

# Morgellons in the World Health Organization ICD11

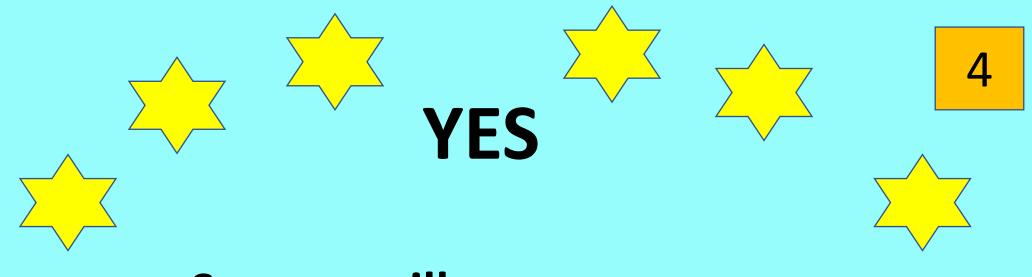
Jenna Luché-Thayer Global Network on Institutional Discrimination, Inc. Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes

### Representation of Morgellons in the ICD11

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- The World Health Organization (WHO) is part of the UN system and implements a comprehensive global stakeholder process for International Classification of Diseases codes, otherwise known as ICD codes.
- ICD codes are used globally to identify and record diseases, injuries and deaths. In many countries, ICD codes are tied to insurance plans and reimbursement for medical care.
- Is it possible to make radical changes to the ICD codes for Morgellons?

## Your Dream Team

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- Your Dream Team is a stakeholder group that needs to establish its legitimacy with WHO and other United Nations entities.
- International representation is critically necessary when working on global issues such as Morgellons.
- Multiregional representation in a stakeholder group is required for credibility with WHO and other UN entities.
- Professional skill sets are required, plus knowledge of the UN and diplomacy.



## Success will mean persons suffering from the complex and devasting disease of Morgellons could potentially gain access to diagnosis and treatment options.

### An Example of a Dream Team

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- The Ad Hoc Committee for Health Equity in ICD11 Borreliosis Codes includes highly skilled professionals from North America, the Asia Pacific region, Africa, South America and Eastern, Western and Northern Europe.
- Many members are scientific and medical experts who have worked on borreliosis for two and three decades.
- Our members have conducted many studies and published many hundreds of peer-reviewed publications. They serve as leaders, clinicians and professors across numerous well respected academic and research centers.

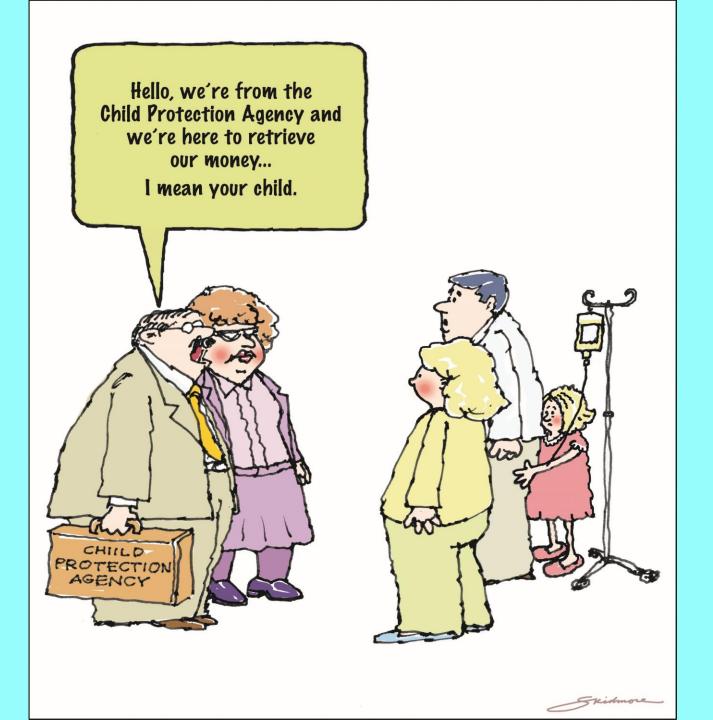
- Members who consult regularly to WHO and governments on the development of health systems, surveillance practices, patient-centered care, ageing, zoonosis and other specialized areas.
- Other members are experts in law, governance, accountability, institutional reform, climate change, capacity building and human rights.
- Members who have worked extensively with the private sector, from multinational corporations in multiple countries to local private education centers.
- Someone has to manage the whole process

