

## PRESS RELEASE

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### **BOSTON UNIVERSITY EVENT SUNDANCE AWARD-WINNING, OSCAR-CONTENDER FILM & PANEL DISCUSSION**

#### **Film excerpt and panel on little known, hidden disease afflicting tens of thousands in Massachusetts**

**Boston, MA** — An event at Boston University's Tsai Performance Center (685 Commonwealth Avenue, Boston, MA 02215) on Wednesday, October 10, 5:30-8 pm, will focus on a little known public health issue: the highly disabling disease ME/CFS, which afflicts 21,000-52,000 people in the state. This event is similar to recent events hosted at Mass General Hospital on September 13, and at MA Dept. of Public Health in March. These events were attended by a total of 245 public health and health care professionals.

For more information and to register: <https://bit.ly/2Q7R62H>

The event features the film [UNREST](#), a Sundance and Boston Globe award-winning documentary short-listed for an Oscar nomination, with a panel discussion with ME/CFS experts, including advocates, patients, doctors, and researchers. The audience will be healthcare professionals, researchers and the public.

This event raises awareness about a devastating disease largely forgotten by the medical community: ME (Myalgic Encephalomyelitis), also known as CFS (Chronic Fatigue Syndrome). ME/CFS has severe neurological, immunological and energy production impairments. There are 1 million to 2.5 million Americans stricken with ME/CFS; 75% are women.

**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.

Rivka Solomon, from the Massachusetts ME/CFS & FM Association, an advocacy organization, said, "This event will raise awareness about a severely debilitating disease which disables 1 to 2.5 million Americans, many of whom live invisible lives, due to being homebound and bedridden. We hope to change the conversation about ME/CFS by helping medical professionals and the public understand the devastation ME/CFS brings to a family and a community."

Recently, Massachusetts officials have given ME/CFS their attention:

**On Capitol Hill:** MA Senator Ed Markey introduced a Senate Resolution (SR508) for ME/CFS on May 15th, co-sponsored by Senators Susan Collins of Maine, Elizabeth Warren of MA and others. Sen. Markey and MA Congressman Jim McGovern are new champions for ME/CFS; [Sen. Markey held a congressional briefing](#) on the disease; and additional MA members of Congress, including McGovern, Joseph Kennedy and Katherine Clark, wrote the National Institutes of Health asking for research into ME/CFS. Also, in late 2017, Senators Warren and Markey and the entire MA Congressional Delegation issued the following [joint statement](#):

“Without meaningful and immediate investments in biomedical research, the 28,000 people living with ME/CFS in Massachusetts will struggle to find answers to critical questions about the disease’s cause, diagnosis, and treatment. ... We will keep our constituents with ME/CFS in mind as we push for expanded biomedical research opportunities and funding in the U.S. House and Senate.”

**At the state and city level:** In March 2018, the MA Dept. of Public Health hosted a screening of Unrest and an expert panel about ME/CFS for 140 public health professionals. This is the first time any state’s department of health has held an event about ME/CFS. Earlier, Governor Charlie Baker issued a State Proclamation for ME Awareness, as did additional MA cities and towns, including Cambridge, Chicopee, Fall River, North Adams, Northampton, Pittsfield, and Williamstown.

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](#).

Additionally, the [Massachusetts ME/CFS & FM Association](#), a patient advocacy organization, and other groups, have held a number of events across the state to raise awareness about the disease, including but not limited to: the MA State House, Cooley Dickinson Hospital, Wellesley College, Brandeis University, Harvard Medical School, MGH, and Emerson College. Fall and spring events are slated for Dartmouth Hitchcock Medical Center in New Hampshire, Hampshire College, a series of events for MA school nurses in conjunction with Northeastern University School Health Institute, and MGH Institute of Health Professions.

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