

Suggestions for ME/CFS Pathways to Prevention Executive Summary Marilyn Lemmon

Period needed at end of line 21

Period needed at end of line 23

Line 32: million people “in the United States”

Line 63: “extremely” limited research dollars

Line 66: hampers scientific progress “and places an unnecessary additional burden on patients”

Thank you thank you for lines 65-73!

Line 77: community is “extremely” frustrated. Patients ~~want~~ “are desperate for”

Line 95: ~~fatigue~~ post exertion malaise (note: Many patients experience PEM as BY FAR the most significant symptom. Many of us do not have fatigue if we pace ourselves within our (highly limited) limits, as defined by PEM.)

Line 105: ambulatory patients “and patients with limited monetary resources”

Lines 106-107: Post exertion malaise should be first in the list (see note for line 95).

Line 109: “to” should be “into”

Add between lines 112 and 113: “A huge increase in funding is necessary for this to be possible.”

Line 125: poor quality studies “(due primarily to the extreme paucity of funding)”

Line 135: Add something like “Many patients have had experience with prescribed exercise programs that have only made them worse.”

Line 136: guidance for including graded exercise therapy “or the prescription of inappropriate GET”

Line 137: may include some “very gentle”

Line 152: for subgroup analysis “(again due to the extreme paucity of funding)”

Line 166: Note: What symptoms?

Lines 183-184: lack of a standard case definition “and the extreme lack of funding”

Line 318: ~~finite~~ “extremely limited”

351: We “highly” recommend

Line 352: on the state “and funding” of ME/CFS treatment “in the near future”.

Line 387-388 in the “near” future

Somewhere it should say something like “The NIH has been woefully inattentive to the funding needs of this illness and needs to make up for this with a large increase in funding and attention in the very near future.”