

**Public Comment**  
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First, credit where credit is due. Thanks to the Social Security Administration (SSA) for its recent revision of ME/CFS disability guidelines. Thanks to the Food and Drug Administration (FDA) for its efforts to ease the approval path for prospective ME/CFS treatments.

So much for the good news; now for the bad. The contradiction in the Pathways to Prevention (P2P) program is so perverted, that only Donald Rumsfeld could appreciate it.

Let me explain. Back in September 2012, a group of patients met with a National Institutes of Health (NIH) official named Dr. Michael Gottesman. Patients asked him why ME/CFS had been largely ignored for over two decades. Dr. Gottesman replied this was due to a lack of concrete scientific, clinical, medical findings and published papers. In other words, no evidence, no support. The thousands of published journal articles apparently didn't interest him.

Flash forward to today. Recently, the Agency for Healthcare Research and Quality (AHRQ) revealed the evidence review plan for the NIH's P2P process for ME/CFS.

But any evidence review begs the question: What evidence is the P2P process reviewing? Is it reviewing the evidence that Dr. Gottesman implied doesn't exist? In that case Dr. Gottesman seems to have spoken in error. Or, is Dr. Gottesman correct, and there really is no evidence to review? In that case, what on Earth is P2P doing?

If I could ask Donald Rumsfeld, maybe he'd say the purpose of P2P is to find an absence of evidence, a rationale to continue ignoring us. Since we mere patients are almost completely locked out of P2P, who's to say? We can say what we do see: evidence of absence.

There is an absence of any serious attempt to frame ME/CFS as the systemic biological illness that we experience it to be. There is an absence of any effort to re-imagine a so-called empirical approach in government research, an approach that has demonstrably failed even to measure the illness reliably, let alone do anything to treat it. In P2P, there is an absence of any serious attempt to engage patients in a desperately needed rethinking of the research approach to this illness.

I urge that P2P either be opened up, or ended.