

Coding for Justice

An interview with Jenna Luche-Thayer

The World Health Organisation's classifications for Lyme Disease are contributing to violations of human rights, says Jenna Luche-Thayer.

Jenna Luche-Thayer is an international human rights activist with 32 years' experience fighting to defend the rights of some of the most unfairly treated people in the world. She also has Lyme disease, and is using her talents to tackle abuses of human rights in people with Lyme.



She won the 'Power of Lyme' award at the recent ILADS (International Lyme and Associated Diseases Society) conference in Boston for leading a committee of experts working to get changes in the coding of Lyme and related diseases by the World Health Organisation (WHO).

She kindly agreed to an interview with Australian journalist Marie Brown at 10pm her time, squeezing it into her packed program.

Marie: What are the WHO codes and why do they matter?

Jenna: The codes (known as ICD codes – which stands for International Classification of Diseases) underlie all the important activities to do with health in the world.

If a disease and all its different manifestations are given proper codes, then it is recognised world-wide. Research funds will be allocated to the disease, treatments will be reimbursed, and statistics on sickness and deaths due to the disease will be collected.

Lyme has five ICD codes and they are not organized in the same way as codes for other illnesses that can affect many body organs. Most forms of Lyme have no ICD code at all, including chronic Lyme.

For example, the disease syphilis has similarities to Lyme. Like Lyme, is caused by a spiral-shaped bacterium (spirochete) and may affect many different body organs. Syphilis has about ten times more ICD codes than Lyme and there are many more complications listed under each of its codes.

Just as an aside, there are codes for some very unlikely 'conditions'. There is one for being 'struck by a duck', and another for being 'burned when water skis catch fire'. Illness or injuries resulting from these rare events have ICD codes, yet most of the ways chronic Lyme can present in patients have no code at all!

I believe the current inadequate coding for Lyme is a root cause of the many ways in which patients are having their human rights violated.

The WHO is in the process of updating the codes from their current version (ICD10), which has been in use since 1990, to ICD11, due to be published in 2018. We are working to get our input into the development of the ICD11 codes for Lyme.

Marie: You believe that politics underlies the poor codes for Lyme disease. Why do you think Lyme is such a political disease?

Jenna: It always comes down to power and money and in the case of Lyme Disease there are multiple layers of corruption.

Pharmaceutical companies are doing very well from their disease-modifying drugs which are used in neurodegenerative diseases, autoimmune diseases and atypical arthritis. Undiagnosed Lyme can mimic these (and other) diseases and can be treated with generic antibiotics for a fraction of the cost of these disease-modifying drugs.

My own illness was misdiagnosed for 17 years. I was told it was multiple sclerosis (MS), lupus and various autoimmune diseases. If I had accepted the diagnosis of MS, pharmaceutical companies would have gained 500,000 dollars for my treatment over the last ten years. Contrast this with the six hundred dollars that it cost for me to take generic antibiotics for 6 months, which got me into remission.

Apart from pharmaceutical companies gaining by misdiagnosis, the current coding means national health systems and private insurers save billions of dollars by denying the seriousness and breadth of the disease.

They don't want to have to pay to treat a chronic disease. No one wants to pay for this disease. And at the moment it is the patients that are bearing the cost.

Marie: What has the committee you led achieved?

Jenna: We have produced a document called "Updating ICD11 Borreliosis Diagnostic Codes" and lodged it with the WHO.

In it we gave evidence from more than 240 scientific papers of the many ways that Lyme can appear in patients, which means more and better codes are needed for Lyme.

Our report also documents ten ways in which the human rights of Lyme patients are being violated.

Human rights are defined by the United Nations (UN) and apply to all patients. For example, you cannot deny access to diagnosis and appropriate care.

You cannot obstruct access to treatment options that meet internationally accepted standards. You cannot discriminate against patients.

And you cannot discriminate against human rights defenders – such as the doctors, scientists and researchers that are working to help patients with chronic Lyme.

As well as submitting the report to the WHO, we also sent the report to Dr Dainius Pūras, the UN's special rapporteur for the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Thirteen days later he asked for a meeting with representatives of our committee - typically a response takes months! He also invited members of the committee to come to his annual presentation to the UN committee for human rights.

Marie: That's wonderful progress! Does that mean the ICD codes will be changed?

Jenna: Just because the WHO has accepted our report and put it on record, it doesn't mean they will take action based on what it suggests.

