

Public Comment Anonymous

Dear Members of the CFSAC and Attendees:

Introduction

Thank you very much for this most important opportunity to add written comments to the CFSAC webinar for December 10 - 11 , 2013. **In keeping with the guidelines, I state my wish that my comments herein remain ‘anonymous’.** Thank you for that respect.

About Me Personally

Disease – Medical Fixes / Cures

For **information purposes**, some years prior to being stricken with ME/CFS I have had other serious diseases—an intestinal parasite and Primary Hyperparathyroid disease. Point being, in both cases of disease there was a medical fix—I was so grateful to get my ‘life back’ – returning to being fully active, healthy and busy in my life both personally and professionally; working full time—and being an active productive member of society.

This experience with serious illness has enabled me to know full well when there is a serious medical problem attacking my body—and my wonderful doctors are there to help me.

There is a stark contrast between a return to good health and, hence, the ability to actively live life fully-functionally in all aspects – and then there is substantial **DIS**ability in all aspects of life with ME/CFS—and THAT is what I am talkin’ about.

Healthy and FULL OF LIFE . . . And Then Along Came ME/CFS

There I *was*--an active, energetic, athletic person—worked full time—managed the domestic household chores on a day-to-day regular basis—busy active social life with family and friends—free to choose to and able to go on vacation—free to choose to and able to dash out of the house on a whim, at a moment’s notice—on any given day/every day—for ‘anything and everything,’ be it for physical exercise/activity, errands, grocery shopping, socializing, appointments, etc.—**then boom**—ME/CFS hit—and ALL of the above was taken away—erased—stolen away by the serious illness of ME/CFS.

Good health and an active busy professional, personal, domestic, family and social life as I knew and ‘lived’—that life is **NO** more. The collective we can tend to take our robust healthy active fully-functional lives for granted—as that is our ‘norm’ /‘the norm’—we expect to live our lives that way!

I am more than grateful to my good and caring doctors—both family doctor and specialists, and to the dedicated scientists and researchers at home and world-wide striving hard to get to the answers at the core of ME/CFS; using current up-to-date science getting to the roots of ME/CFS as a biological profoundly debilitating disease.

CFIDS On-Line Survey

As you know, CFIDS has put out several on-line surveys to the ME/CFS community. Some months back I was answering the survey questions—when one particular question, with pre-stated answers that we check in boxes, really got me questioning the survey itself.

Specifically that question was---What keeps you in this disease (i.e. from getting well)?

- My forthright answer—in the comment section was/is—**The FACT that there has been NO scientific medical fix!**

Time Passes Stealing Precious Life Times and Moments Away

Seven years have now passed with being ‘held hostage’ with this debilitating disease of ME/CFS; it is now towards the end of 2013—and that description of a completely altered ‘life with ME/CFS’ remains the same; there is **NO** improvement.

For the most part I am housebound—seven years now—pushing to get *out of the house once a week on an outing—most often an appointment*; some weeks getting out of the house does not happen – and then the after-math crash from pushing to use/exert all the energy required for an outing.

I love life; I love the world!

Along with everyday life activities are the fun celebrations in life like weddings and, also, the very tragic life events as in the death of a dear parent.

Unfortunately, because of the ‘chains of ME/CFS’ limiting my activity—I was **UNable** to take a one hour flight to see my dear beloved father before he **died**; leaving this life forever. I call this a **TRAGEDY** and **DEVASTATION—and I want you to know that!**

Weddings—what more delight is there!! There begs a **question**, however—How will I ever be able to travel/fly across the country to our adult child’s wedding?? **Answer—I WON’T; not possible—won’t happen !**

We all know of **young couples** who have **lost the chance and life-privilege of giving birth and raising a family**—because of the debilitation of ME/CFS.

And, life continues to go on all around us . . . as **WE—pw ME/CFS** continue to live our daily lives in chronic illness **AND in isolation**—and as time passes, that time leads to years and decades of **UNlife** like this.

Participant in a Research Study on Complex Chronic Diseases re ME/CFS

I am pleased to say that I am a participant in a research study on **Complex Chronic Diseases** re ME/CFS headed by a large team of Experts/Researchers. My testing for this phase has been completed, as the study is ongoing. At a subsequent appointment with my Neurologist, my doctor shared with me that a problem with my mitochondria was identified in this study on Complex Chronic Diseases. A dictionary definition of mitochondria follows.

- **Mitochondria** are the cell's power producers. They convert energy into forms that are usable by the cell
- Small spherical or rod like bodies, bounded by a double membrane, in the cytoplasm of most cells: contains enzymes responsible for energy

A problem with MY mitochondria has been scientifically identified—interesting; very interesting—a basic definition of mitochondria references ‘energy’—and the research testing has found a biological problem with energy—AND I have been (previously) diagnosed with ME/CFS wherein ‘energy’ is a significant biological problem—accounting for substantial diminished level of activity function in all aspects of daily life.

Recent science shows that there is profound immunological, neurological and metabolic dysfunction in pw ME/CFS.

