

P2P Loetta Vann

As a patient of 29 years I would like to thank you for this effort, and hope that your work will forward the advancement of knowledge, treatment, and prevention of M.E./C.F.S. Diagnosed with ME nearly three decades ago, and a subsequent diagnosis of CFS 7 years later, I've learned a few things about my illness that are not taught in school or published in journals. I know my personal array of symptoms go in and out of meeting established criteria (all of them).

Your report reflects significant insight and includes one area of study that has been grossly ignored that I hope to highlight and encourage. Longitudinal Studies (163)! "Longer follow-up and a lifespan perspective are needed to understand M.E./C.F.S. effects on the whole individual (e.g., patient decision-making, patient expectations, sexual health and childbearing). The symptoms patients consider clinically meaningful are not in the scientific literature; this discordance must be rectified".

To date there has not been a single comprehensive study that tracks the life cycle or long term prognosis of individuals battling M.E. or C.F.S. no matter what criteria is used. Patients are currently dropped or excluded from studies during times of remission or lessening of the severity of symptoms. Much could be learned by better understanding the intermittent crash cycle, even though those cycles might be of longer duration than those observed in a transient patient population. This is especially important because of the comparative heterogeneous nature of patients found in the care of "C.F.S. Experts." Long term patients, that have modified life styles and have become somewhat skilled in managing the push crash cycle, are rejected from existing studies, and expert care. I wonder if the co-morbid conditions long term patients develop over time (especially those not found in family histories) should be collected and quantified.

During extended periods when I live a sheltered existence with minimal stress, an abundance of support and love, little medical intervention, and the ability to engage in meaningful activities at my own pace I thrive with scant awareness of my limitations. I love to walk in the park, talk to my dogs and enjoy making soup and small meals. Although the trade my husband and I made to reduce symptoms was costly. We live our lives without the joy or burden that comes with having children; I surrendered my beloved career, and rarely leave my home or attend events. Since contracting a suspected virus (along with many of my study-abroad

classmates) my immune, endocrine, and central nervous systems changed; as did my life.

You report that evidence suggest neurocognitive dysfunctions—found in MRI and PET imaging, and immunologic and inflammatory pathologies, as well as neurotransmitter signaling disruption, microbiome perturbation, and metabolic or mitochondrial abnormalities.” (82-86). You could add to that Autonomic Nervous System problems, signs of probable Autoimmunity, cardiovascular dysfunctions, Temporomandibular Joint Syndrome, Irritable Bowel Syndrome, Interstitial Cystitis, Irritable Bladder Syndrome, Raynaud’s Phenomenon, Prolapsed Mitral Valve, Migraine, Allergies, Multiple Chemical Sensitivities, Hashimoto’s thyroiditis, and Sicca Syndrom

We know multidisciplinary teams can be helpful in chronic diseases but we need medical practitioners who possess a recognized expertise in M.E./C.F.S, a pronounced multi-system disease. For this basic care to become available Centres of Excellence must be established where patients can be referred and biomedical research organized. Currently M.E./C.F.S. patients need to visit many doctors to cobble together a medical and support team as they are able to endure redundant expensive and potentially harmful tests. Those with out the stamina the support or the financial means slip through to be come untreated and often homeless (71). ME/CFS cannot be managed by GPs Instead GPs need to know where to refer these patients.

Education for physicians is critical and needs recognition in the regular part of the curriculum at all medical schools

I hope NIH will cooperate with the international research agreements to use either the CCC or the ICC for research and clinical purposes, until we have a better understanding of the problem.

What is not discussed in your report is the paultry funding levels provided at the national level. I understand why folks look to profit-driven research. However, if profit stems from the development of drugs and diagnostic testing there will not be motivation to understand past geographical outbreaks, travel medicine and the subsequent effects of vaccines recommended to travelers, or to the political reopening of previously closed borders to travelers during the 1980s. As world travel became less restrictive natural immunity and vulnerability considerations might be considered. I my case it was a study abroad program into recently opened area of China in 1985. A better understanding of how we got into this situation may lead to better prevention but it might not translate into

increase to profits for the manufacture of pills, diagnostic tests or equipment.

Shall M.E./C.F.S. be called “a multifaceted condition (2)”, “the disease (11)” an “illness (21)” or an syndrome?

Thank you for your help

Sincerely,

Loetta M Vann