

**Public Comment**  
**Matthew Lopez-Majano**

It often feels as though we (patient community) speak a different language than Health and Human Services (HHS) agencies and that this results in ongoing communication problems between us. This is complicated by the ongoing lack of openness and transparency by HHS.

At the FDA meeting on April 25th 2013, (<http://www.fda.gov/Drugs/NewsEvents/ucm369563.htm>), time was spent querying participants and restating things to make sure listeners understood the intent of the speakers. As a result, in its Voice of the Patient report (<http://www.fda.gov/downloads/ForIndustry/UserFees/PrescriptionDrugUserFee/UCM368806.pdf>), FDA was able to characterize the patient experience in a way that no other government agency has done before.

After that meeting, at least one noted clinician/researcher restructured the questions posed to patients and is looking for additional ways to ensure more accurate understanding of patient experiences, symptoms, etc.

It seems that Dr. Unger has begun to understand how threatened patients feel by the term "malaise". To laypeople the connotation is "feeling out of sorts". This means that the phrase "post-exertional malaise" gives very little indication of the intensity, severity and extent of the serious problems that post-exertional malaise produces. How did Dr. Unger begin to understand how seriously and negatively the term "malaise" impacts us? It started during a conversation between advocates and Dr. Unger. During that conversation, there were opportunities to clarify points and answer questions.

During public comment we have the opportunity to provide input but there is no way to know if you have understood what we say. And during CFSAC meetings, we have no way of asking clarifying questions to ensure that we understood what you have said. Simply put, as currently structured, there is no opportunity on our part or yours for clarification to ensure that we understand each other. And given that some agencies do not respond to questions submitted by advocates between meetings, or instead respond by reiterating things we are already well aware of, we have no opportunities outside of CFSAC to get answers.

We endure this illness, minute by minute, week by week, decade by decade and as a result, we have a wealth of knowledge and experience.

If you are truly interested in this illness and in helping us, surely there are questions you have, that we can help provide answers to. But we currently have no way of doing so.

We must find ways to ensure substantive discussion and accurate understanding on everyone's part.

**“Goal 4: Increase Efficiency, Transparency, and Accountability of HHS Programs**

HHS's Open Government efforts will break new ground in enabling the public to give feedback to HHS programs. **HHS can help stakeholders contribute knowledge and experience to help it do jobs better**, and HHS can support new kinds of collaborative teamwork that will deliver better results for our citizens. HHS will move forward toward new strategies, new tools, and a **new culture of public participation and collaboration in its affairs**. • <http://www.hhs.gov/strategic-plan/goal4.html> (emphasis added)

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