# **Decades of Harmful** Lyme Propaganda **Revealed &** Overturned in ICD11

## Jenna Luché-Thayer

## **International Classification of Diseases (ICD) codes are developed by the**

## World Health Organization (WHO)

193 countries
shape & use ICD
1CD10 → ICD11

## **ICD codes are developed by WHO**

With accurate codes robust data can guide

- medical & public health
- research & policy
- & save healthcare expenses

Lyme ICD codes unchanged since 1990s 25 years of outdated codes

## **ICD** codes

### Several highly unusual & rare conditions currently have their own ICD codes

W61.62XD Struck by duck
W55.1 Bitten by a cow
V91.07 Burn due to water skis on fire
R46.1 Bizarre personal appearance

What gets in?

## R46.1 Bizarre personal appearance



### ICD10 prevents proper diagnosis & treatment of Borreliosis, e.g. Lyme & Lyme-like illness

Almost all UN member countries have ratified health human rights, yet many Lyme patients are desperately marginalized & suffer gross human rights abuse by the hands of state actors

**ICD10** mirrors Lyme opinions of the Infectious Diseases Society of America (IDSA) and CDC

Lyme ICD10 codes support 14 human rights violations across 11 Human rights treatises

In October 2017, the UN Special Rapporteur for 'the right of everyone to the enjoyment of the highest attainable standard of physical & mental health' gave his annual report.

This report focused on corruption & assessed the healthcare sector against other sectors.

Globally, the health sector is the most corrupt sector. —Dainius Pūras Special Rapporteur

Lyme is one example.

1990s-2007 202 patents on Lyme borrelioses were accumulated by those **IDSA** members associated with the **IDSA Lyme guidelines** development & their affiliates in government & other private entities

Roughly 10 percent of these 202 patents were disclosed during the guideline development

The Situation of Human Rights Defenders of Lyme and Relapsing Fever Borreliosis Patients: Edition One IDSA Members and Organizations Associated with IDSA Holding LB-Related Patents in 2007 [69] 1. \*Raymond J. Dattwyler [US & 21. NIH/National Institute of Allergies foreign patents] and Infectious Diseases (NIAID) 2. \*Stephen Dumler [US Patents] 22. NYMC 3. Alan Barbour [US & foreign 23. Pasteur Merieux/Connaught 24. Rx Technologies patents] 4. Stanley Stein and Hoffman-25. SmithKline Beecham (under GlaxoSmith Kline)  $\rightarrow$  Danish Dr. Laroche 5. Ira Schwartz & New York Medical Court Pedersen advises the College (NYMC) Danish government and medical 6. Avant Immunotherapeutics practitioners on LB and is 7. Aventis Pasteur supported by GlaxoSmithKline 8. Baxter → Susan O'Connell, IDSA 26. State of Rhode Island promoter worked for Baxter 27. Stony Brook University (SUNY) 9. Becton-Dickinson 28. Texas A&M University 10. Boston Medical Center Corp. 29. Tufts New England Medical Biomerieux Center 30. Tufts US patents with Paratech 12. Cambridge Biotech 13. CDC and GlaxoSmithKline 31. Tulane University 14. Columbia University 15. Immunetics 32. University of California 16. Johns Hopkins University University of Connecticut 17. Mayo Clinic 34. US Army/US DHHS 18. Medimmune and Aventis, 35. Vical Inc. Medimmune 36. Viro Dynamics 20. University of Minnesota 37. Yale University & Yale's Office of Cooperative Research Patents \*co-authors undisclosed COIs during the 2006 IDSA Lyme Guidelines development

### One of hundreds of examples of IDSA & affiliates'

### private Lyme science

VS

### publicized Lyme guidelines

#### Patents Do Not Lie

2007 Lyme Patent Language from IDSA Lyme Guideline co-author Raymond J. Dattwyler [et al] in filed patent No. 7605248 <u>Recombinant</u> <u>constructs of *Borrelia burgdorferi* [70]</u>

The language in this patent states:

"Currently, Lyme Disease is treated with a range of antibiotics, e.g., tetracyclines, penicillin and cephalosporins. However, such treatment is not always successful in clearing the infection.

Treatment is often delayed due to improper diagnosis with the deleterious effect that the infection proceeds to a chronic condition

"One of the factors contributing to delayed treatment is the lack of effective diagnostic tools."

