

# 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”

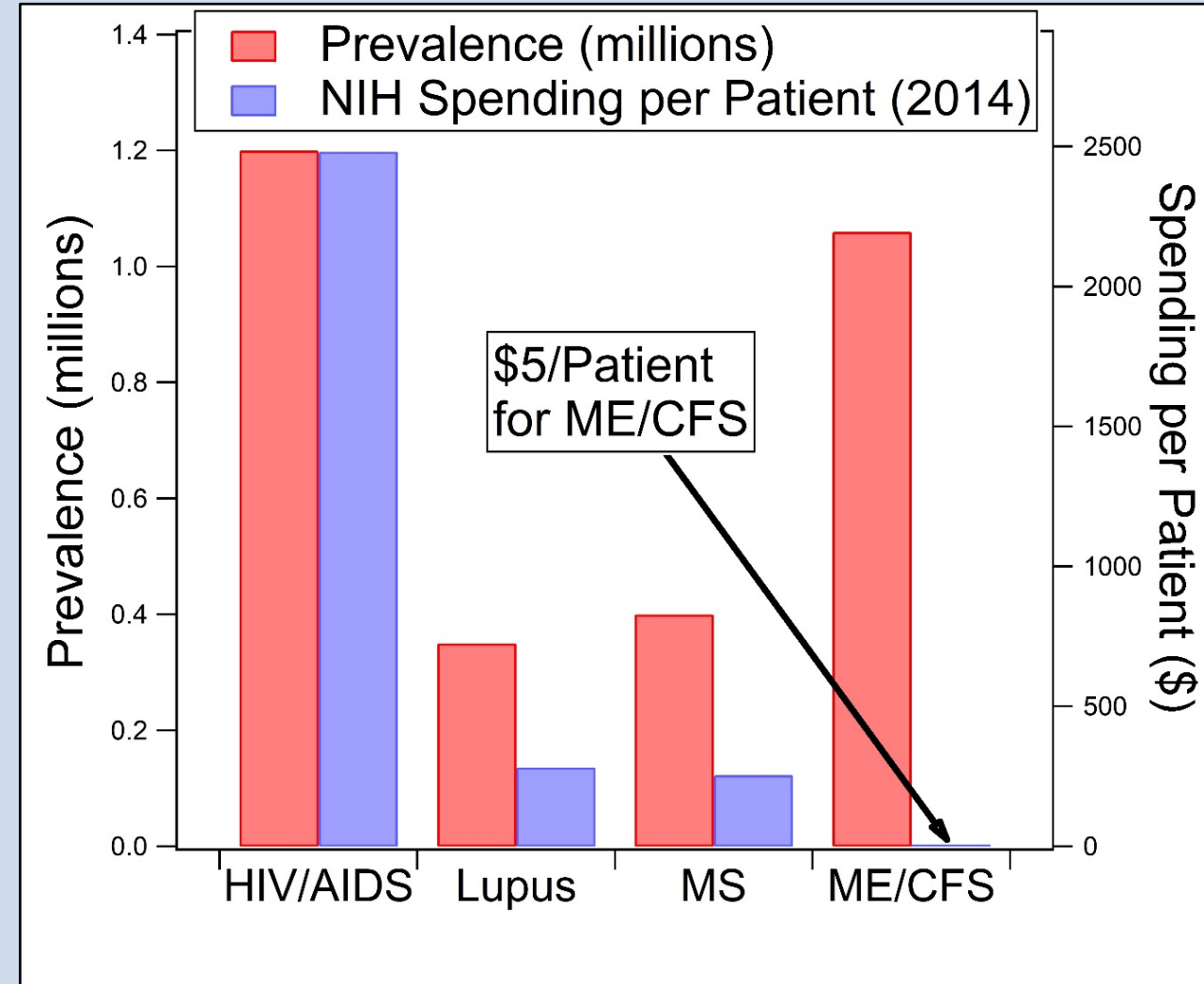
- **“The primary message of the committee’s report** is that ME/CFS is a serious, chronic, complex, systemic disease... [that] frequently and dramatically limits the activities of affected patients.”
- **“Fewer than 1/3<sup>rd</sup> of medical school curricula** and less than half of medical textbooks 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 "UNREST" PRODUCED BY JENNIFER BREZA DIRECTED BY BEAR MCCREARY EDITED BY SAM HEESSEN CHRISTIAN LAURSEN  
CASTING BY KIM ROBERTS COSTUME DESIGNER EMILIANO BATTISTA EXECUTIVE PRODUCERS DEBORAH HOFFMANN RUTH ANN HARNISCH REGINA K. SCULLY  
EXECUTIVE PRODUCERS DAN COGAN JAN DARLING LYNDSEY WEINMAN LISA GUNN DONNA FAIRMAN WILSON  
PRODUCED BY JENNIFER BREZA LINDSEY DRYDEN PATRICIA E. CALLESPIE AILSA NAHMAS  
DIRECTED BY ANNE TROLDOTJ GABRIEL PRODUCED BY JENNY RASKIN MONA ELIASSEN MITCH AND DEBBIE MENAGEO  
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](http://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

