

## **Sampling/summary of responses to survey “What is your response to the IOM report?”**

**Conducted by Massachusetts CFIDS/ME & FM Association between Feb 32 and March 20, 2015**

### **Introduction**

We conducted this survey, which was open to the community, to provide input about the Institute of Medicine Report on ME/CFS from patients and others to the IOM Working Group of the Chronic Fatigue Syndrome Advisory Committee. The Working Group is preparing draft recommendations regarding the IOM report for review and action at the next CFSAC meeting, which is not yet scheduled at this time. Any recommendations CFSAC develops and approves will be passed to the Assistant Secretary of Health as recommendations for future action.

The Office of the Assistant Secretary of Health (OASH) has stated: “We are committed to working with our Federal partners, stakeholders, and experts in the field, as well as with the HHS Chronic Fatigue Syndrome Advisory Committee, to review the report’s recommendations and appropriate next steps.”

It is important to note that specific decisions about how/whether to respond to the IOM report (accept, reject, promote, follow the recommendations outlined in the report itself, etc.) are at the discretion of the several departments of HHS who commissioned the study. CFSAC can only recommend. Of course, individuals and organized ME/CFS groups are free to use the report in any way they wish.

***About the survey.** There were 86 responses to the survey. 65% were from the U.S.; the remainder were from U.K, Canada, Ireland, Italy, Norway, Sweden, Australia, and New Zealand. The list below represents a sampling of the responses to each question; the full set of responses has been provided to CFSAC’s IOM Working Group.*

### **1. What are the positive things in the report that we can use to move forward?**

- Need for more research was clearly stated
- Recognition of ME/CFS as serious, systemic disease. Not psychogenic. “Real.” Disabling.
- A lot of publicity following the publication of the report
- New diagnostic criteria are fairly close to the CCC; requires PEM
- Recommends getting rid of name “Chronic Fatigue Syndrome”; new name represents a clean break with the past
- Clear diagnostic criteria that recognize the major symptoms
- Very comprehensive review of literature/research to date; extensive references
- IOM has prestige and what it says will be respected; independent, authoritative; legitimizes the disease
- Clear follow up steps: Recognizes need to education physicians, calls for more research funding, recommends “czar”
- Positive diagnosis, not “diagnosis of exclusion”

## **2. What questions do you have?**

- What will happen to patients who don't meet the new criteria (e.g. don't experience PEM)? Will they still have "CFS"?
- Will this affect my disability?
- Will mixing in SEID-diagnosed patients with others mess up research?
- Will all the other symptoms patients have (neurological, neuroendocrine, immune, pain/sore throat; waxing/waning) also be recognized by doctors if they are not included in the new criteria?
- Will the new criteria replace all other ME/CFS case definitions/criteria?
- What happens next? Who is responsible for implementing the report?
- How will we know what HHS is doing as a result of the report? Who will determine the content of the CDC "Toolkit"?
- Why weren't severe ME patients considered?
- Why wasn't the CCC adopted as the 50 experts recommended? How will the new SEID criteria be reconciled with the international community?
- How can SEID be used as a diagnosis if there is no code?
- Why weren't patients consulted, especially about the new name?
- Where's the research funding?

## **3. What goals would you like to see accomplished with regard to this disease in the next 3 - 5 years?**

### **Are these goals supported by the report?**

- ME/CFS represented in the Precision Medicine initiative
- A ME/CFS "czar"
- Educating doctors/other health care providers and the public/families that the disease is "real" ("I never want to be insulted by a doctor again!"). Rejection of psychiatric origin theory.
- More (much more!) funding for research – treatments and a cure
- A "home" in an NIH Institute that has money!
- A diagnostic test or biomarker
- Teach about ME/CFS in medical schools; adoption by a medical specialty
- Full endorsement of the IOM report
- "Patient's Guide" to go along with doctor's Clinical Guide
- More specialist centers where patients can get treatment
- Better treatment and management recommendations
- Get rid of the name "Chronic Fatigue Syndrome" and all studies that included patients who don't have Post-Exertional Malaise
- Accept the name SEID – reject the name CFS
- Research that defines sub-groups then studies them
- Educate doctors about simple management strategies that help – pacing, avoid over-exertion