The 2006 IDSA Lyme Guidelines claim: LB is 'easily treated, easily cured' LB infection is easily cleared with antibiotics Two-tier testing process should be utilized, and for those patients who test negative in the ELISA model, that "no further testing" is necessary.

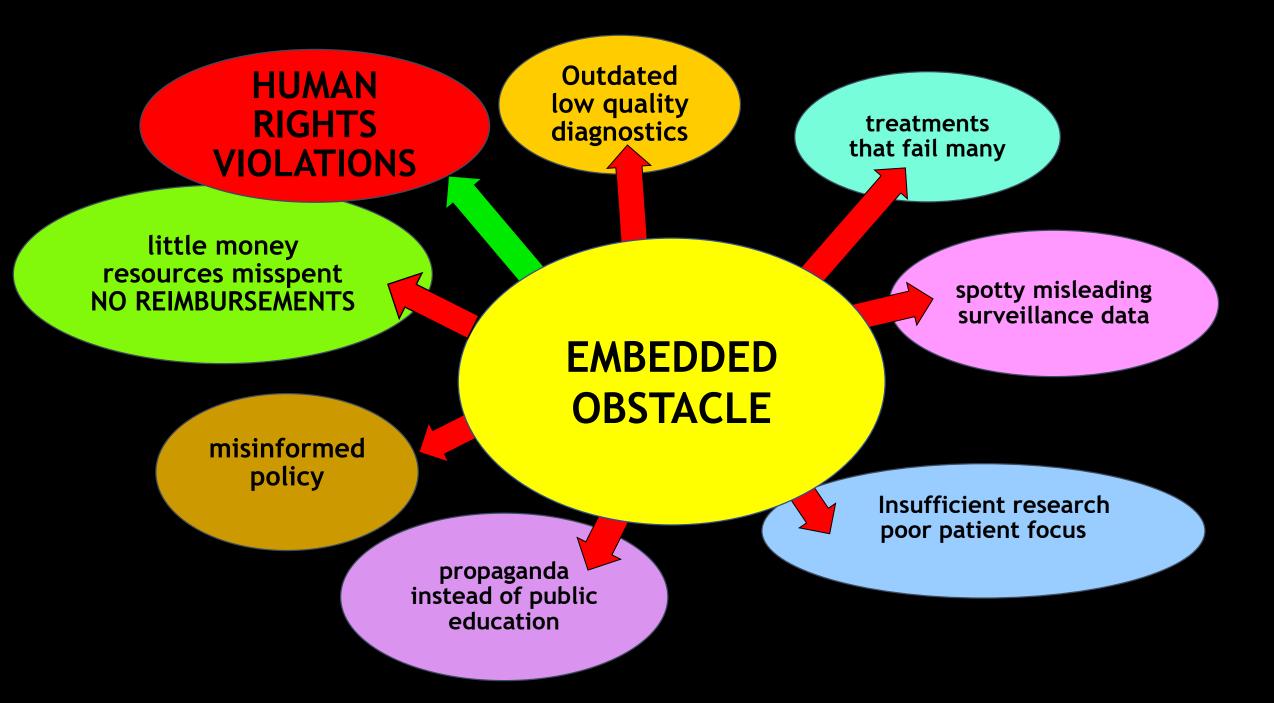
Versus

## Susan O'Connell:

IDSA promoter
Guidelines contributor
Reported doctors

After her lab was shut downbonus & job





**ICD10** supports human rights violations across **11** treatises

- African Charter on Human & Peoples' Rights
- Convention Against Torture
- European Convention for the Prevention of Torture & Inhuman or Degrading Treatment or Punishment
- Convention on the Elimination of All Forms of Discrimination against Women
- Convention on the Rights of the Child
- Convention on the Rights of Persons with Disabilities
- European Convention on the Protection of Human Rights
   & Fundamental Freedoms
- European Social Charter
- International Covenant on Civil & Political Rights

   International Covenant on Economic, Social, & Cultural Rights (ICESCR)
- •International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)

#### **1.** Right to highest attainable standard of health

- authorities allow insurers & state programs for low income families to deny medical care
- policies result in obstruction to necessary medical care for those with insufficient economic resources to pay out-of-pocket for their medical care.
- patients limited to programs for low income families are given inferior care
- 2. Right to life
- Due to outdated and politicized State Lyme policies, disability, bankruptcy and suicide result for many Lyme patients.
- Threats of loss of license and livelihood against doctors who treat Lyme patients according to protocols that have met internationally accepted standards results in many doctors turning away Lyme patients, leading to patient suicides and death.