### A Human Rights Strategy

- In order to succeed in changing the codes, the Ad Hoc Committee could not limit itself the medical and scientific debate.
- Such debates have failed to move the agenda for decades
- We had to break from the medical and scientific paradigm and tie our negotiations to human rights—IDSA, CDC, NIH and most public health institutions across the globe would be disadvantaged by stepping into OUR FRAMEWORK
- Our adversaries are NOT HUMAN RIGHTS EXPERTS—they are human rights perpetrators

- We DID NOT refer to diagnostic testing as a choice between technologies. We framed the deliberate obstruction to the access of diagnostic tests which meet legitimate standards.
- We DID NOT debate the pros and cons of various treatment options. We framed the deliberate obstruction to the access of treatment options which meet international standards.
- We documented and spoke the ugly truth of how those who provide medical care to this patient group are routinely threatened with the loss of their livelihoods.

- We exposed the inhumane shameful acts by governments and organizations paid to seize sick children.
- We revealed the immorality and indecency in practices whereby persons, able to manage an illness with generic antimicrobials, were offered euthanasia.
- Most importantly, we directly tied all these human rights violations explicitly to the limited ICD10 codes for Lyme.









# Our Reports were Comprehensive in Nature <sup>12</sup>

- The Reports documented all peer reviewed medical and scientific evidence to move the ICD agenda and specified every human rights violation associated with this epidemic.
- Our Dream Team could only promote recognition of those complications for which there are solid peer-reviewed publications.
- This means that although ICD11 is an historic improvement over previous versions, complications which are both common and severely debilitating are still missing from ICD11.

### What is Feasible for ICD Representation? What is peer reviewed?

The following conditions were recommended for code assignments:

**Congenital Lyme disease, persistent infection, Borrelial lymphocytoma,** Granuloma annulare, morphea, localized scleroderma, lichen sclerosis and 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, Meningo-vascular and **Neuroborreliosis** —with cerebral infarcts, Intracranial aneurysm, Lyme Parkinsonism, Late Lyme meningoencephalitis or meningomyelo-encephalitis, Atrophic form of Lyme meningoencephalitis with dementia and subacute presenile dementia, Neuropsychiatric manifestations, late Lyme disease of liver and other viscera, late Lyme disease of kidney and ureter, late Lyme disease of **Bronchus and lung and Latent Lyme disease, unspecified.** 

•The Reports required an elaboration of each and every failure on the part of State Actors with regard to this global public health crisis, as well as their complicity in the related profiteering and corruption.

These Reports were only the first step.

### **Political Action**

- Top-level political support is needed
- We had to gain audience with decision makers responsible for the topics covered in our Reports.
- The most strategic support for this agenda meant we needed to gain audience with two particular UN Special Rapporteurs. These were the Special Rapporteurs for health human rights and the defenders of human rights.
- It is also important to have mentors and point persons to guide and facilitate —*the Ad Hoc Committee*

### WHO ICD11 Digital Beta Platform

- We were required to master a complex digital Beta platform, as well as provide comprehensive documentation which built a global medical and scientific rationale for changing the codes.
- We enlisted the help of graduate students recruited from Canada and Finland to enter many hundreds of data points across the ICD11 system to support our recommendations.
- Every entry was on standing record for the world to see and was thoroughly documented.

### **Applicable Human Rights Treatises**

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- African Charter on Human and Peoples' Rights
- Convention Against Torture
- European Convention for the Prevention of Torture and 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 and Fundamental Freedoms
- European Social Charter
- International Covenant on Civil and Political Rights
- International Covenant on Economic, Social, and Cultural Rights —Article 12 states steps for the realization of the right to health include those which:
  - reduce infant mortality and ensure the healthy development of the child
  - improve environmental and industrial hygiene
  - prevent, treat and control epidemic, endemic, occupational and other diseases
  - create conditions to ensure access to health care for all.
- International Convention on the Elimination of All Forms of Racial Discrimination



- The right to liberty and security of the person has been held to prohibit unauthorized disclosure of personal health data.
- The right to bodily integrity and security of the person have been held to prohibit the administration of medicine to a child against parents' wishes.
- The right to freedom from cruel, inhuman, or degrading treatment or punishment has been held to oblige governments to secure the adequate health and wellbeing of prisoners.
- The right to bodily integrity is interpreted to be part of the right to security of the person, the right to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health.
- The right to health includes the human rights in patient care as well as economic and political human rights which define the context of patient care provided by human rights defenders.