- CBT as supportive therapy as for any chronic illness (not a cure for ME/CFS “false illness beliefs”); GET for mild cases only and implemented very cautiously with appropriate warnings attached
- Awareness and treatments for other conditions in addition to ME/CFS; it’s possible to have ME/CFS AND depression
- Study severely ill patients as well as ambulatory ones
- Development of new drug treatments; FDA approval of treatments and drugs (Ampligen) that have been shown to work
- Accurate information on websites
- More patients correctly diagnosed and treated (who can then make themselves available for research)

#### **4: What parts of the report are problematic for you?**

- The diagnostic criteria omitted many, many symptoms which are common, especially in the more severely ill patients: neurological, neuroendocrine, immune, pain.
- “Criteria should list the other symptoms that patients frequently experience and which support the diagnosis”
- Neurological symptoms were not included; without this we risk getting stuck in a psychiatric category again
- Psychiatric illness is not an exclusion; will no exclusions cause doctors to miss other illnesses which are also present and could be treated?
- Not enough focus on severely ill patients
- No clear guidance on whether SEID = ME = CFS; if not, what happens to ME and CFS?
- New diagnostic criteria have not been validated
- Will these new criteria be used in research studies; if so, will the results just add to the confusion we have now because of heterogeneous groups?
- The new name SEID is just as demeaning as CFS; doctors won’t take it seriously; SEID is not inclusive of all the symptoms so does not truly describe the disease
- Should have been more input from patients before deciding on the new name
- SEID is OK as a temporary name; clean break from CFS. Translate “SEID” into medical terminology.
- Why change to a temporary name when we may have the “real” name in a few years
- New criteria are too general, too broad, and can capture patients who don’t have the disease (e.g. depressed patients) especially if the doctor interprets “exertion intolerance” as “fear/avoidance of exercise”. SEID could become another wastebasket diagnosis.
- No treatments are covered; should not educate doctors how to diagnose if you don’t tell them also how to manage/treat.
- International impact was apparently not considered; how to get other countries to cooperate
- People are spending way too much time niggling (especially about the name) when they should take this and move forward
- Not enough funding for research – that is what we really need

- “What is problematic is patients who are still saying the IOM report is wrong and not representing them. The division in our community is very problematic and hinders efforts for recognition.”

**5: Do you have other comments about the Report you would like to share?**

- IOM sponsors should report back to CFSAC (and the patient community) what they are doing as a result of the report
- The medical education materials need to be good; will doctors (and insurance companies) accept them?
- IOM and P2P report need to be on the same page; P2P had way too much “multi-modal”/ CBT/GET as treatments for the severe systemic disease described in the IOM report
- Use the report as a lever to get more research funding; keep CCC and ME-ICC as diagnostic criteria and keep the name ME/CFS for now; the report has a lot of good scientific review which should be widely disseminated.
- The only reason for excluding neurological symptoms was to close the door on naming the disease ME.
- So grateful CFS/ME is now recognized as a real disease and has a real name.
- “Most important to me is the validation that this is a real, serious [disease] and in need of study. I think that’s more important than the various objections/concerns I’ve seen so far.”  
“IOM has given us a useful tool here to move forward with. The ME groups and advocates need to focus on this and our positive aims.”
- “Any hold ups now will cost the community especially those without a diagnosis who need to know how best to manage this disease. Suggestions that the criteria should be tested before implementation are not necessary...don’t waste time now; test criteria later and revise if necessary. Don’t waste this opportunity.”
- “The two most important things today should be the continued research and widespread education in medical circles internationally. We shouldn’t be wasting money and time getting bogged down in a renaming exercise.”
- “It’s too bad the name issue has gotten most of the attention but overall I think [the report] is excellent.” “Thank the committee for its hard work.” “Please do not be discouraged by the many complaints...we have been sick so long that it is hard to trust....” “Thank you thank you IOM committee members for your intelligence and empathy”
- “The report focuses too heavily on...PEM....I was sick for 20 years before I developed PEM”
- Need a better clinical guide.
- Stop the fighting and focus all our energies on getting more money for research.
- ME/SEID patients and organizations need to form a national alliance and all work together.
- “We should thank the IOM Committee for doing such a thorough job, and for their bravery in reporting what the evidence showed and what they believed to be in the best interest of advancing both science and patient care, even though they must have known some patients would object to some of the recommendations.”