

PRESS RELEASE

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MGH INSTITUTE OF HEALTH PROFESSIONS HOSTS GROUNDBREAKING EVENT FOR NEGLECTED DISEASE

Film excerpt and panel on a disease often dismissed yet afflicting millions

Boston, MA — On Tuesday, January 15, the MGH Institute of Health Professions [hosts an event](#) for over 600 healthcare professionals, researchers and graduate students, and the public, to learn about the highly disabling disease ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome). [The program](#) will be held at 341 Huntington Ave, Boston, MA, in Northeastern University's Blackman Auditorium, at 5:30-7 pm (doors open 5 pm). Pre-registration not required.

The larger New England healthcare, academic and disability communities, as well as the public, are also invited to attend this program titled **Invisible Disability: Providing Compassionate Care for a Person with ME/CFS**. The program moderator is Massachusetts General Hospital's Ronald Tompkins, MD, ScD, a co-director of the [ME/CFS Collaborative Research Activities at MGH](#) and the Harvard Affiliated Hospitals. This is a new endeavor funded by the [Open Medicine Foundation](#), where Dr. Tompkins is a Scientific Advisory Board member.

The Centers for Disease Control calls ME/CFS "[America's hidden health crisis](#)." ME/CFS is a devastating disease largely forgotten by the medical community, leaving most doctors misinformed about how to diagnose and treat the illness. ME/CFS causes neurological, immunological and energy production impairments. It afflicts 1-2.5 million in the U.S. and 17-24 million around the globe, with 75% being women.

Rivka Solomon, event coordinator for the [Massachusetts ME/CFS & FM Association](#), said:

“We believe this is the largest event ever held for ME/CFS. It is not a rare disease, yet it has lived in the shadows. Now it is finally getting real attention. We hope at this event medical misinformation will be replaced with the facts: ME/CFS is a serious disease that significantly limits a patient’s ability to live a normal life. Yet it is severely under funded by the NIH, resulting in tragically little research and patients’ lives ruined. Without more NIH funding the status quo will continue: no known cause, treatment or cure. We expect this ground breaking event, held in the medical mecca that is Boston, will start to change all that.”

The Institute of Medicine (now called the National Academies) said in its [milestone 2015 report](#):

- “ME/CFS is a serious, chronic, complex, systemic disease...”
- “Fewer than one third 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... [Yet] 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... There is an urgent need for more research...”

The January 15th program features the film [UNREST](#), a Sundance and Boston Globe (GlobeDocs) award-winning documentary short-listed for an Oscar nomination, with a panel discussion that includes patient advocates, a healthcare professional and a researcher.

Film: UNREST merges a love story with a medical mystery and a fight for health care equality. Jen Brea is working on her PhD at Harvard and is months away from marrying when she gets a mysterious fever that leaves her bedridden. Disbelieved by doctors, she turns her camera on herself and discovers a hidden world of millions with ME/CFS confined to their homes and bedrooms.

UNREST has received extensive Massachusetts and national media attention: [The Boston Globe](#), [NPR’s Here & Now](#), [NPR’s Science Friday](#), [Cosmopolitan](#) and [Vogue](#), [Today Show](#), [New York Times](#), [Los Angeles Times](#), [Chicago Tribune](#) and [more](#).

Political advances: Recently, Massachusetts Senator Ed Markey, a champion for ME/CFS patients, introduced a Senate Resolution (SR508) for ME/CFS, co-sponsored by Senators Susan Collins of Maine, Elizabeth Warren of MA and others. [Sen. Markey also held a congressional briefing](#) on the disease. In 2017, the MA Congressional Delegation issued a [joint statement](#) in support of ME/CFS patients.

For more information about Massachusetts ME/CFS advocacy and this event:
www.MassMECFS.org

For more information about national advocacy: www.MEAction.net and <https://solvecfs.org> and <https://ammes.org/>

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