We have a lot more work to do at a political level to get them to take notice of, and act on the report.

Marie: You believe that pointing out the human rights violations that occur to patients with Lyme is an important approach in dealing with the WHO and the UN, don't you?

Jenna: Looking at this from a human rights perspective can help break up some of the log-jam that's occurring.

The medical and scientific debate is going to go on for a long time because Lyme is such a complex disease, but no one can deny that obstruction of access to care is not a human rights abuse.

Marie: Thank you for the work you have done for Lyme patients world-wide. Why did you get involved?

Jenna: When I finally discovered I had Lyme after 17 years of misdiagnosis I realised I had joined one of the most marginalised patient groups in the world. I decided to use my professional skills to address the situation.

Marie: Do you have a message for Australian patients?

Jenna: I recommend everyone with Lyme watches the movie "The Dallas Buyers Club", which tells the lengths the first patients with HIV AIDs had to go to in order to obtain drugs. Lyme patients are in a similar marginalised position now.

Don't wait for someone to help you. We cannot wait for the medical systems and governments to take charge of our care. You must do everything you can to protect and preserve your health.

There will be ways you can get the treatment you need without having to spend hundreds of thousands of dollars or remortgaging your house.

And remember, this is a political disease. It has to be dealt with politically.

And there are increasing numbers of people getting involved – because more and more people are being affected by Lyme. There may be as many as 10 million Lyme borreliosis patients worldwide.

And when one person fighting for Lyme patients gets knocked down, another five stand up!

You can find out more about Jenna and her mission by watching [this video](#) from the ILADS conference.

Copies of the document “Updating ICD11 Borreliosis Diagnostic Codes: Edition One” can be purchased [here](#). We have reproduced the document’s Forward below:

“This is the beginning of the end.

It is the end of 40 years of gross human rights abuse against persons living with Lyme and relapsing fever borreliosis and other coinfections from tick borne diseases.

It is the end of State actors promoting policies that:

- *obstruct access to treatment options that meet internationally accepted standards;*
- *obstruct access to antimicrobials for systemic infections in the brain and nervous system;*
- *encourage the misapplication of fraudulent psychosomatic terms to deny access to antimicrobials for systemic infections; and*
- *force ingestion of psychotropic drugs.*

It is the end of State actors giving resources to entities and individuals that attack, smear, defame or stigmatize these human rights defenders or the patient group.

It is the end of policies and practices that support of disease-based discrimination and deny human suffering by parsing symptoms, misapplying fraudulent psychosomatic terms to deny medical care and suppressing ethical scientific and medical advances.

It is the end of financial status determining access to antimicrobial treatment options and persons becoming disabled because they are denied access to generic medicines.

It is the end of sick children under treatment being forcibly removed from their parents and their parents being falsely accused of Munchausen by Proxy.

It is the end of policies and practices that encourage euthanasia and disability over the use of antimicrobials and generic medicines shown to restore the well-being and independence of many thousands.

It is the end of attacks on the human rights defenders of this group. The defenders encompass all medical practitioners and scientific researchers dedicated to ensuring this patient group will enjoy the highest attainable standard of physical and mental health.

It is the end of State actors giving resources to entities and individuals that attack, smear, defame or stigmatize these human rights defenders or the patient group.

It is the end of policies and practices that support of disease-based discrimination and deny human suffering by parsing symptoms, misapplying fraudulent psychosomatic terms to deny medical care and suppressing ethical scientific and medical advances.

It is the end of:

- *laws that encourage corruption and drive these abuses;*
- *government institutions and officials responsible for promoting scientific and medical innovations being patent holders in the same arenas of competition; and*
- *State actor policies and practices that impoverish patients while enriching private insurers and private medical and scientific investors.*

It is also the beginning.

All those concerned with public health, access to health care, scientific advancements that serve the common good, social justice and human dignity need to fully understand this situation.

The human rights abuses experienced by this patient group and their human rights defenders have been institutionalized over the span of four decades and encompass all actors found in modern medical and public health systems.

These abuses are not limited to persons living with Lyme and relapsing fever borreliosis and other coinfections; they encompass more patient groups every day.

These abuses represent trending practices and policies flourishing in systems with weakening accountability and transparency. They are driven by insatiable greed and lack of empathy ... and are boldly corrupting public institutions, elected officials and intergovernmental bodies.”