# **3.** Right to freedom from torture & cruel, inhuman & degrading treatment

State policies restricting antibiotic access for the bacterial infection caused by Lyme cause patients suffering from Lyme & co-infections to suffer unnecessary pain, disability, bankruptcy, & death

**Patients are offered euthanasia and sick children are seized from their homes.** 

State Actors cause doctors mental & emotional anguish when they are forced to abandon patients or barred from applying clinical practice guidelines that have been vetted through internationally accepted standards

## unconscionable removal of children under medical care



#### 4. Right to participation in public policy

State funds & their partners disseminate articles that recommend Lyme patients & their human rights defenders be excluded from participating in Lymerelated policies.

Participation in Lyme-related public policy by Lyme patients & their human rights defenders is 'empty theater' with no evidence of political commitment to change status quo & prioritize patient care.

State colludes for wrongful financial incentives to drive preplanned outcome to suppress science & maintain status quo to deny breadth & seriousness of the epidemic, deny treatment based on clinical diagnosis & obstruct access to treatment options that meet internationally accepted standards.

## Bogus Lyme policy making



#### 5. Right to bodily integrity

Practitioners fail to obtain free and informed consent from patients before treatments begin.

#### 6. Right to liberty and security of person

Lyme patients are forced into psychiatric care for wrongful diagnosis of psychosomatic illness and denied medical care for persistent infection

7. Right to privacy and confidentiality

Lyme patient medical information is shared without their consent to State authorities who are harassing their doctors (human rights defenders) for providing Lyme patients treatment options that meet internationally accepted standards

#### 8. Right to information The State fails to provide information regarding the risk of disability and death from undiagnosed and undertreated Lyme

The State routinely misinforms the public regarding the reliability of the diagnostic serology tests and increases their risk from disability and death from undiagnosed Lyme. Practitioners fail to provide Lyme patients with information about treatment options and the potential risks and benefits of these options.

9. Right to nondiscrimination & equality

Medical practitioners, hospitals & policymakers are encouraged to claim Lyme patients have psychosomatic issues rather than biological illness & to obstruct access to medical care for infection & other complications.

#### **10.** Right to decent working conditions

Clinical practice guidelines of a professional medical society that have been vetted through internationally accepted standards & its members are defamed, harassed & threatened by members & State actors who belong to a competing medical society & their affiliates

#### **11.** Right to freedom of association

Authorities use penalties to prevent practitioners who use guidelines that have been vetted through internationally accepted standards to travel to conferences

Authorities prevent scientists from providing presentations who promote diagnostics tests that compete with the authorities (& their partners) patented tests

## Defamation & threats to livelihoods



#### **12. Right to due process**

Practitioner facing disciplinary proceedings is unable to obtain access to all the evidence presented against him/her in advance of the hearing.

A doctor in medical judgment suit has been put on strict limitations & not given a 'hearing' date two years after the commencement of the proceedings

#### **13. Right to science**

Article 27–State actors and private interests deny of interfere with the "right freely to participate in .. and to share in scientific advancement and its benefits" and "the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author".

#### 14. Right to a remedy

The State takes no action to address any of the violations previously described.

### **Updating the Codes**

## Our report includes 100s of peer-reviewed studies describing missing or under-elaborated conditions

Congenital Lyme disease, persistent infection, Borrelial lymphocytoma, Granuloma annulare, morphea, localized scleroderma, lichen sclerosis & atrophicus, Lyme meningitis, Lyme nephritis, Lyme hepatitis, Lyme myositis, Lyme aortic aneurysm, coronary artery aneurysm, late Lyme endocarditis, Lyme carditis, Late Lyme neuritis or neuropathy, Meningovascular & Neuroborreliosis – with cerebral infarcts, Intracranial aneurysm, Lyme Parkinsonism, Late Lyme meningoencephalitis or meningomyelo-encephalitis, Atrophic form of Lyme meningoencephalitis with dementia & subacute presenile dementia, Neuropsychiatric manifestations, late Lyme disease of liver & other viscera, late Lyme disease of kidney & ureter, late Lyme disease of Bronchus & lung & Latent Lyme disease, unspecified.

