



# Town Hall

CDC Evidence Review of ME/CFS Diagnosis & Treatments

Wednesday, June 23, 2021

# Agenda

1. Intro (5 mins)
2. #MEAction Key Stances (15 mins)
  - a. *Community discussion (25 mins)*
3. #MEAction Action Steps (15 mins)
  - a. *Community Q&A (25 mins)*
4. Conclusion (5 mins)



# CDC Evidence Review

1. U.S. Centers for Disease Control and Prevention (CDC) published a notice of request for public comments on its **systematic review draft report for diagnosis and treatment of ME/CFS**. The report is open for public comment from May 16 - August 16, 2021 on regulations.gov.
  - a. <https://www.regulations.gov/document/CDC-2021-0053-0002>
2. #MEAction explainer article with timeline and takeaways on our advocacy:
  - a. <https://www.meaction.net/2021/06/04/cdc-releases-flawed-review-of-me-cfs-treatments-for-public-comment/>
3. Michiel Tack full public comment available at mecfs Skeptic.com:
  - a. <https://mecfskeptic.com/comments-on-the-cdc-evidence-review-on-me-cfs/>





## Our Key Stances

1. On the evidence review draft report
2. On the CDC's ME/CFS program
3. On our advocacy & activism

I.

**This evidence review is fatally flawed  
and we should oppose its publication**



# Draft Report Conclusion

*“Evidence on effective treatments for ME/CFS remains limited. Although **graded exercise** and **CBT** were **more effective** than inactive control therapies (usual care, usual specialist care, or an attention control) in improving fatigue, function, and other outcomes, the **magnitude of effects** was **small to moderate** and **methodological** and other **limitations** (imprecision, inconsistency, uncertain generalizability) **precluded strong conclusions**. **Other therapies** were **not shown to be effective** or require additional evidence to verify effectiveness. Non-ME/CFS conditions were common in patients presenting with fatigue.”*

**It is inappropriate for this report to recycle this flawed conclusion that GET and CBT are effective therapies for people with ME, even with the included caveats.**



# Problems with the Evidence Review

1. The review has significant methodological flaws
  - a. Treats all diagnostic criteria as equally applicable to pwME (e.g. Oxford)
  - b. Important physiological evidence ignored.
  - c. Ignores patient surveys showing harm of graded exercise therapy
  - d. The decisions about which studies to include/exclude in this review impacts the final results.
2. The reviewers applied their methodology in inaccurate & inconsistent ways
  - a. Some studies rated "medium risk of bias" are clearly "high risk of bias."

**The conclusions that reviewers drew based on their findings are wrong & not warranted, and they are also harmful to pwME who have PEM.**



## II.

**CDC's ME/CFS program is failing pwME,  
their "patient partnerships" efforts  
deserve no confidence**





# III.

**This is a fight worth having.  
We must show up to protect everyone.**



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le afew.*

“The past is never dead.  
It’s not even past.”

~ William Faulkner





# Community Discussion: Key Stances

(25 mins)



## ACTIONS TO TAKE

1. Share your solidarity with #MEAction (*now*)
2. Sign onto our official response (*early August*)
3. Join our Severe ME Day rally (*TBD, between Aug. 9-11*)

*Email [ben@meaction.net](mailto:ben@meaction.net) if you have a suggestion or offer of support for our technical response or creative activism ideas.*

# SHARE NOW

Publicly support #MEAction's criticism of CDC

*I attended @meactnet town hall about CDC's flawed report on #MEcfs now out for comment. Failed leadership and faux patient partnership means @CDCgov produced something that's bad for doctors AND patients. #pwME need real treatments now!*



# SIGN LATER

- #MEAction will publish our full response to the CDC evidence review by the **1st week of August**. Encourage everyone to read, sign and share it.
- We will submit our response with list of supporters by **August 16** deadline through [regulations.gov](https://www.regulations.gov).



# #MEAction response to CDC evidence review will

- **INSIDE:** Participate in the official [public comment process](#) through regulations.gov with specific, informed and impactful criticisms of the flaws in the draft report.
- **OUTSIDE:** Go beyond comment process to call out CDC on their faux patient engagement, and shame them for their neglect and failed leadership
  - *Read more about #MEAction's dual [inside/outside](#) strategic approach*
- **OPEN** to community before it is submitted to the CDC, so anyone can sign onto and support, without having to write an individual public comment (duplicative comments will be removed by CDC).
- **FOCUS** on the areas where the evidence report's flaws do the most harm to pwME, and target comments towards what will have most impact.