- **Ronald Tompkins, MD, ScD**, Founding Dir., Center for Surgery, Innovation & Bioengineering, MGH; Sumner M. Redstone Professor of Surgery, Harvard Medical School; Attending Surgeon, 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

## 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**

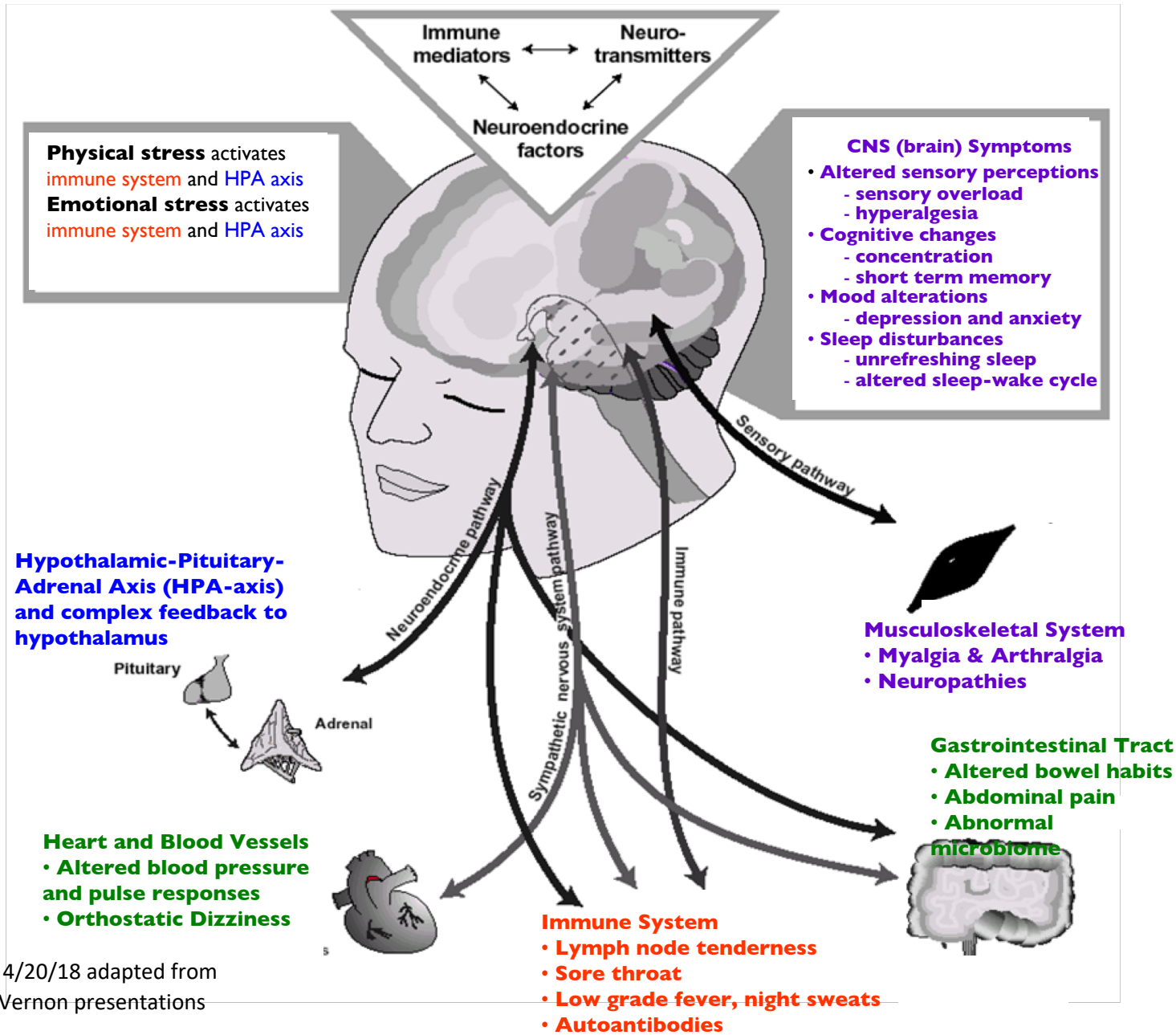
*\*Must be moderate-severe and present >50% of time*

## 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](http://www.unrest.film/cme)