

Public Comment
CFSAC | December 2014
Anonymous

Stakeholders with disabilities (especially stakeholders with disabilities associated with ME/CFS) need adequate time to consider and comment upon meeting agendas/subject matter.

The announcement and scheduling of the December 2014 CFSAC meeting, for example, has denied stakeholders who experience:

- postexertional neuroimmune exhaustion (PENE) and
- neurosensory disturbances (NSDs) such as sensory overload
adequate time to consider and comment upon the meeting agenda/subject matter

Without adequate time to consider and comment upon the meeting agenda/subject matter:

- (a) stakeholders who experience PENE and NSDs are denied equality of opportunity;
 - (b) stakeholders who experience PENE and NSDs are excluded from full and effective participation and inclusion in society; and
 - (c) the inherent dignity of stakeholders who experience PENE and NSDs has failed to be respected, including their freedom to make their own choices
- (Language adopted from <http://www.un.org/disabilities/convention/conventionfull.shtml>)

To exclude the voices of individuals with disabilities (especially disabilities associated with ME/CFS) is discriminatory in and of itself, but this exclusion is further negatively compounded when one recalls that many of these same individuals--those with more severe forms of ME/CFS-- are known (individually and as a group) to have been excluded from ME/CFS research as well.

Add to the exclusionary practices above:

- the illegal censoring and manipulation of CFSAC recommendations by federal employees (See "Another CFSAC Violation" by Jennie Spotila and comments, www.occupycfs.com) and
- the illegal hoarding and censorship of public information by federal employees (See multiple blogs by Jeannette Burmeister and comments, www.thoughtsaboutme.com).

The federal employees responsible for discrimination and other illegal activities as identified above should be relieved of their employment with the federal government.

Additionally, until ME/CFS is recognized by the federal government to be a neuro-immune disease and until the marginalization of and discrimination against individuals with ME/CFS by the federal government ends, no patient registry should exist.

And finally, it is ridiculous and backward "that international calls cannot be accommodated."

Sincerely,
Anonymous