The situation of borreliosis patients and their defenders show fourteen violations across eleven human rights treatises.

### Human Rights Violations of Patients and their Human Rights Defenders



#### Right to highest attainable standard of health

- State health authorities allow insurers and state programs for low income families to deny medical care for Lyme and Lyme-like illness.
- These policies result in obstruction to necessary medical care for those with insufficient economic resources to pay out-of-pocket for their medical care.
- Patients who are limited to programs for low income families are given inferior care.

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# Right to freedom from torture and cruel, inhuman and degrading treatment

- State policies restricting antibiotic access for the Lyme and Lyme-like illnesses cause patients to suffer unnecessary pain, disability, bankruptcy, and even death.
- State Actors cause doctors mental and emotional anguish when they are forced to abandon their patients or are barred from applying clinical practice Guidelines which have been vetted through internationally accepted standards. This results in patients suffering unnecessary pain, disability, bankruptcy, and even death.

#### Right to life



 Outdated and politicized State Lyme policies result in disability, bankruptcy and suicide for many Lyme patients.

#### Right to liberty and security of person

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

#### Right to privacy and confidentiality

• Lyme patients' medical information is shared without their consent to State authorities who harass their doctors for providing Lyme treatment options which meet internationally accepted standards.

#### Right to information

- The State fails to provide information regarding the risk of disability and death from undiagnosed and inadequately treated 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 versus lack of treatment.

#### Right to bodily integrity

- Practitioners fail to obtain free and informed consent from patients before treatments begin.
- Threats of loss of license & livelihood against doctors who treat Lyme patients according to protocols which have met internationally accepted standards results in many doctors turning away Lyme patients, leading to patient suicide & death.

#### *Right to participation in public policy*

- State Actors fund grantees and other affiliates to disseminate articles which recommend Lyme patients and their human rights defenders be excluded from participating in Lyme-related policies.
- Participation in Lyme-related public policy by Lyme patients and their human rights defenders is 'empty theater' with no evidence of political commitment to change status quo and prioritize patient care. As an example, State Actors collude for wrongful financial incentives to drive preplanned outcomes which suppress science and maintain status quo.

#### Right to nondiscrimination and equality

• Medical practitioners, hospitals and policymakers are encouraged to claim Lyme patients have psychosomatic issues rather than biological illness, resulting in obstruction to medical care for infection and complications.

# Lyme policy making



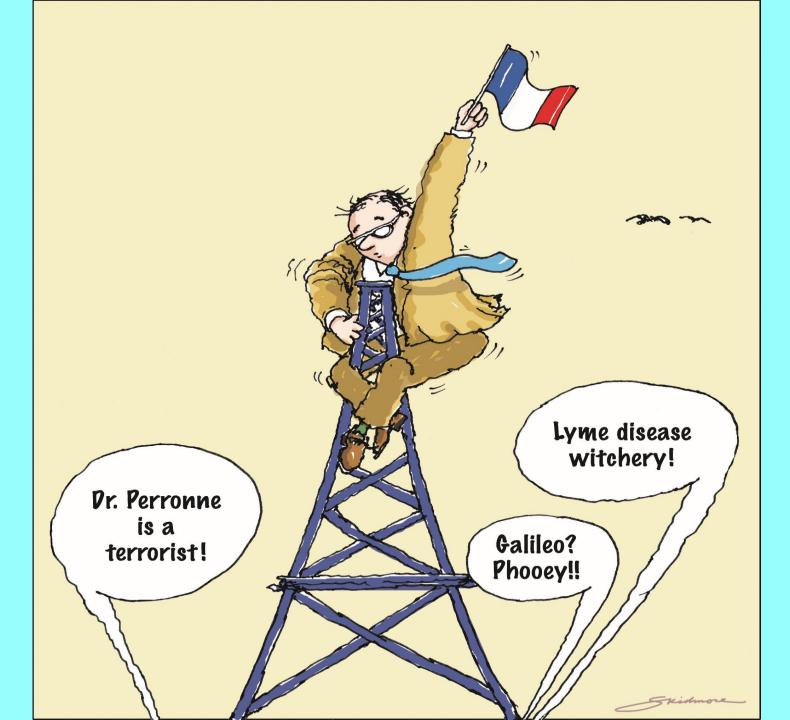
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#### Right to decent working conditions

 Clinical practice Guidelines of a professional medical society meeting internationally accepted standards and its members are defamed, harassed and threatened by State Actors who belong to a competing private medical society and their affiliates.

