

HAMPSHIRE COLLEGE

Culture, Brain & Development Program

Co-sponsors: Mass. ME/CFS & FM Assoc.; Five College Program in Culture, Health & Science;
Smith College Center for Community Health Equity Research

Presents

UNREST & Panel on ME/CFS

(Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)

- **Opening: Dr. Pamela Stone**, Director FPR-HC, Culture, Brain, and Development Program, and Senior Faculty, School of Critical Social Inquiry, Hampshire College. Plus, **Rivka Solomon**, Mass. ME/CFS & FM Assoc.
- **UNREST (25 min)**
- **Panel and Q&A:** World-renowned ME/CFS researcher; Hampshire College alumna, caregiver; Doctor treating ME/CFS; and patient advocate
- **UNREST (70 min)**

Institute of Medicine

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

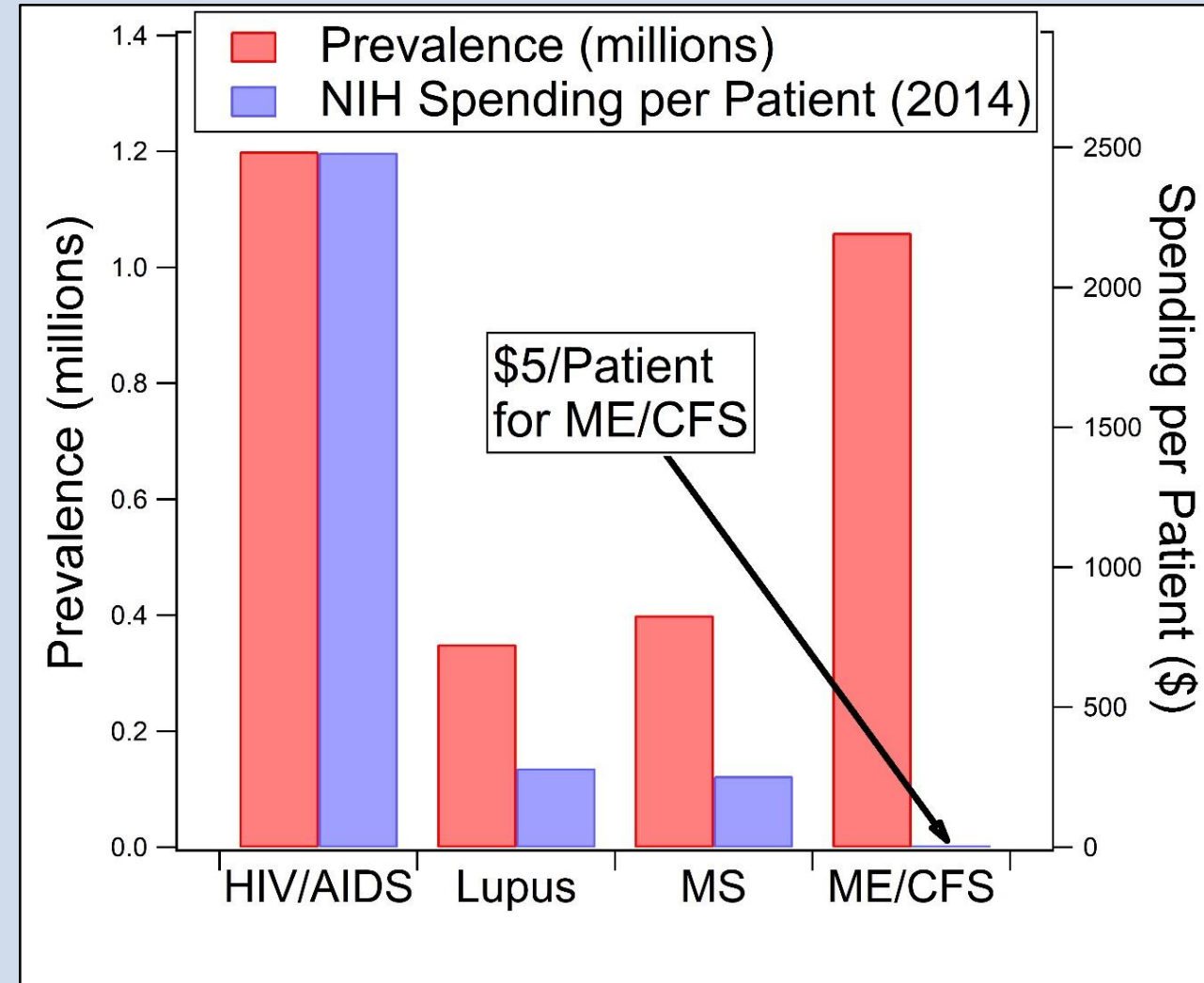
- **“The primary message of the committee’s report** is that ME/CFS is a serious, chronic, complex, systemic disease... [that] frequently and dramatically limits the activities of affected patients.”
- **“Fewer than 1/3rd of medical school curricula** and less than half of medical textbooks include information 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.



