

Testimony

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Restoring ME/CFS Research, Education, and Patient Care to New Jersey

I wish to inform the CFSAC and other stakeholder in the ME/CFS Community that there is a brief window of opportunity to potentially restore ME/CFS research, education, and other, related, scholarly activities to one of this country's most populated states: New Jersey. The Governor of New Jersey, Chris Christie, has formed a UMDNJ Advisory Committee the purpose of which is to advise him as to the future of the University of Medicine and Dentistry of New Jersey (UMDNJ). The options range from keeping UMDNJ, the largest, free-standing, academic healthcare University in the United States, intact and as is, to completely dismantling the University and dividing its components and assets amongst other institutions within the state. The Committee is now willing to accept comments from the public.

The impetus for the establishment of the UMDNJ Advisory Committee may reside in the corroded image of UMDNJ, forever charred into this nation's psyche, by its purposeful, \$35 million dollar, double-billing of Medicare. However, of equal or perhaps greater concern to the ME/CFFS Community is the February, 2010 decision of the University to ban ME/CFS research, education and related scholarly activities from the University using the pretext that such activity is not "professional" but rather "personal." According to that policy, any and all scholarly activity related to ME/CFS can only be performed outside of regular, normal business hours. Moreover, the University's portal to the internet cannot be used for any ME/CFS-related research, nor can the

University's email client server be used to correspond with anyone about anything related to ME/CFS.

The University's policy to ban ME/CFS scholarly activity came after two, related New Jersey Medical School decisions:: (1) that the worldwide distributed and read *Consensus Manual for the Primary Care and Treatment of Chronic Fatigue Syndrome*, commented upon, and approved for publication by, the Senior Editor of Harvard University Medical Press, Dr. Anthony Kamoroff, was not a peer-reviewed publication, and (2) that five years of service by a faculty member on the CFSAC did not constitute professional, academic service at the national level.

UMDNJ controls all three of the state's medical schools, as well as the state's only dental school, school of nursing, school or health related professions, school of public health, and graduate school of biomedical sciences. The ban of scholarly activity in the University is, therefore, of significant impact to patients in New Jersey, as well as to the advancement of ME/CFS research, and healthcare provider education and training within the United States. Equally important, however, is the precedent that this establishes for other medical schools and schools training healthcare professionals throughout the United States.

UMDNJ's actions are clearly an attack on academic freedom – the right of college and university faculty to pursue their academic interest wherever they may lead – and should be opposed on that basis if for no other reason. It seems logical that if UMDNJ wishes to continue as a university, then it must afford its faculty the rights afforded to all University faculty, and comply with the principle of academic freedom. However, of greater concern to the ME/CFS community, is the stark contrast between UMDNJ's actions and the CDC's policy towards ME/CFS as articulated by its Director in 2006, Dr. Julie Gerberding,

who stated, “*We are committed to improving the awareness that this [ME/CFS] is a real illness and that people need real medical care and they deserve the best possible help that we can provide.*” Why does the Department of Health and Human Services’ continue to provide funding to UMDNJ when UMDNJ announced in 2010 that ME/CFS activity is personal and not professional? The Department of Health and Human Services continues to give money to a University which knowingly and deliberately violates one of its agency’s mandates. Why?

Governor Chris Christie’s UMDNJ Advisory Committee has already held hearings at which it has heard much comment from current University employees expressing the desire for UMDNJ to be retained in its current configuration. Current employees who may have a vested interest in retaining UMDNJ in its current corpus. The ME/CFS Community may wish to express a different point of view, and the CFSAC may wish to make a recommendation to the U.S. Secretary of Health based upon the facts conveyed here and, perhaps, after its own, further investigation. According to what was published by UMDNJ, “your thoughts about medical education in New Jersey and the future of our University,” may be submitted via email to: publiccomment@gov.state.nj.us.”

The window of opportunity for submitting comments is not specified. I would not wait long.

Thank you for your attention.