

MGH INSTITUTE OF HEALTH PROFESSIONS

Invisible Disability: Providing Compassionate Care for a Person with ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)

Opening Remarks & Moderator

- **Ronald Tompkins, MD, ScD**, Sumner M. Redstone Professor of Surgery, Harvard Medical School; Attending Surgeon, MGH; Founding Dir., Center for Surgery, Innovation & Bioengineering, MGH; Scientific Advisory Board of Open Medicine Foundation, focusing on ME/CFS; Co-Director, ME/CFS Collaborative Research Activities at MGH and the Harvard Affiliated Hospitals

UNREST Film Excerpt

Panel

- A healthcare provider treating ME/CFS
- Individuals living with ME/CFS, or their caregivers

Institute of Medicine

2015 Report: “Beyond ME/CFS: Redefining an Illness”

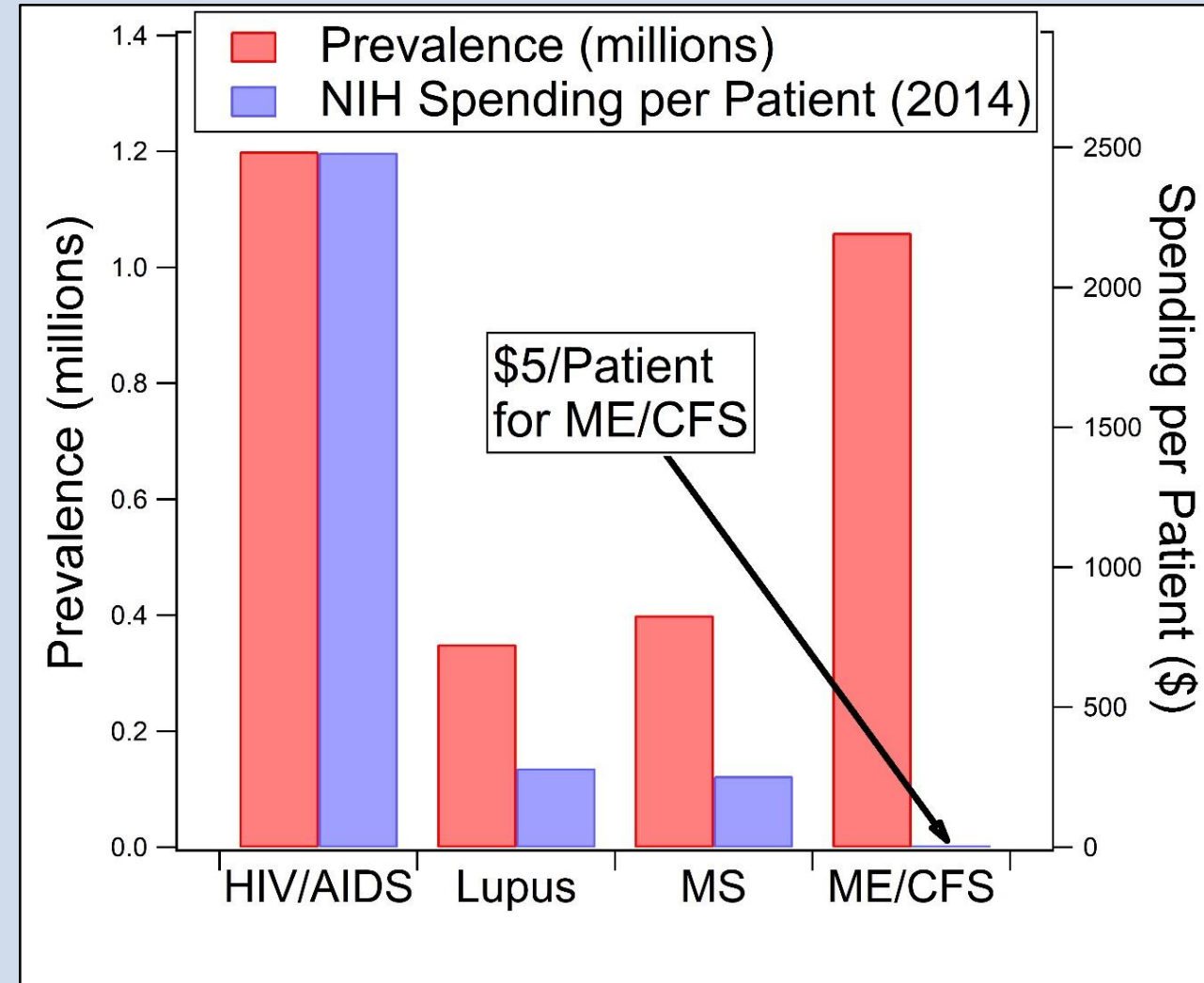
- **“The primary message of the committee’s report** is that ME/CFS is a serious, chronic, complex, systemic disease... [that] frequently and dramatically limits the activities of affected patients.”
- **“Fewer than 1/3rd of medical school curricula** and less than half of medical textbooks include information about ME/CFS.”
- **“Many health care providers are skeptical** about the seriousness of ME/CFS, mistake it for a mental health condition, or consider it a figment of the patient’s imagination... **It is ‘real.’ It is not appropriate to dismiss these patients...**”
- **“Many people with ME/CFS report being subject to hostile attitudes** from their health care providers, as well as to treatment strategies that exacerbate their symptoms.”
- **“Remarkably little research funding** has been made available to study the etiology, pathophysiology, and effective treatment of this disease, especially given the number of people afflicted... **There is an urgent need for more research...**”

