

PRESS RELEASE

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Contact: Rivka Solomon
Events@masscfids.org // (617) 471- 5559

TWO WESTERN MASSACHUSETTS PUBLIC HEALTH EVENTS INCLUDE SUNDANCE AWARD-WINNING AND OSCAR-CONTENDER FILM

Healthcare professional panels on little known and hidden disease afflicting tens of thousands in Massachusetts

Northampton, MA — Two upcoming Western MA events will focus on a public health issue: the highly disabling disease ME/CFS which afflicts 21,000-52,000 people in the state. The events are similar to the one the MA Dept. of Public Health hosted in March 2018 for 140 public health and health care professionals, including school nurses.

The Western MA events feature a screening of [UNREST](#), a Sundance and Boston Globe award-winning documentary that was also short-listed for an Oscar, followed by a panel discussion with healthcare professionals and patient caregivers. The audience will be healthcare professionals, but the public is invited too.

MAY 31st, NORTHAMPTON, MA: Thursday, 5:30 pm, at [Cooley Dickinson Hospital](#), 30 Locust St. (Dakin Conference Room). **Opening remarks: Northampton Mayor David Narkewicz**

JUNE 9, SHELBURNE FALLS, MA: Saturday, 7:30 pm at [Memorial Hall Pothole Pictures](#), 51 Bridge St.

These film and panel events raise 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 1-2.5 million Americans stricken with ME/CFS; 75% are women.

The events' speakers include: **On May 31st:** The President of MA School Nurse Organization; the head nurse at Northampton Integrative Medicine, who has been treating ME/CFS patients for 17 years; a Hampshire College alumna who is an ME/CFS advocate and caregiver for her brother bedridden by ME/CFS. **On June 9th:** A doctor from Northampton Integrative Medicine who has been treating ME/CFS patients for 10 years, and an ME/CFS advocate who is the caregiver for her homebound daughter with ME/CFS.

Film: UNREST, about ME/CFS, 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 confined to their homes and bedrooms.

Rivka Solomon, from the Massachusetts CFIDS/ME & FM Association, which is co-organizing this event, said, “We are dedicated to raising awareness about this 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 by helping people working in the field of public health to understand the devastation ME brings to a family and a community.”

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

On Capitol Hill: Senator Ed Markey and Congressman Jim McGovern are new champions for ME/CFS; [Sen. Markey held a congressional briefing](#) on the disease; and additional members of Congress, including McGovern, Kennedy and 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 expert panel about ME/CFS for 140 public health professionals. This is the first time any state’s department of health held an event about ME/CFS. Earlier, Gov. Baker issued a State Proclamation for ME Awareness, as did additional 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](#).

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www.MassCFIDS.org