

P2P Michael Walzer

To whom it may concern:

> Draft 389:

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> Line 10 : "Unfortunately, ME/CFS is an area where the
> research and medical community has frustrated its

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> Line 11: constituents, by failing to assess and treat the
> disease and by allowing patients to be stigmatized."

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> This observation pretty much says it all. How such a
> severely debilitating illness can be ignored is beyond me as
> a patient and US Citizen? I have contributed significant tax
> dollars to fund public health programs throughout the
> decades of my professional career. I have gone from a
> significant member of family, society, higher education, and
> professionalism to a bed/housebound person with cognitive
> decline and severe exhaustion, due to underlying physiologic
> problems.

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> I am married to a medical doctor who has watched in
> amazement, how safe drugs like Ampligen, haven't been rushed
> to market, so patients and families don't have to be split
> or relocate to get access to this drug , in order to see if
> it will help ME patients quality of life.. My life as I knew
> it was stolen 9 years ago. I am observer of my children's
> life.

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> This disease without significant research dollars from our
> government (re-allocated from other diseases) for expedited
> research into treatments and cross collaboration with other
> similar like diseases and medications like MS, AIDS, and
> other inflammatory/anti-viral/immune deficient diseases will
> leave me/and all ME patients in a horrific condition. You
> can not understand unless you listen and act. Imagine one
> day you become so sick, then abruptly you lose your family, career,
> ability to participate in life. Its a reality!

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> Lack of medical education is needed. Most importantly, real
> drug treatments addressing the multitude of underlying
> physical dysfunctions that ME clinical and research experts

- > are aware of and hope to find is what gives me hope. Please
- > address the failing noted above, by making things right.
- > Provide significant research dollars and medications to help
- > a severely disabling disease with NO FDA treatment? Please
- > don't provide antidepressants and stimulating drugs that
- > don't address the underlying physiology. Please place your
- > focus on the route of the problem with a serious sense of
- > urgency and commitment to research dollar.
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- > Last, if line 10 and 11 aren't enough. It is time to change
- > the silly name of this disease. It is a symptom of many
- > illnesses, and certainly not a proper name for immune and
- > viral activation,etc with documented post exertional
- > malaise. Thank you for your time. God speed!
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