Source: Institute of Medicine (now the National Academy of Medicine)

Key Facts About ME/CFS

(IOM REPORT)

- **1 to 2.5 million Americans afflicted**
- **75% are women**
- **70% can't work; 25% are home- or bed-bound**
- **No diagnostic test, no FDA-approved treatment, no cure**
- **Symptoms persist for years; recovery is rare**
- **84-91% not diagnosed or misdiagnosed**
- **Only a handful of medical experts nationally**
- **ME/CFS costs economy \$17 - \$24 billion annually**
- **NIH research funding very low (about \$5-6 million per year)**



Data: Dimmock ME, Mirin AA, Jason LA (2016). "Estimating the disease burden of ME/CFS in the US and its relation to research funding". J Med Therap 12/16.



UNREST

SHELLA FILMS and LITTLE BY LITTLE FILMS PRESENT IN PARTNERSHIP WITH IMPACT PARTNERS and CHICKEN & EGG PICTURES
PRODUCED BY JENNIFER BRICA "UNREST" WITH BEAR MCCREARY PRODUCED BY SAM HEISEN CHRISTIAN LAURSEN
EDITED BY KIM ROBERTS EMILIANO BATTISTA DIRECTOR OF PHOTOGRAPHY DEBORAH HOFFMANN COSTUME DESIGNER RUTH ANN HARNISCH EXECUTIVE PRODUCERS REGINA K. SCULLY
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unrest.film



UNREST

(excerpt)

- **Sundance and *Boston Globe* (GlobeDocs) award-winning documentary. Short-listed for an Oscar nomination. Aired on PBS Independent Lens**
- Available on all online streaming outlets
- **Get CME (Continuing Medical Education) credits for watching UNREST: www.unrest.film/cme**

About ME/CFS

ME/CFS is an acquired, chronic, multi-systemic disease characterized by significant relapse after physical, cognitive, or emotional exertion of any sort.

The disease causes immune, neurological, energy metabolism and cognitive impairment, sleep abnormalities, and autonomic dysfunction, resulting in significant functional impairment accompanied by a pathological level of fatigue.

The cause of the disease remains unknown, although in many cases symptoms may have been triggered by an infection or other prodromal event.

