



Petition: Don't Hire Shoddy Contractor—ME Treatment Guidelines Need Community, Expert Input!

August 26, 2018

TO: Dr. Inger Damon, Director of the Division of High-Consequence Pathogens and Pathology, CDC

We are alarmed that the CDC intends to issue a sole-source contract with the Pacific Northwest Evidence-based Practice Center (EPC) to expedite the development of federal evidence-based treatment guidelines for myalgic encephalomyelitis/chronic fatigue syndrome (ME).

We demand that this contract not be issued and that the project be put on hold for the following reasons:

1. CDC has undertaken this project and the sole source contract without any discussion with or involvement of people with ME or the doctors who treat them.
2. The EPC previously conducted a systematic evidence review in 2014, but failed to account for the use of the Oxford definition and other overly broad diagnostic criteria used in many studies and which do not require a hallmark symptom of this disease—post-exertional malaise (PEM). This led to the erroneous conclusion that GET and CBT were effective treatments for people with ME.
3. The ME community made repeated attempts to engage the EPC in addressing multiple methodological concerns, but was ignored until 2016.
4. When the EPC finally reanalyzed its review in light of those criticisms two years later, it found there was insufficient evidence for the efficacy of GET and CBT. However, EPC refuses to publish this reanalysis in a peer-reviewed journal. This leaves the 2014 review publication intact, despite the EPC's subsequent revision of the recommendations.
5. Patients are seen by a small number of expert clinicians who have decades of experience with ME. Research in ME is performed by a small group of dedicated scientists. The involvement of both are essential to the development of logical, ethical treatment recommendations for people with ME. The uneven quality of the peer-reviewed literature in this underfunded disease means that expert scientists and clinicians' involvement is absolutely critical: they are best positioned to assess the available evidence and make recommendations. Yet CDC has not clarified how they will reach out to incorporate the knowledge and experience of those who know the disease best.



This project must be put on hold, and the CDC must collaborate with the ME community to ensure that they address the challenges that still exist, engage the community in a transparent and collaborative process to develop the project protocol, and incorporate expert knowledge in the evidence review and in any resultant treatment guidelines.

We urge you to pause this process immediately and meet with #MEAction at your earliest convenience to discuss these concerns.

WHY IS THIS IMPORTANT?

The CDC is repeating a terrible mistake. They are attempting to quietly hire The Pacific Northwest Evidence-based Practice Center (EPC), at Oregon Health and Science University, for a sole-source contract to help them develop new federal guidelines for ME treatment (<https://www.fbo.gov/spg/HHS/CDC/PGOA/25153/listing.html>). Unfortunately, this same contractor was hired four years ago to do a similar literature review of the evidence base for ME treatments by a CDC sister-agency, the Agency for Healthcare Research and Quality (AHRQ).

The previous EPC project turned out to be a years-long struggle for the ME community. Advocates pointed out the problems with the unsuitable literature used to produce EPC's work over and over, only to be repeatedly brushed off. When the EPC published its report in 2014, it included recommendations for GET and CBT and concluded that PACE was a good trial with little bias!

Only through the dogged work of many ME advocates and an #MEAction [petition](#) to CDC and AHRQ did EPC finally issue a reanalysis TWO YEARS LATER. However, they still refused to publish this 2016 addendum in a peer-reviewed journal, making their conclusions effectively invisible to developers of treatment guidelines for ME. This is not a contractor whose expertise or quality of work the CDC should trust.

We have very little time. The CDC is trying to rush through this sole-source contract of EPC with a minimum time for us to respond. We only have until August 31, 2018.

Sign this petition to demand that the CDC not issue this contract, put the project on hold, and meet with #MEAction immediately to assure us they will:

1. Create a TRANSPARENT and COLLABORATIVE approach to future guidelines for ME that engages advocates and community representatives; and
2. Include experienced ME researchers and expert practitioners in any process that leads to treatment recommendations for ME.