

Re:

**COMMENTS ON: DRAFT EXECUTIVE SUMMARY - NATIONAL
INSTITUTES OF HEALTH**

**Pathways to Prevention Workshop: Advancing the Research on
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome**

I write to you with the background of a sufferer for 25 years and the founder of the Springfield, Ohio, M.E./FM Support Group.

I concur with many other advocates that using Pathways to Prevention was inappropriate to review this complex and controversial disease.

My main symptom is post exertional malaise. This symptom is not simply being "tired". It is the feeling of being hit by a truck after running a marathon at high altitude with a hangover while coming down with the flu. The experience is unlike anything I experienced before sudden onset in August of 1989. I have found only those who have experienced this symptom can grasp the severity.

The CFS Advisory Committee submitted useful feedback on this report and I ask you to consider those comments to be my recommendations as well. Specifically, I ask that you use the recommendations referring to the inclusion of post exertional malaise as well as retiring the Oxford Definition and adopting the CCC.

Again, I do not believe the P2P process was appropriate for this endeavor.

Time and money could have been saved if HHS had adopted the CCC as the experts recommended many months ago.

Strong insistence that the government fund research into the cause and treatment of this disease should be a priority in an endeavor to help the M.E. community.

Thank you,

Colleen Steckel
Springfield, Ohio, M.E./FM Support Group