(US Government's Chronic Fatigue Syndrome Advisory Committee)

- **Not** a psychological/psychiatric disease
- **Not** “just fatigue”

Panel Discussion and Q & A

Panel Moderator

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Panelists

- **Lisa Hall, RN**, head nurse at Northampton Integrative Medicine, working with ME/CFS patients 17 years
- **Rivka Solomon**, ME/CFS patient advocate and event coordinator with Mass. ME/CFS & FM Assoc. (Alternate: **Mary Dimmock**, mother of adult son with ME/CFS, and national advocate.)
- **Robie Robitaille**, ME/CFS patient advocate and support group leader with Mass. ME/CFS & FM Assoc. (Alternate: **Bob Robitaille**, father of adult daughter with ME/CFS, and advocate with Mass. ME/CFS & FM Assoc.)

ME/CFS Clinical Diagnostic Criteria -- IOM 2015 Report

CORE criteria (*required*)

- Impaired function accompanied by fatigue, persisting >6 mo
- Post-exertional malaise (PEM)* in which physical or mental activities result in a delayed exacerbation of symptoms and reduction in functioning. (Can often be severe.)
- Unrefreshing sleep*

Plus, either or both

- Cognitive impairment*
- Orthostatic intolerance

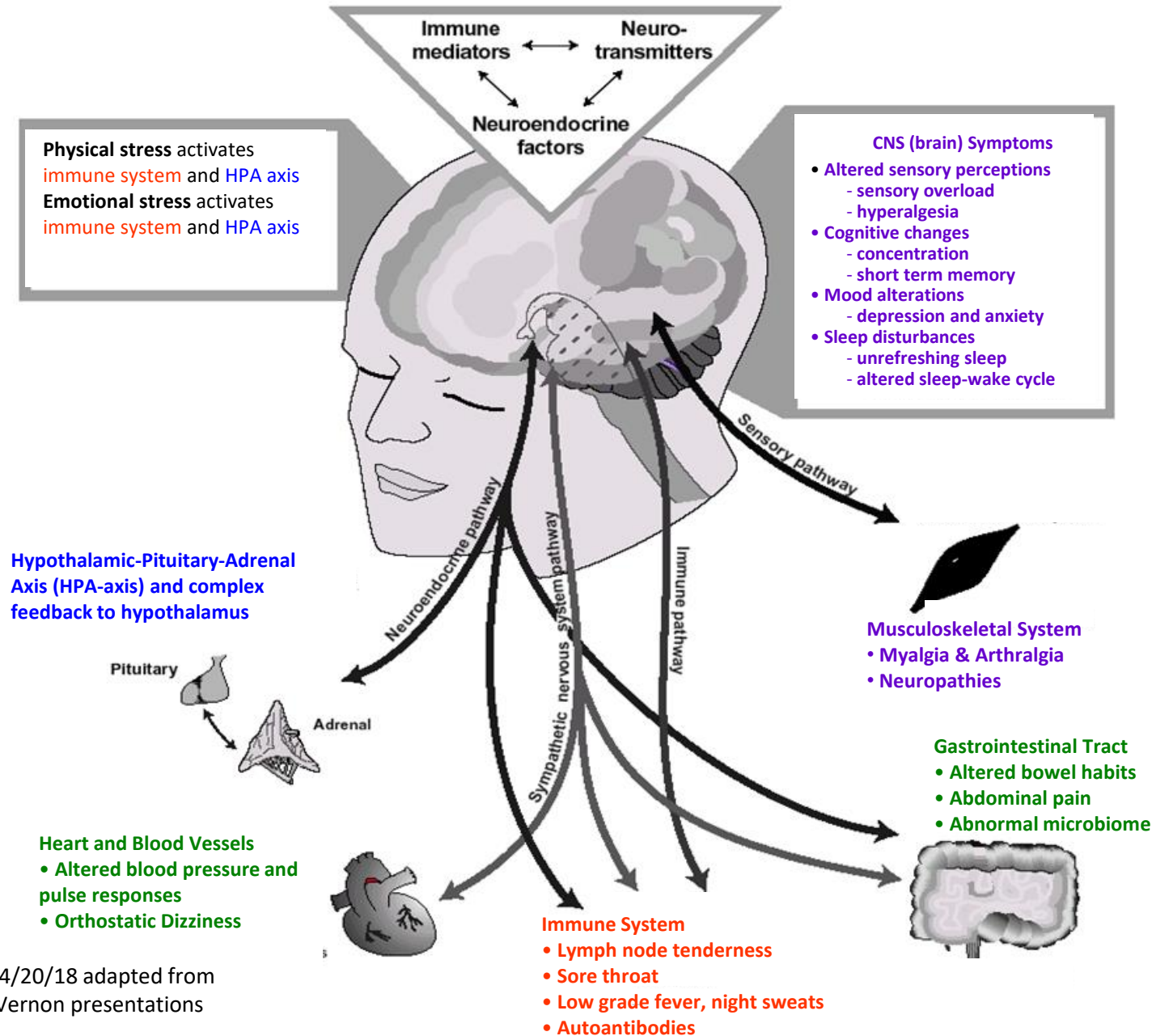
**Must be moderate-severe and present >50% of time*

