Public Comment – Anonymous – dated June 12, 2014
CFSAC Committee Meeting – June 16 and 17, 2014

Dear Members of the CFSAC and Attendees:

Thank you for this opportunity to provide written comments as to the **grave concerns** that we persons with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) continue to face **decade after decade.**

In keeping with the guidelines, I state my wish that my comments herein remain '*anonymous.*' Thank you for that respect.

Let me first sincerely thank the many dedicated doctors, researchers and others who continue to strive to help the ME/CFS patient community despite the ongoing roadblocks put in place to the contrary.

And now to . . .

The PROBLEM

ME/CFS—**by the actions and inactions of HHS, NIH and CDC in the U.S. government—**has been trivialized and fraught with obfuscation and denial as to its existence—indeed, as a **serious biological disease**. **HHS, NIH and CDC in the U.S. contract services from the field of psychiatry in the U.K. to achieve the goal of burying ME/CFS as a psychological disease** – with the likes of Wessely, Sharpe and White.

> To current date—for over 30 years HHS, NIH and CDC have been intent on the obfuscation of ME/CFS and declaring that ME/CFS be 'labelled' / 'hidden away' as a psychological disease when, in fact, **ME/CFS is a debilitating biological disease requiring effective biological treatments.**
>
> > These irresponsible, harmful and negligent actions, inactions and behaviour patterns have left us—now millions of people world-wide with ME/CFS—with no effective treatments, to ROT in the serious life-stealing debilitating illness of ME/CFS. This equates to an **ongoing serious Crime Against Humanity**.

Meager budgeted funding allotted to ME/CFS has been largely directed at psychological research and psychological treatments (funding has also been fraudulently misappropriated to other departments from the ME/CFS budget).

This **MIS**represented erroneous psychological direction for a biological disease has directly resulted in the spread nationally and internationally of ME/CFS—affecting an estimated 1 million + US citizens and 17 million + global citizens; and **ME/CFS continues to spread because of HHS, NIH, CDC's gross negligence.**

With **NO biological treatments in over 30 years for ME/CFS**, recommended treatments of CBT (Cognitive Behaviour Therapy), GET (Graded Exercise Therapy) and anti-depressants—geared to psychological disease—are thrown at ME/CFS patients and are ineffective at best and potentially harmful to ME/CFS patients in worsening the disease—**this being a biological disease in need of biological research and biological treatments . . . as ME/CFS continues to spread devastating and destroying real people's lives of all ages.**

The table below, with a selection of specific words and phrases, aims to describe actions and the harm caused to and against persons with ME/CFS over decades.

Gross negligence to public health	A modern day crime against humanity	Abusers of Power	Lies, Deceit, Cover-ups and **UN**truths
Sociopathic behaviours	Injustice towards ME/CFS patients	Prejudicial Treatment/Ongoing Neglect	Arrogance in Authority
Bullying of Seriously Ill People	Complete **DIS**regard for Public Health	Purposeful Negligence and Irresponsibility	Corruption—'Above the Law'
Reprehensible	**UN**conscionable	Irrational	Criminal
Flawed	Fraudulent	Harmful—**Decades of Neglect**	Human Cruelty
Destruction Devastation	**DIS**ability Equals **Poverty**	**Lives stolen**; patients housebound and/or bedbound with ME/CFS	**Lives lost; Deaths** directly resulting from ME/CFS
Careers **gone**	**Suicides** because of **no meaningful treatment** for ME/CFS	Family and social life—**gone**	Life experiences and the ability for physical activity—**gone**
Killing us 'Secretly'	Stealth Viruses, Latent Viruses, Retroviruses	**ME/CFS linked to Lymphomas**—same viruses implicated	**DIS**trust
UNfathomable	**IN**excusable	Disgusting	Killing us and generations to come
Foolish	Moronic	**NON**sensical	Supreme Stupidity
Absurd	Outrageous	Scandalous	Conspiracy

***Liken to Erin Brokowich*	***Liken to Water Gate*	Completely Lacking in Integrity	Lacking in Social Conscience and Moral Justice
Real People—Real Lives—Destroyed by Political Games and Egos	Garbage Psychological Treatments for a Biological Disease	ME/CFS Patients Relegated to the Waste Bin by HHS, NIH, CDC	Gross Incompetency—Decades of **MIS**treatment

****This is the stuff that real life movies are made of, i.e. **Erin Brokowich** and **Water Gate**—based on the facts—and corruption and cover-ups in government. And this continues . . . Specifically with the games and politics being played with ME/CFS; the result of which is **destruction of human lives on a massive scale**.

A grave situation, indeed, for persons stricken with ME/CFS.

So, who is next—next to be targeted with ME/CFS?
HHS, NIH and CDC continue to deny the global health crisis of ME/CFS;
And leave ME/CFS patients to ROT—HHS, NIH and CDC are
Directly Responsible for the Global Health Crisis of the Spreading Pandemic of ME/CFS.