#### Right to freedom of association

- Authorities use penalties to prevent practitioners who use Guidelines which meet internationally accepted standards to travel to conferences.
- Authorities prevent scientists from providing presentations promoting diagnostics tests which compete with the authorities' (and their affiliates') patented tests.





#### **Right to due process**

- A practitioner facing disciplinary proceedings is denied access to all evidence presented against him/her in advance of the hearing.
- A doctor in a medical judgment suit is put on strict limitations and has not given a 'hearing' date two years after the commencement of the proceedings.

#### Right to a remedy

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

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

	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 Lyme	1C1G.1	Disseminated Lyme borreliosis
G63.0	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

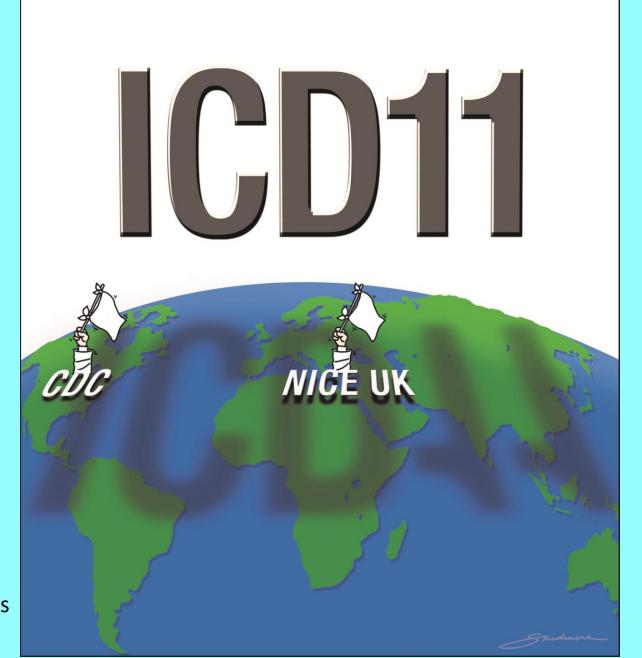


### **NEW CODES**

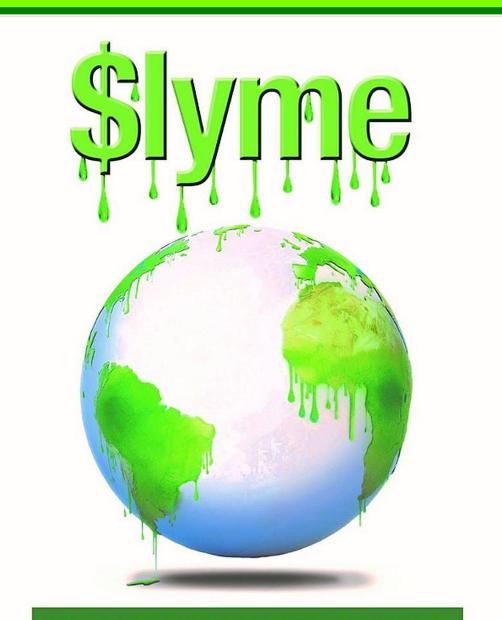
- 5 life threatening complications
- 6 out 14 complications are central nervous system
- Most of the codes can be applied to late stage and chronic complications/infection
- Indicate unreliable diagnostics and treatment failure
- Lyme is NOT easy to diagnose treat and cure
- 400 percent increase in codes
- Many secondary codes can now be added to primary code
- ICD11 will be continuously updated—process to be determined

# Thank you!

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#### HOW MEDICAL CODES MORTALLY WOUND CORRUPTION AND SCIENTIFIC FRAUD

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