All through the years, rolling into decades, as well as currently in this *labyrinth* of getting to the scientific roots and answers to crack the code of ME/CFS—there have been and ARE many dedicated doctors, scientists and researchers working tirelessly to find the answers to this horrid biological disease of ME/CFS; and we cannot applaud them or thank them enough for their never-ending dedication.

Outdated MISinformation

With documented history, over the years and decades, as well as currently there have been and are trivializations, diminishment and **DISmissals** as to the seriousness of this biological disease called ME/CFS.

The question **MUST** be asked—Why all the **DIS**respect, **DIS**regard and **MIS**information surrounding ME/CFS?

Recommended default treatments like GET (Graded Exercise Therapy) and CBT (Cognitive Behaviour Therapy) are being thrown at this disease of ME/CFS—which ultimately cause more harm than good.

ME/CFS is **NOT** a psychiatric disease/disorder; proven to be a **known fact**.

DENIAL of the **critical second day** of the stress/activity test that proves exercise intolerance in ME/CFS; see Professor Dr. Kenny de Meirleir—Exercise intolerance occurs primarily after physical exertion. Two peak exercise capacity tests **separated by 24 hours show exercise capacity is reduced after 24 hours in pw ME/CFS**—begs the question of **WHY—what is the agenda here in denial of the critical second day?** Day 1 ‘only’ will prove . . . **nothing!**

Let us, together, move forward in the common goal with state-of-art science to get the timely answers to cure people with ME/CFS of this debilitating **BIOLOGICAL** illness.

A Little More

Importantly to note: ME/CFS, as debilitating as it is—**IS spreading globally**; tragically, this disease has been let to spread globally—attacking men, women, **young children, teens**, adults of all ages.

Being familiar, as we all are here, with the devastation in health and a ‘stolen life’ that comes with ME/CFS, certainly begs the question—How can anyone **wish** this debilitating

chronic disease on anyone, especially on **younger people**—children and teens—young adults—to *live* like this in never-ending debilitating ILLness; ME/CFS stealing our/their lives away??

By standing by **or** standing in the way to stop and prevent timely progress by experts and researches from cracking the code to ME/CFS, spread of ME/CFS is **exactly** what **IS** happening. This is a **devastation and growing health crisis** of **global** proportions—affecting millions of us world-wide, **including young people AND children**—stripping their lives and life experiences away from them **without ever having lived life and the many wondrous experiences**.

It is **unconscionable** that such a disease has been **left to run rampant and trivialized**—an **atrocity against humankind**. **How** could this happen? **How** could this **be allowed** to happen ??

I cannot imagine, **can you**, that anyone would sincerely want such a devastating outcome?

WHO will be targeted with ME/CFS next—will it be you ? – a near and dear family member – a child—your child—your teen, your spouse ? – a grandchild; your grandchild ?? The person next to you or someone in their family ?? There are **NO boundaries** for this serious disease of ME/CFS—there is **NO**where to run from/to with this disease of ME/CFS and it **IS** spreading; that **is a fact**.

For those who think that ME/CFS is a female-only disease—look again—and at the same time recognize that—**gender** is of **no consequence**—**we are all first and foremost people / humans**. MANY males are stricken by ME/CFS and are speaking up and giving visible faces / voices to ME/CFS on behalf of **all** of us—**ME/CFS is not gender specific**.

What Are We Asking For ? WHAT Are the Needs ??

We need **money—LOTS of money**—to enable the research for a cure to this complex disease called ME/CFS—in the relatively recent past, **millions of dollars designated to ME/CFS were ‘quietly shuffled elsewhere’**. Isn’t this a **fraudulent act??** It **IS** INjustice!

We want **timely scientific answers** to this horrid debilitating biological disease called ME/CFS; and we are calling for **cancellation of the IOM Contract** and for **immediate adoption of the CCC**—in support the 50 global ME/CFS Experts and Researchers in their open letter dated October 25, 2013 to the Honorable Kathleen Sebelius, U.S. Secretary of Health and Human Services, as well as the open letter dated November 9, 2013 from the 171 ME/CFS Advocates world-wide.

A change in attitude and outdated mindset is called for to reflect the current scientific biological knowledge of ME/CFS. It is time for the **current significant research progress to be celebrated**; along with **much appreciation** given to the doctors, experts and researchers giving us hope, dedicated to finding the biological scientific answers to ME/CFS—dedicated to caring for the health of their patients—millions of us worldwide!

Let us **get serious about cracking the code** and solving this mystery of the debilitating **complex chronic disease named ME/CFS** in a timely manner. **Time is running short** for some of us with ME/CFS—**who will it strike next?** Will it be **you** or **your family** ??

In Conclusion

With all sincerity and a personal and collective thank you to the CFSAC and all attendees at the CFSAC December 2013 meetings for your most important consideration in listening to our voices as we speak up on behalf of pw ME/CFS – the people, the patients, the community—including the **young and the very young—we are the voices for them AND the coming generations.**

Please listen. Please support us. Please help us. Let's **STOP** ME/CFS with a cure! Thank you!