In Comes the HHS *‘Rammed In’* IOM Contract and P2P *‘Jury Model’*—Devoid of ME/CFS Experts Because that would be BIAS – WHAT a Spin on Reality!!!
This IS Insanity

To this end, despite biological research exploding worldwide striving to get to the answers to ME/CFS—the HHS continues to put up roadblocks and rammed in the IOM contract in the fall of 2013 to define/redefine ME/CFS—for their purposes—their ‘political’ agenda; NOT for the good and the health of ME/CFS patients. HHS’ purposes/political agenda/objective/predetermined outcome—to continue to keep ME/CFS buried as a psychological disease and simply about broad-based ‘fatigue’ versus the **serious complex biological disease that ME/CFS is—spreading, stealing our lives away / killing us.**

> It is a well-known fact that ME/CFS is NOT a psychological/psychiatric illness; the FACT is that **ME/CFS is a serious biological illness—indeed a complex debilitating disabling disease.**

Covering up the truth about ME/CFS and disregarding ME/CFS as a serious biological disease—causes harm and kills ME/CFS patients, all the while as the disease spreads. Such utter foolish **disregard for public health; this has directly caused and created a global health crisis.**

The HHS IOM contract to redefine ME/CFS = **the continued harm of ME/CFS patients and allows the continued spread of ME/CFS!!**

A jury model for P2P—Pathways to Prevention. ***Really?!*** Patients on trial with the illness of ME/CFS to be judged by a jury . . . How **absurd.**

The Fix – Your Responsibility to Make this Right – What the ME/CFS Community Needs to Right the ONgoing Harmful Wrongs Against Us

Fifty International ME/CFS Experts and Researchers, in an unprecedented act, explicitly advised the U.S. government—HHS, Secretary Sebelius, AGAINST the IOM contract to set a 'redefinition' of ME/CFS; the ME/CFS Experts were completely disregarded by HHS.

- **STOP the IOM contract as per the ME/CFS Experts**.

The ME/CFS Experts also spoke of further harm to ME/CFS patients with and IOM definition.

- **STOP the IOM contract; STOP further harm to ME/CFS patients as per the ME/CFS Experts.**
- **STOP the P2P (with no ME/CFS Experts)—an extended arm of the HHS—IOM contract—STOP the harm to ME/CFS patients.**

The ME/CFS Experts and Researchers further called for the adoption of the CCC—Canadian Consensus Criteria—which already defines the complex chronic disease of ME/CFS; and let's move forward from there.

- **ADOPT the CCC—Canadian Consensus Criteria—as per the ME/CFS Experts.**

Psychiatrists' influence of ME/CFS from the UK—services contracted by the US government, i.e. HHS, NIH, CDC for the psychiatric labelling of ME/CFS.

- **STOP this psychiatric affiliation; it is wrong, deceitful and destructive and results in extreme harm to the health of ME/CFS patients—blocking meaningful research and effective biological treatments. This is criminal!**

Dr. Ian Lipkin has recently been forced to take fund raising to the streets to raise $1.27 million for a biological research project for ME/CFS—a world-renowned scientist DENIED even this meager funding because it is for **ME/CFS 'biological' research**. This **refusal follows the pattern**—do HHS, NIH, CDC not want Dr. Lipkin getting to the biological answers of ME/CFS? Over the years and decades, this has been an ongoing pattern with HHS, NIH and CDC to deny adequate funding to researchers for getting to the **biological answers to ME/CFS**. Oh, yes, **meager funding gets approved largely for psychological studies—which is basically what the IOM contract and P2P jury are all about.**

- **Give the funding of $1.27 million to Dr. Ian Lipkin.**
- **AND give much MORE, i.e. adequate funding to Dr. Ian Lipkin and other researchers and scientists currently working to break the code to the biological mysteries and ravages of ME/CFS.**

CONCLUSION

Thirty years of CBT, GET and anti-depressants thrown at ME/CFS patients—How's that worked so far for ME/CFS patients/people to regain our health and our lives? It hasn't! This is garbage treatment for ME/CFS patients who have been relegated to the waste bin for 30 + years with a serious biological disease. **STOP** this inextricable harm of locking us into an 'un-life,' sentenced to a lifetime of ME/CFS—our lives stolen away in all aspects with serious complex disease with NO meaningful treatment.

The HHS, NIH and CDC **are directly responsible** for creating and perpetuating obfuscation and **MIS**representation of the serious biological disease of ME/CFS and **causing HARM to the patient population of ME/CFS sufferers worldwide**—**and all the while ME/CFS continues to spread because HHS, NIH and CDC have allowed this to happen**. This is **criminal.**

STOP this **crime against humanity** with the obfuscation of ME/CFS—painting ME/CFS to be a psychological disease ***and*** lumping it into broad-based 'fatigue'—when in fact—ME/CFS is a debilitating biological disease—a complex disease. **STOP** this injustice NOW.

Support the ME/CFS patient community and the devoted and dedicated doctors and researchers striving tirelessly to help us get to the answers for meaningful helpful treatments to the millions of us worldwide.

Give AMPLE funding for ME/CFS biological research—we need to **save lives from the destruction and devastation and the further spread of this disease.**

ME/CFS is a serious disease and it is linked to cancer, specifically lymphomas—there is a link—this is deadly serious. One adult member in a household has **ME/CFS**; a number of years later the other adult in the same household is diagnosed with **Non-Hodgkin's lymphoma**—however, onset of NHL predates diagnosis to the same time frame as the other adult in the same household with onset of ME/CFS. **Same household; same time-frame—same agents linked to both serious diseases—ME/CFS and Non-Hodgkin's lymphoma--cancer**. There is treatment for cancer—NHL—NO treatment for ME/CFS. This is abhorable—gross negligence—and the disease of ME/CFS continues to spread. This is just the tip of the iceberg!!!!

Thank you. This is a **pivotal time for ME/CFS research**. We need your help; we need **proper funding for biological research**. **It is your duty, your responsibility to make this grievous wrong—right!!**

We want **return to good health and the ability to be active in our lives**, and to be able to once again be **active contributing members of society;** we want out of **poverty that disability with ME/CFS brings**. **This is what we want; this is our due; this is our right—our human rights.**