

# The Mayday Project

Mayday 2015 Primer

# Introduction

What we will cover:

- The Mayday Project Organization information
- Why we protest the IDSA
- How to protest using science
- What our goals are
- How to protest within the law

# What is the *Mayday Project* organization?

An organization dedicated to raising awareness about the multitude of injustices that continue to be inflicted upon those suffering from Lyme disease and other tick borne illness. Research, education, advocacy, and support.

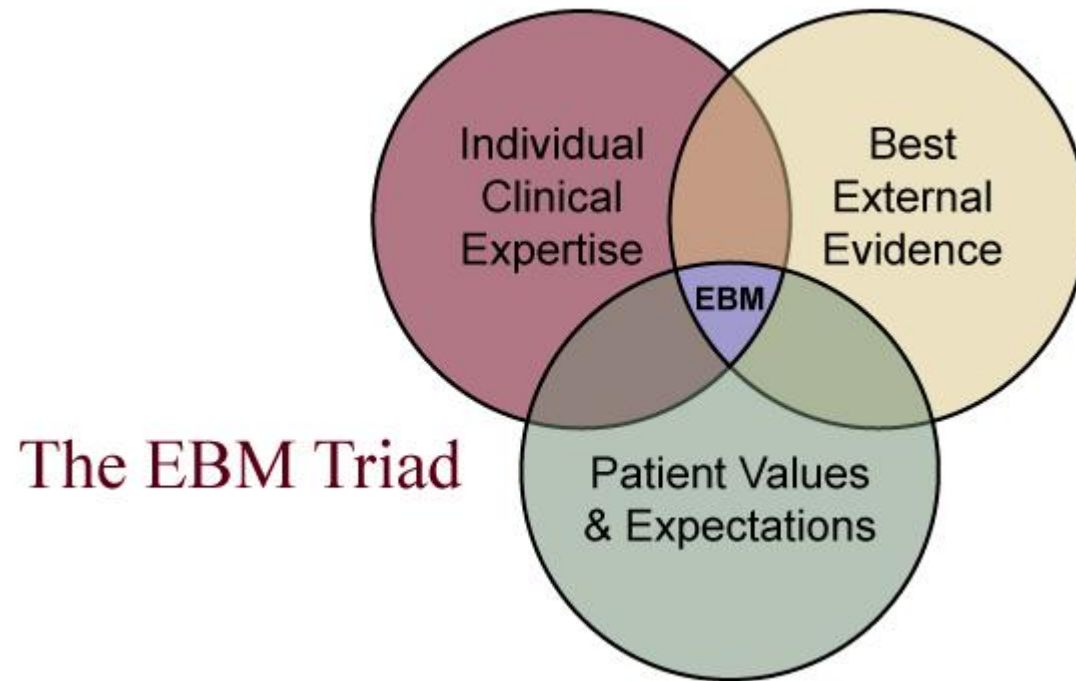
# Why We Protest the IDSA

IDSA guidelines:

- ignore the principles of evidence based medicine
- discourage physicians from providing treatment to severely ill patients
- dismiss extensive evidence for chronic Lyme disease
- misrepresent expert opinion as science

# Why We Protest the IDSA

IDSA guidelines ignore the principles of evidence based medicine



Source: <http://med.fsu.edu/index.cfm?page=medicalinformatics.ebmTutorial>

# Why We Protest the IDSA

Discourage physicians from providing treatment to severely ill patients

*Insurance companies & state health departments sometimes investigate and remove the licenses of physicians willing to treat outside the IDSA guidelines*

Source: DeLong, A., Blossom, B., Maloney, E., Phillips, S. (2012). Antibiotic retreatment of Lyme disease in patients with persistent symptoms: a biostatistical review of randomized, placebo-controlled clinical trials. Contemporary Clinical Trials, 33(6), 1132-1142

# Why We Protest the IDSA

Dismiss extensive evidence for chronic Lyme disease

*Borrelia burgdorferi (Bb) persists following IDSA  
recommended antibiotic treatment*

Source: Phillips, S. (2012). Active infection: Clinical definitions and evidence of persistence in Lyme disease- Contesting the underlying basis for treatment limitations for early and late Lyme disease, as well as chronic Lyme disease, alternatively known as “Post-Lyme disease syndrome.”

Barbour, A. (2012). Remains of Infection. *Journal of Clinical Investigation*, 122(7), 2344-2346.