## WHO released the draft ICD11 June 2018

Lyme in ICD11 does not resemble an infection that is 'easy to diagnose, treat & cure'

## **The New Global Face of Lyme**

E		r	
ICD10 Codes		ICD11 Codes	
A69.2	Lyme Disease	1C1G	Lyme borreliosis
M01.2	Arthritis due to Lyme	1C1G.0	Early cutaneous Lyme borreliosis
G01	Meningitis due to	1C1G.1	Disseminated Lyme borreliosis
G63.0	Lyme Polyneuropathy due to Lyme	1C1G.10	Lyme Neuroborreliosis
		1C1G.11	Lyme Carditis
		1C1G.12	Ophthalmic Lyme borreliosis
		1C1G.13	Lyme arthritis
		1C1G.14	Late cutaneous Lyme borreliosis
		1C1G.1Y	Other specified disseminated Lyme borreliosis
		1C1G.1Z	Disseminated Lyme borreliosis, unspecified
		1C1G.2	Congenital Lyme borreliosis
		1C1GY	Other specified Lyme borreliosis
		6D85.Y	Dementia due to Lyme Disease
		9C20.1	Infectious panuveitis in Lyme disease
		9B66.1	Infectious intermediate uveitis in Lyme disease
		8A45.0Y	Central Nervous System demyelination due to Lyme borreliosis



## **Updating the Codes**

ICD11 now recognizes fifteen complications from Lyme borreliosis whereas the ICD10 recognized three complications from the disease.

Fourteen of the fifteen codes can apply for late stage & chronic forms of the illness.

Of the fifteen new codes, six describe infection in the central nervous system. ICD11 confirms Lyme has affinity for 'immune privileged sites' such as the central nervous system.

# Five of the fifteen codes identify complications documented as life threatening including

- Lyme Neuroborreliosis
- Lyme Carditis
- Congenital Lyme borreliosis
- Dementia due to Lyme Disease
- Central Nervous System demyelination due to Lyme borreliosis

ICD11 codes for Lyme now describe a disease that may cause severe & potentially fatal central nervous system complications & can be passed from mother to child. Peer-reviewed scientific & medical publications were entered into WHO record with our recommendations for these codes—these publications & the science they represent have been validated by WHO

Many of these publications had been rejected or suppressed by NICE, CDC, NIH, IDSA and IDSA affiliates.

#### **EXAMPLE** of Validated SCIENCE

TABLE 1 Congenital Lyme

Congenital	References	Rheum Dis Clin North Am. 1989;15(4):657-677. [Pu
Lyme disease Borrelia burgdorferi can potentially infect the fetus and cause adverse fetal outcomes **	Bale JF, Murph JR. Congenital infections and the nervous system. <i>Pediatric Clinics of North America</i> . 1992;39(4):669-690. doi:10.1016/s0031-3955(16)38370-5. [PubMed]	Macdonald AB. Human fetal borreliosis, toxemia of death. Zentralblatt für Bakteriologie, Mikrobiolog Medical Microbiology, Infectious Diseases, Virology 1986;263(1-2):189-200. doi:10.1016/s0176-6724(86
	Brzostek T. [Human granulocytic ehrlichiosis co-incident with Lyme borreliosis in pregnant womana case study] [in Polish] <i>Przegl Epidemiol</i> .	Maraspin V, Cimperman J, Lotric-Furlan S, Pletersk Erythema migrans in pregnancy. <i>Wiener klinische V</i> 2000;111:933-40. [PubMed]
	2004;58(2):289-94. [ <u>PubMed</u> ] Gardner T. Lyme disease. In: Remington JS, Klein JO, eds. Infectious	Markowitz LE, Steere AC, Benach JL, Slade JD, Bro during pregnancy. JAMA: The Journal of the Ameri 1986;255(24):3394. doi:10.1001/jama.1986.033702
	Diseases of the Fetus and Newborn. 5th ed. Philadelphia: Saunders; 1995:447-528chap 11. Gardner T. Lyme disease. In: Remington JS, Klein JO. Infectious diseases of	Schlesinger PA, Duray PH, Burke BA, Steere AC, Sti transmission of the Lyme disease Spirochete, Borre Internal Medicine. 1985;103(1):67. doi:10.7326/00 [PubMed]
	the fetus and newborn infant. 4th ed. Philadelphia: W B Saunders Co; December 13, 1994.	Silver RM, Yang L, Daynes RA, Branch WD, Salafia C in Murine Lyme disease. Infection and Immunity. 1
	Goldenberg RL, Thompson C. The infectious origins of stillbirth. American Journal of Obstetrics and Gynecology. 2003;189(3):861-873. doi:10.1067/s0002-9378(03)00470-8. [PubMed]	Strobino BA, Williams CL, Abid S, Ghalson R, Spierl pregnancy outcome: A prospective s of two thousand American Journal of Obstetrics and Gynecology. 19 doi:10.1016/0002-9378(93)90088-z. [PubMed]
	Gustafson JM, Burgess EC, Wachal MD, Steinberg H. Intrauterine transmission of Borrelia burgdorferi in dogs. <i>American Journal of Veterinary</i> <i>Research</i> . 1993;54(6):882-890. [PubMed]	Weber K, Bratzke H-J, Neubert U, Wilske B, Duray a newborn despite oral penicillin for Lyme borrelio <i>Pediatric Infectious Disease Journal</i> . 1988;7(4):280 doi:10.1097/00006454-198804000-00010. [PubMed]