Other symptoms

- Chronic pain
- Immune and Infection manifestations
- Neuroendocrine manifestations
- Gastrointestinal manifestations
- Sensitivities to light, sound, touch, medication

More Info: *IACFS/ME Primer (2014) and Pediatric Primer (2017)*

ME/CFS: A multisystem illness that causes global impairment



RESEARCH EVIDENCE

HPA-axis:

- Low CRH
- Low-normal cortisol (lack am rise)
- Low GH
- Euthyroid sick syndrome (low T3, high RT3)

IMMUNE:

- Low NK cell function
- Altered cytokine patterns
- Low IgA, IgG, IgG subclasses
- Viral reactivation or T-cell dysfunction contributing to high anti-viral IgG levels.
- Autoimmune and neuroimmune manifestations.
- ANA positive, low, nonspecific
- Altered microbiome.
- Mast cell activation syndrome

ANS/OI/cardiovascular

- Abnormal Tilt table and Lean Test: OH, POTS
- Adrenergic, muscarinic receptor autoantibodies.

ENERGY: Abnormal exercise testing. Abnormal cellular metabolism. Illness worsens after activity. Mitochondrial dysfunction.

CNS: Abn brain blood flow by SPECT, fMRI, PET and elevated brain lactate

Abnormal Neurocognitive tests—cognitive slowing, diminished executive function

Abnormal Sleep studies

Basic Clinical Management

1) **Validate the patient's experience and educate about the disease**

2) **Assess support needs**

Shelter, food, school or work accommodations, disability, assistive devices, caregivers

3) **Educate patients about pacing to minimize PEM**

Physical and cognitive activity management to stay within a patient's specific energy limitations.

Important: CDC no longer recommends cognitive behavior therapy (CBT) and graded exercise therapy (GET). These therapies could cause harm by encouraging patients to push beyond their energy limits.

4) **Treat/manage symptoms**

Pharmacological and other approaches for sleep, orthostatic intolerance, cognitive issues, pain, GI issues, and sensitivities, such as to sound, light and medications.

5) **Treat comorbidities**

E.g. fibromyalgia, primary sleep disorders, postural tachycardia syndrome (POTS), mast cell activation disorder, secondary depression, celiac disease, allergies

Beyond the basics: Disease experts have had success in improving function and decreasing symptoms with the selective use of more advanced treatments such as immune modulators

Adapted fr: CDC ME/CFS website <https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/index.html>, IACFS/ME Primer, and Alison Bested's published article <https://www.ncbi.nlm.nih.gov/pubmed/26613325>

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**Robie Robitaille and Rivka Solomon
ME/CFS patient advocates
with the Massachusetts ME/CFS & FM Association**



Thank you for coming!

Contact Mass. ME/CFS & FM Assoc.: MassMECFS.org

- Education, patient support and advocacy
- Volunteer, ask Q's (including today), hold an event at your institution
- Sign up for our newsletters

Future project?

- Focus a grad school or work project on ME/CFS

Handouts

- Fact Sheets
- Clinician and researcher handouts

Watch UNREST

- On all online streaming outlets
- ***Get Continuing Medical Education credits: www.unrest.film/cme***