Lin, X., McHugh, A., Damle, N., Sikand, V., Glickstein, L., Steere, A. (2011). Burden and viability of *Borrelia burgdorferi* in skin and joints of patients with Erythema migrans or Lyme arthritis. *Arthritis and Rheumatism*, 63(8), 2238-2247.

Schmidli, J., Hunzicker, T., Moesli, P. (1988). Cultivation of *Borrelia burgdorferi* from joint fluid three months after treatment of facial palsy due to Lyme borreliosis. *Journal of Infectious Diseases*, 158, 905-906.

Haupt, T., Hahn, G., Rittig, M., Krause, A., Schoerner, C., Schonherr, U., ... Burmester, G. (1993). Persistence of *B. burgdorferi* in ligamentous tissue from a patient with chronic Lyme borreliosis. *Arthritis and Rheumatism*, 36, 1621-1626.

Sapi, E., Bastian, S., Mpoy, C., Scott, S., Rattelle, A., Pabbati, N., ... Luecke, D. (2012). Characterization of biofilm formation by *Borrelia burgdorferi* in vitro. *PLOS ONE*, e.0048277

# Why We Protest the IDSA

Misrepresent expert opinion as science

*Only 15% of IDSA treatment guidelines are based on randomized controlled trials (RCTs) which are considered the highest level of evidence. More than half are based on expert opinion or not supported by RCTs.*

Source: Keller, D. (2009). Infectious disease treatment guidelines weakened by paucity of evidence. Retrieved from <http://www.medscape.com/viewarticle/712341>



# Why We Protest the IDSA

The result of the flawed guidelines:

- thousands of patients are misdiagnosed and denied treatment
- thousands remain sick and suffer terribly
- chronically ill patients must pay out of pocket for medical treatment that is necessary
- thousands of people are devastated

# How to Protest Using Science

pro•test

noun

'prō, test/

1.

a statement or action expressing disapproval of or objection to something.

# How to Protest Using Science

How to protest using science

1. Avoid personal stories
2. Become familiar with the science, past and current
3. Avoid 'psuedo science' websites and theories
4. Have a clear and concise message

# How to Protest Using Science

How to protest using science

## 1. Avoid personal stories

- Share science, not stories
- Use stories to support the science, but only if necessary.

# How to Protest Using Science

How to protest using science

2. Become familiar with the science, past and current
  - Read peer-reviewed articles that support our cause
  - Read peer-reviewed articles that don't support our cause

# How to Protest Using Science

How to protest using science

## 3. Avoid 'psuedo science' websites and theories

- Use science that comes from a peer-reviewed journal

*Peer review is a process by which a scholarly work is checked by a group of experts in the same field to make sure it meets the necessary standards before it is published or accepted in a journal.*

Helpful hints on recognizing a peer reviewed article or journal:

<https://www.angelo.edu/services/library/handouts/peerrev.php>

<http://guides.lib.jjay.cuny.edu/content.php?pid=209679&sid=1746812>

# How to Protest Using Science

How to protest using science

3. Avoid 'psuedo science' websites and theories

- *If protesting online, if possible link directly to the article itself*
- *If you can't link directly to the article, provide the first author's name and the year of publication*

# How to Protest Using Science

How to protest using science

## 4. Have a clear and concise message

- No personal stories
- Don't dump a lot of information at one time
- Stand behind our goals



# What Our Goals Are

The IDSA needs to revise the guidelines to follow Kathleen Lohr's four important attributes of clinical practice guidelines:

1. Reliability and reproducibility
2. Scientific validity
3. Clinical applicability
4. Clinical flexibility

This includes “routine maintenance” to ensure guidelines are relevant and reflective of current scientific information.

Source: Keller, D. (2009). Infectious disease treatment guidelines weakened by paucity of evidence. Retrieved from <http://www.medscape.com/viewarticle/712341>.

# What Our Goals Are

Improved testing

Further research on diagnosis, co-infections, and treatment

Security for doctors and insurance coverage for patients

Most importantly...

Alternative treatments should not be dismissed. Treatment decisions should be made on a case-by-case basis between the patient and the physician.

Source: Stricker, R., Johnson, L. (2014). Lyme disease: Call for a “Manhattan Project” to combat the epidemic. PLOS Pathogens, 10(1), e1003796.