COMMENTS ON: DRAFT EXECUTIVE SUMMARY

NATIONAL INSTITUTES OF HEALTH

Pathways to Prevention Workshop: Advancing the Research on Myalgic

Encephalomyelitis/ Chronic Fatigue Syndrome

The report provides a helpful background to the needs of ME/CFS patients.

I would like to comment on these lines:

50 (...) and 163 symptoms have been associated

51 with ME/CFS.

I believe this must be a misunderstanding of point made by Dr Nacul in the Workshop that there are 163

unique combinations of Fukuda symptoms of which only 35 require post-exertional malaise (also called post-
exertional crash or post-exertional amplification of symptoms).

Post-exertional malaise (PEM) is by the leading physicians and researchers considered to be the hallmark

symptom of ME/CFS. In the 1990s believed fatigue was believed to be the key symptom, as evident in the

Fukuda criteria, but as the clinical experience has increased and science has progressed it has become

clear that it is in fact PEM which is the cardinal feature of ME/CFS. Therefore the 2003 Canadian Consensus

Criteria (CCC) was created, including PEM as a required symptom and selecting a much more homogenous

patient group.

Hence, it is very problematic that Fukuda does not require PEM as a mandatory symptom. The point was that

128 combinations of Fukuda do not include the cardinal symptom of PEM. Is this definition, and others without

PEM as a mandatory symptom, then really identifying ME/CFS?

I ask you to change lines 50-51 to reflect that there are not 163 symptoms associated with ME/CFS, but that

the Fukuda criteria can mean 163 unique combinations of symptoms, 128 of which do not require PEM, which

by a large body of experts is considered the hallmark symptom of ME/CFS.