# GATHER TOGETHER

- Severe ME Awareness Day (Aug. 8) is to remember those who suffer from and have died from severe ME.
- #MEAction will host a virtual event the week of Severe ME Day to highlight our communal grief and outrage at the the harm and abuse our government allows our most vulnerable community members to continue to suffer.



*Would you like to help with this event or have a creative idea? Email [ben@meaction.net](mailto:ben@meaction.net)*







# Community Discussion: Actions

(25 mins)



Thank you!

Additional Background Slides

# #MEAAction resources on diagnostic criteria

1. [Demystifying The Diagnostic Criteria For ME And Related Disease](#)
2. [Diagnostic Criteria: Researchers And Clinicians Survey Results](#)
3. [Why U.S. ME/CFS Clinician Coalition Uses IOM Criteria to Educate Clinician](#)



# HOW WE GOT HERE: A TIMELINE

- **2014:** Problems with the first EPC evidence review
- **2015:** Advocates fight for a reanalysis
- **2016:** CBT & GET effectiveness claims downgraded
- **2018:** #MEAction opposes rehiring EPC for new review
- **2021:** New review reproduces old problems, CDC pauses plans for treatment guidelines

#MEAction article: [CDC releases flawed review](#)

## 5 Key Takeaways

1. EPC consistently reproduces flawed evidence reviews
2. CDC without excuse, ignores ME advocates warnings
3. Good news: CDC puts treatment guidelines on hold
4. Bad news: publishing flawed review would harm people with ME
5. NIH indicted by the lack of evidence to review

**#MEAction article: [CDC releases flawed review](#)**

## CDC: Developing ME/CFS treatment guidelines on hold

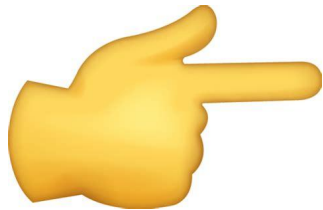
*“...the systematic review **provided little new data** and the process for **guideline development would not be likely to provide an advance** over what is currently available from the ME/CFS Clinician Coalition and IACFSME. We will be completing the Systematic Review and **will not be proceeding** with guideline development **until clinical trial data becomes available.**”*

CDC Chronic Viral Disease Branch Chief, Dr. Beth Unger

If we want to discuss...



We also need to talk about...





# NIH: Emperor has no clothes

- What the evidence review gets right:
  - **Lack of clinical treatment trials for repurposed drugs**
- Need clinical trials data to move HCP
- NIH asleep at the wheel; not accelerating ME/CFS
- Need resources, not just workshop discussions

*“I've been very concerned for several years, about the lack of understanding of ME/CFS... We do have a lot more research going on in that...”*

NIH Director, Dr. Francis Collins,  
Congress Subcommittee Hearing on Long COVID (April 28, 2021)

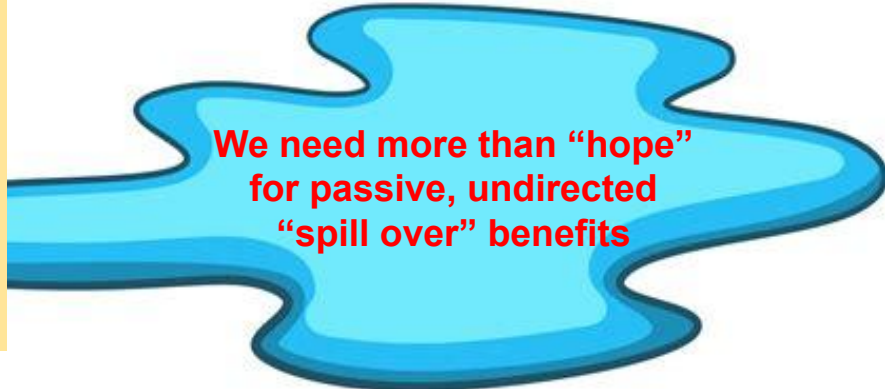


# This is why #MEAAction

- Has called out NIH's stated ME/CFS plan as [not enough](#) for pwME
- Criticized NIH [failed leadership](#) and expressed "lack of confidence" in IAWG
- Urged Congress to [hold NIH accountable](#) for their implementation

*“my hope would be that... studying the long COVID circumstance... We should learn something that will **spill over** and [be] a useful way into our understanding of CFS.”*

NIH Director, Dr. Francis Collins,  
Congress Subcommittee Hearing on Long COVID (4/28/21)



**We need more than “hope”  
for passive, undirected  
“spill over” benefits**