#### Congenital References Lyme disease MacDonald AB, Benach JL, Burgdorfer W. Stillbirth following maternal Lyme disease. N Y State J Med. 1987;11:615-616. [PubMed] MacDonald AB. Gestational Lyme borreliosis. Implications for the fetus. Im Dis Clin North Am. 1989;15(4):657-677. [PubMed] Ionald AB. Human fetal borreliosis, toxemia of pregnancy, and fetal h. Zentralblatt für Bakteriologie, Mikrobiologie und Hygiene. Series A: ical Microbiology, Infectious Diseases, Virology, Parasitology. :263(1-2):189-200. doi:10.1016/s0176-6724(86)80122-5. [PubMed] spin V, Cimperman J, Lotric-Furlan S, Pleterski-Rigler D, Strle F. nema migrans in pregnancy. Wiener klinische Wochenschrift. (111:933-40. [PubMed] owitz LE, Steere AC, Benach JL, Slade JD, Broome CV. Lyme disease ng pregnancy. JAMA: The Journal of the American Medical Association. ;255(24):3394. doi:10.1001/jama.1986.03370240064038. PubMed esinger PA, Duray PH, Burke BA, Steere AC, Stillman MT. Maternal-fetal smission of the Lyme disease Spirochete, Borrelia burgdorferi. Annals of nal Medicine. 1985;103(1):67. doi:10.7326/0003-4819-103-1-67. Med] r RM, Yang L, Daynes RA, Branch WD, Salafia CM, Weis JJ. Fetal outcome urine Lyme disease. Infection and Immunity. 1995;63(1):66-72. [PubMed] pino BA, Williams CL, Abid S, Ghalson R, Spierling P. Lyme disease and nancy outcome: A prospective s of two thousand prenatal patients. rican Journal of Obstetrics and Gynecology, 1993;169(2):367-374. [0.1016/0002-9378(93)90088-z. [PubMed] er K, Bratzke H-J, Neubert U, Wilske B, Duray PH. Borrelia burgdorferi in wborn despite oral penicillin for Lyme borreliosis during pregnancy. The atric Infectious Disease Journal. 1988;7(4):286-288.

