

Public Comment
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2014 will have been an atrocious year for patients with ME from around the world. We have a patient in Denmark taken against her will at her parent's home and forced into cognitive behavioral therapy and exercise therapy, and her parents have been forbidden to visit. Karina Hansen has been ripped of her human rights for over 18 months now.

Meanwhile in the US, patient advocate Jeannette Burmeister has been deprived of timely and complete FOIA documents, and went to federal court for this. HHS has been deemed neglectful in this case and forced into paying attorney fees of nearly 140,000\$. We are learning about NIH and HHS people wanting to cover up, refusing to answer questions, and generally having a lot of contempt for the ME patient population. Reading Jeannette's blogs will enlighten you on this regard. <http://thoughtsaboutme.com>

The second resource which I respect is the work of Jennifer Spotila who analyzes the outcomes of CFSAC, and abysmal funding from NIH. We have learnt that top notch scientists like Ian Lipkin (Columbia University) has been refused for a microbiome grant from the NIH and prize winning geneticist Ron Davis from Stanford University could not get a ME/CfS grant either. We know that in at least one occasion the grant reviewer said there was no reason to research us since this was a psych illness. <http://www.occupycfs.com>

The P2P is not only complete waste of resource, but is going to harm us patients in the most cruel way. via the P2P, the main articles for review by the non-experts pertain mostly to psychological issues. Most of the research pertaining to the biology and some clinical trials have been left behind, as if they didn't exist. Leave alone the fact that PACe trial was seriously flawed and yet it was included. Leave alone that none of the committee members have actually seen or cared for a patient with ME. And let's not even approach our well seasoned experts, who have lived through the outbreaks and have more knowledge about ME than everybody at NIH and HHS, most of whom push pencils and are so focused on bureaucratic business that they have no clue that behind these labels, behind the contempt and disdain, there is a population of very sick patients who have no access to health care, and we are truly abandoned by our governments who want once more to bury us and save the government some precious money.

The nature of our illness, with its patients being so sick and unable to fight and request appropriate levels of fundings have made it possible for the disease to go under the radars for as long as 30 years. it's a sad state of affairs when after 30 years of struggles, you find out your government spends more on male pattern baldness than a life altering disease.

I hope that the members of the CFSAC will recognize the harms that is about to be done with the P2P, and I hope that their recommendation to HHS will be to fund our researchers, 10 million for each team who does biomedical research.

It is time for CFSAC members recommend to HHS that a congressional hearing be convened to understand exactly why HHS and NIH refused to send the FOIA info requested and to ensure that efficiency and funding parity with similar diseases, like MS gets funded at an equal rate. Members of CFSAC, be bold and firm in your requests. We need allies and we need health care and sound research. Please advocate for our ME experts. They have not been consulted on neither IOM or P2P (which I call pathways to corruption)

The level of neglect from HHS and NIH is extraordinary, and it is very clear that our disease suffers stigma and discrimination and contempt at the government level and at scientific levels. This has got to change.