Massachusetts ME/CFS & FM

ASSOCIATION

EDUCATION, SUPPORT & ADVOCACY SINCE 1985

Education

- Screenings of UNREST with panel discussion
- Speakers at annual event
- Dissemination of medical education materials

Patient Support

- Information, phone line, support groups
- Disability application assistance
- Physician referral service

Advocacy

- More research funding from NIH
- Support from members of U.S. congress and state legislators



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 DAN COGAN IAN DARLING LYNDY WEINMAN LISA GUNN DONNA FAIRMAN WILSON
CASTING BY JENNIFER BRICA LINDSEY GRYDEN PATRICIA E. CALLESPIE ALYSA NAHMAS
EXECUTIVE PRODUCERS ANNE TROLDTFJELD HARRIET JENNY BASKIN MONA ELLASSEN MITCH AND DEBBIE MENAGED
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 and Q & A

Moderator

- **Dr. Pamela Stone**, Director FPR-HC, Culture, Brain, and Development Program, and Senior Faculty, School of Critical Social Inquiry, Hampshire College

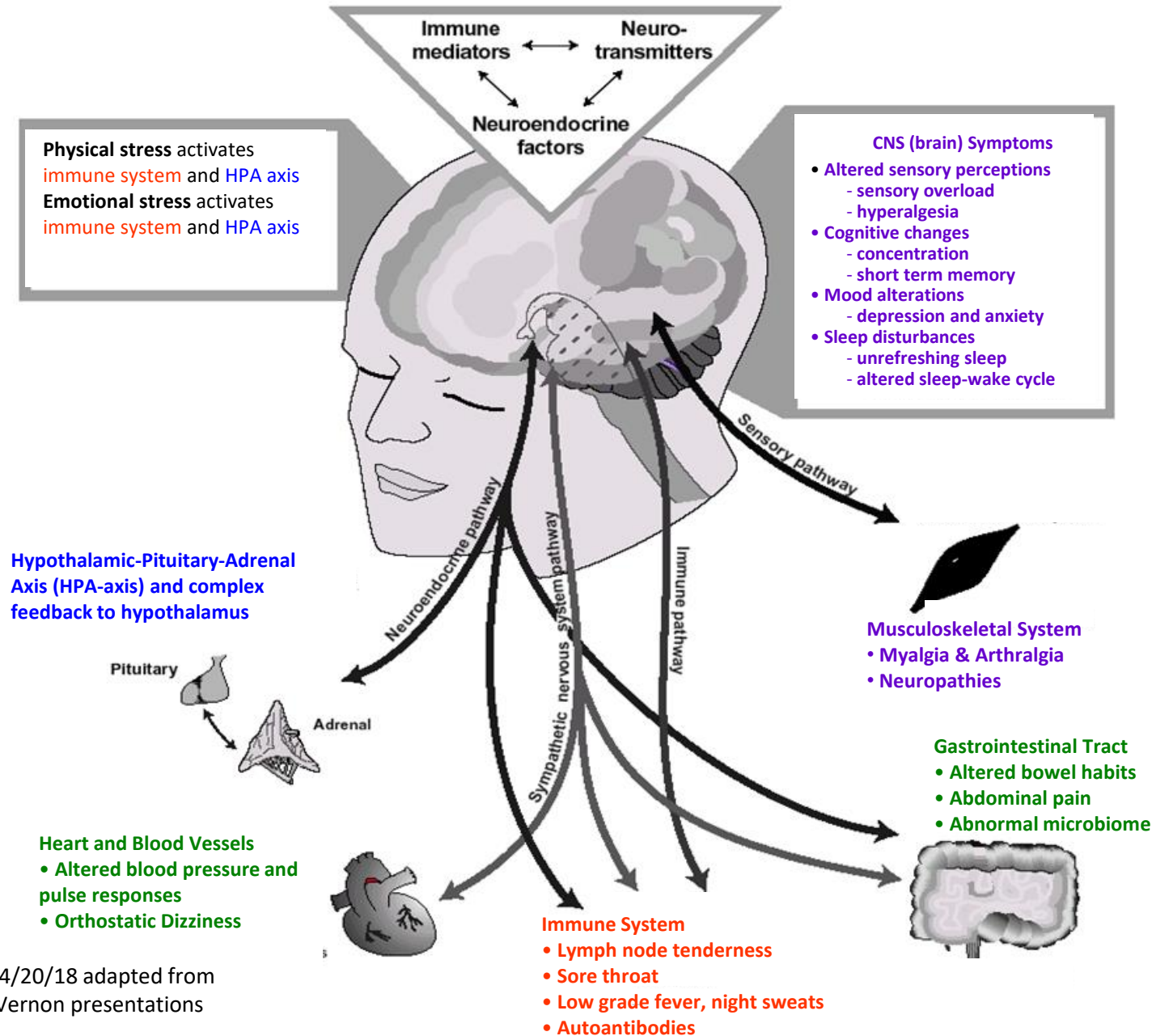
Panel

- **Ron Davis**, Prof. of Biochemistry & Genetics at Stanford Univ.; Dir. of Stanford Univ.'s Genome Tech Ctr., & Stanford CFS Research Ctr.; Open Medicine Foundation's Scientific Advisory Board; member of Nat'l Academy of Sciences; son has ME/CFS.

Additional panelists

- **Darren Lynch MD**, Northampton Integrative Medicine, working with ME/CFS
- **Ashley Haugen**, Hampshire College alumna, advocate, caregiver for brother
- **Rivka Solomon**, Advocate with Mass. ME/CFS & FM Assoc.

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

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, chemicals, perfumes

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

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 Basted's published article <https://www.ncbi.nlm.nih.gov/pubmed/26613325>

Panel and Q & A

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Thank you for coming!

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

- Education, patient support and advocacy
- Volunteer, ask Q's, hold an event at your institution
- Sign up for newsletter

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***