was seen by about 70 doctors and she carries a heavy folder as a proof of it. Among others, she was seen by dermatologists, internists, rheumatologists, neurologists, infectologists, etc. When finally, an allergologist suspected a ‘Mediterranean illness’. She had her tests sent to Europe and was diagnosed with Lyme disease. Since May she is taking two oral antibiotics a day. She already feels better and although she does not know how long she will be treated for, she feels relieved to

have found specialized doctors that are ready to learn and study to treat her. She is also relieved because her insurance has so far covered all expenses.

### STRENGTH

Paola talks about the disease with such expertise that she seems to be a doctor. By listening to her, one might think that the discipline, persistency and strength that was taught by her parents might be enough for her to fully fight the infections. However, by listening with enough attention, one can perceive that behind such confidence, there is a lot of uncertainty that scares her. She is now 70% recovered but what will happen tomorrow? Thus, she keeps looking for a doctor that will give her advice. Even with all the support she receives from her husband and two kids, she feels left alone and each day is a challenge.

*“I can’t work for now. There is also a difficult psychological aspect behind this illness. It sparks frustration and guilty*

*feelings. You feel you’ve become a burden. We have so far spent 24.000 USD from our own pocket. One must learn to manage all these feelings. I don’t believe in God and since I was a child I was taught that no one will come to save me, but I do believe in myself and in medicine. So I wear a ‘superhero cape’, enjoy the good days and I never do plans.”*

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