

# **Update on MassCFIDS Activities**

**Leah Williams**

**CFSAC Meeting**

**December 13-14, 2017**

## Massachusetts CFIDS/ME & FM Association

*Education, Support and Advocacy since 1985*

**Mission:** To improve the lives of all people affected by ME/CFS and FM, advancing awareness, care, treatment and research.

- **Patient Services:**

- Provided physician referrals to 68 people, responded to 49 other requests for services/info.
- Sponsored 3 in-person support groups

- **Education and Awareness:**

- Updated website to reflect new information at CDC (developed with input from the Technical Development Working Group) and to post new fact sheets on pediatric cases developed by Faith Newton and the CFSAC Pediatric Education Working Group.
- Established relationship with Dr. Unutmaz at Jackson Laboratory in Farmington, CT, one of the NIH Collaborative Research Center funding recipients.

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- **Education and Awareness (cont.):**
  - **MassCFIDS Annual Event**
    - Linda Tannenbaum, CEO, Open Medicine Foundation, gave a talk on recent research at our annual meeting (Newton-Wellesley Hospital, Nov. 4, 2017).
    - Informal meeting with local researchers beforehand.
  - **Massachusetts Academy of Family Physicians**
    - Invited to make presentation at annual meeting in March 2018.
  - **Massachusetts Department of Public Health**
    - Met with Commissioner Bharel and staff in June 2017.
    - Letter to all physicians in Massachusetts in preparation.
- **Advocacy**
  - **Massachusetts State Legislature**
    - Telemedicine, Right-to-Try initiatives in progress.

## **Massachusetts CFIDS/ME & FM Association**

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- **Screening of UNREST (Nov. 12, 2017), co-organized with Rivka Solomon**
  - Largest community organized screening in the world with more than 260 attendees.
  - More than 75 health care professionals and researchers attended for free, thanks to generous donors.
  - 19 co-sponsors assisted with promoting the event:

MA Dept. of Public Health, Division of Women's Health at Brigham & Women's Hospital, Disability Law Center, Cambridge Women's Commission, Arlington Disability Commission, Disability Policy Consortium, Our Bodies Ourselves, American ME and CFS Society, Cambridge Women's Center, MEAction, Hadassah Northeast, ReelAbilities Film Festival Boston, Old Schwamb Mill Museum, BU Women's, Gender & Sexuality Studies Program, Opening Doors to the Arts, Boston Women's Fund, Mass NOW, Boston International Film Festival and the Arlington International Film Festival.
  - MEAction developed an online guide for future screenings.

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## Screening of UNREST, Nov. 12, 2017



Rivka Solomon introducing the statement of support from the entire Massachusetts federal congressional delegation, including Senators Markey and Warren.



Post film panel discussion, moderated by Deborah Becker, Senior Correspondent/Host at WBUR (left), Boston's National Public Radio Station, included a researcher, an ME advocate, a patient, and a health care provider.