Many of the new codes describe late stage & systemic complications

- demonstrating the infection is not easy to diagnose
- indicating widespread treatment failure following the standard short-term antibiotics
- underscoring the unreliability of the recommended serology diagnostic technologies

Descriptor codes can be added to primary codes

## **The New Global Face of Lyme**

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		1C1G.11	Lyme Carditis
		1C1G.12	Ophthalmic Lyme borreliosis
		1C1G.13	Lyme arthritis
Example of		1C1G.14	Late cutaneous Lyme borreliosis
Descriptor codes liver & other viscera, late Lyme disease of kidney & ureter, late Lyme disease of Bronchus		1C1G.1Y	Other specified disseminated Lyme borreliosis
		1C1G.1Z	Disseminated Lyme borreliosis, unspecified
		1C1G.2	Congenital Lyme borreliosis
		1C1GY	Other specified Lyme borreliosis
		6D85.Y	Dementia due to Lyme Disease
		9C20.1	Infectious panuveitis in Lyme disease
	ung & Latent ne disease,	9B66.1	Infectious intermediate u∨eitis in Lyme disease
uns	specified	8A45.0Y	Central Nervous System demyelination due to Lyme borreliosis

### **Post Treatment Lyme Disease Syndrome**

CDC's website, 'patients who have symptoms like fatigue, pain & joint & muscle aches after the treatment of Lyme disease have post treatment Lyme disease syndrome (PTLDS) or post Lyme disease syndrome (PLDS)'.

**Guess what?** 

Neither PTLDS or PLDS is recognized in ICD 11, nor were they recognized in the previous versions of the ICD.

### Why won't you find PTLDS in the ICD 11? Because this syndrome has never been validated.

Furthermore, the basis for this syndrome is a psychosomatic condition —MUS— that has been repudiated by the American Psychiatric Association & deleted from the DSM-5 guidance

To date, the terms PTLDS & PLDS are routinely used to deny the epidemic & the medical care of those living with persistent & complicated cases.

#### **WHO ICD Code Process**

**Implementation of ICD11 is set to begin following endorsement at the 72nd World Health Assembly in May 2019.** 

**Rollout will begin immediately**, however, member states have until January 1, 2022 to have fully operational ICD11 in place.

ICD11 represents a multiyear & multi-stakeholder process.

Stakeholders engagement included both government & civil society. Government officials from medical, scientific, financial & military agencies, scientific & medical experts from academia & private sector, a wide range of healthcare providers & healthcare practitioners, patient groups, family caregivers, & the insurance & pharmaceutical industries were all represented through multiple stakeholder events.

## **WHO ICD Code Process**

**The ICD11 revision includes:** 

10,000 suggested revisions
multiple expert group reviews across the globe
31 countries undertook test implementation

ICD 11 is the first version that will have the capacity for continuous updating

These new processes are being determined

Governments & medical societies across the globe were part of the ICD11 process.

Representatives from these bodies who dismiss the <u>validated science</u> of ICD11 Lyme codes will appear *foolish*, *unprofessional & corrupt*.

WHO's powerful validation can be used today to overturn corrupt policies & practices that deny valid diagnostics & treatment options for Lyme patients

## Prevention

Dementia, Alzheimer's & neurodegenerative diseases such as multiple sclerosis, Parkinson's & ALS are skyrocketing & there are `no cures'.

Really? Are you sure about that?

WHO's ICD11 officially recognizes '6D85.Y Dementia due to Lyme Disease' & '8A45.0Y Central Nervous System demyelination due to Lyme borreliosis'. Now 'Prevention of Dementia, Alzheimer's & other Neurodegenerative diseases' requires new public health policies:

- No barriers to Lyme diagnosis are permitted for any person diagnosed with Dementia, Alzheimer's, multiple sclerosis, ALS, or Parkinson's Disease
- Unreliable Lyme serology tests means that persons suffering from these illnesses should be given the option of Lyme empirical therapy
- No barriers to Lyme treatment options are permitted for any person diagnosed with Lyme-related Dementia & Alzheimer's, multiple sclerosis, ALS, or Parkinson's Disease
- Clinical diagnosis of Lyme & access to treatment options that meet internationally validated standards can stop or slow Lymerelated Dementia & Alzheimer's, multiple sclerosis, ALS, or Parkinson's Disease

#### Prevention of Lyme focuses on Ticks NO LONGER

WHO's ICD11 code **`1C1G.2** Congenital Lyme' recognizes Lyme can be transmitted from mother to child. Now **`Prevention of Lyme' requires new public health policies:** 

- No barriers to Lyme diagnosis are permitted for women planning pregnancy & pregnant women
- No barriers to Lyme treatment options are permitted for women planning pregnancy & pregnant women
- Clinical diagnosis of Lyme & access to treatment options that meet internationally validated standards increase the chances for healthy babies, mothers & children

