

Public Comment
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Thank you for the opportunity to address CFSAC.

The “crime” we are faced with is that

HHS has ignored us,

HHS has ignored CFSAC,

HHS has refused to develop a strategic plan for ME(cfs),

HHS has refused to openly and honestly engage with us and

HHS has secretly developed and made arrangements for the IOM study.

The common thread here is **HHS**.

Here are my concerns:

1. I don't agree with your FAQ on IOM Contract – it won't work for me because I know better. I worked in the Pharmaceutical Marketing World for years and in many capacities including case definitions and guidelines. So I just laugh at your statement to support IOM
2. You got a consensus from our ME Experts on the case definition and it falls on deaf ears. They DO NOT have to be in medical organization to make it valid! You tend to forget we are not like most diseases. ME doctors don't have time to get a medical organization developed. They are too busy fighting for our rights (which you ignore), treat us, help us get disability, clinical trials, etc.
3. Don't tell me rules need to be followed. Because you only follow rules when you want. How dare you not approve Ampligen when you provide 1 university an unapproved vaccine in the US. CDC you have no compassion for ME patients. To the FDA which has done a great job in letting patients be involved. Due to the approval to use the unapproved vaccine, I hope we can come to the table again and reach a decision for Ampligen – not for the masses at this time but for people who need a chance at life. How many more people do you want to commit suicide? Yes, It happens if you believe it or not!
4. I applaud support for World Aids. However, we need to start focusing on the US. If you can find 100 million for them year after year – you sure can get funding for us. And think your rationale for limited funding is a disgrace.

5. Finally, you can't name a disease ME/CFS. It is not scientifically accurate. They are two separate diseases. ME is what I have. You need to really figure out what CFS is because under Fukuda it can be anything. You will never find a treatment under this vague, outdated case definition that the Doctor who helped write it can back to CFSAC and told you so! You can make this happen – you need insurance representatives, Medicare, Medicaid, to confirm there is a disease called ME and make sure it is covered by insurance, disability and research for CFS is also referenced to ME. That is why some doctors are afraid to change the name. YOU know darn well it can be done but won't educate the doctors.

We can't run the government based on the past. We need to get up with the time. I am tired of other diseases getting a break and after 25 plus years we are still the most neglected disease. Thanks to the CDC. Tired of listen to the same old story from NIH – stop giving us your same old statement. It can be done – you are the obstacle and you have been for years!

Our government is failing us not just for our disease but also in many facets. It is time to make a difference. And if you can't and your hands our tie. Just tell us the truth vs the BS we get via legal and PR jargon.

Don't you know that we are sick but one of the brightest group of patients with backgrounds in government, doctors, lawyers, pharmaceutical marketers, teachers, etc. WE know better. WE are sick not dumb

What is the problem with Secretary Sebillus? Why won't she address us at this meeting?

If CFSAC recommendations don't start to be approved in the manner that was submitted, this committee has no strength and is weak. CDC need to get there head out of the sand and stop hurting us. You our not experts on our disease! You have no clue. I guess you may have another congressional hearing coming down the pike. You know you are in some trouble with Autism, Lyme, etc. So get your act together.

You don't have this disease (well most of you on CFSAC). So you have no idea what our lives entail. Sorry we don't look sick but believe me we are – I will gladly give you my disease and see how long you last. You don't even get to see the severe patients. That what bothers me the most. They can't even get out of bed.

More Money to RESEARCH

Define ME vs CFS. Make sure ME experts on CFSAC not non experts (they may be great doctors but have no clue on how to treat us so how do you think they will be able to provide the best recommendation for us to have a chance a life)

Until people swallow their pride and make a difference. You are wasting my time.

I want to thank all the experts that support us and have to deal with the disrespect from our gov't (not all, we do have some people helping but don't want to say names because you may send them away).

I lost hope but not the fight! I am not a follower like many in the government. I am not afraid to fight for what is right. The writing is on the wall. Until you start listening to our ME experts. I lost hope in all of you.

Make ME a disease and work with insurances and disability Medicare, Medicaid, etc. to get this done and as fast as possible.

Regards,
Matina