

Massachusetts CFIDS/ME & FM Association

Education, Support and Advocacy since 1985

Update on MassCFIDS Activities

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CFSAC Meeting

June 20-21, 2018

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:

- Continue to provide physician referrals and assistance with disability applications, and to respond to other requests for services/info.
- Sponsor 3 in-person support groups

Education:

- **Massachusetts Academy of Family Physicians**
 - Presented a talk at their 2018 Annual Meeting in March: “Practical Guidance on Diagnosing and Managing ME/CFS”
 - Emphasized not a psychiatric illness, GET/CBT not recommended

Advocacy:

- **May 15-16, Washington DC Advocacy Days**
 - Two participants in person – Susan Buckley, Bob Robitaille, both parents – other constituents by phone/skype/facetime
 - Participated in SMCI organized Lobby Day on May 15 (5 MA offices)
 - Met with rest of MA delegation on May 16 (remaining 6 MA offices)
 - Met with 2 Maine Senators in person, staff for 1 Maine Representative
 - Sen. Ed Markey (D-MA) is co-sponsoring S. Res. 508, introduced on May 15
 - Millions Missing event at Boston City Hall; “virtual” event gallery on website

Raising Awareness: Screenings of UNREST

- **We organized 6 so far, 1 more scheduled, a few more under discussion**
- **Film screening plus panel discussion**
 - **MA Department of Public Health**
 - 140 health care professionals
 - Video of panel available at https://www.youtube.com/watch?v=cq3QDUqq_IY&feature=youtu.be
 - **MA State House**
 - 3 Senators, 3 Representatives, 40 staff and interns
 - Co-sponsor of MA Telemedicine Bill (H.4332)
 - **Others: Regent Theater, Wellesley College, Brandeis University, Cooley-Dickinson Hospital (Northampton)**

Raising Awareness: Screenings of UNREST (cont.)

- **Co-sponsors publicize to constituents/members**
- **Recruit volunteers**
- **Make connections with local researchers and health care providers**
 - Will host 2nd annual researcher forum in November
- **Thanks to Rivka Solomon for helping organize screenings!**
- **6 screenings in MA not directly organized by us**
 - We provided speakers for 2 of these
- **Follow-on interview/video on local PBS station**
<http://connectingpoint.wgby.org/2018/05/chronic-fatigue-syndrome/>

Insurance Survey: Commercial Health Insurers

- **5 question survey in April, publicized within U.S. ME/CFS community**
- **Not Medicare/Medicaid, not disability insurance issues**
- **187 responses, not scientific, probably weighted towards negative experiences**
- **Access to care and cost of care are major issues**
- **62% report very negative or negative experiences**
- **28% say stigma about ME/CFS negatively affected care**
 - “I have been traumatized by the way doctors have treated me.”
 - “The only referral I could get was to a psychiatrist.”
 - “Insurance concluded that ME/CFS does not exist so I was denied coverage.”
- **27% have no or limited coverage for prescribed drugs**
 - “Insurance refuses to pay any drugs if it is coded for ME/CFS.”

Insurance Survey: Commercial Health Insurers (cont.)

- **20% have no access to ME/CFS providers**

“I have not found a provider who says ME/CFS is real and they will not treat it.”

“The specialist who covers ME/CFS is a psychiatrist who treats it as a psychosomatic illness.”

- **21% have no coverage for ME/CFS specialists**

“They refuse an outside referral, there is nothing that can be done for you.”

“The doctors who know anything about ME/CFS are out of network and my insurance pays zero for them.”

- **Only 31% say insurance is generally OK**

“I have pretty good coverage but the premiums are very high.”

Insurance Survey: Commercial Health Insurers (cont.)

- **Several respondents are so discouraged or traumatized that they no longer seek any medical care.**
- **Represents a catastrophic failure of the health care system**
- **Specific insurance companies had multiple negative responses**
- **More info at www.masscfids.org/news-events**

Name Change:

- **Massachusetts ME/CFS & FM Association starting July 1, 2018**