

Bringing ME/CFS/SEID Further into Mainstream Medicine – Dr. Jon Kaiser

Those of us working in this field are fortunate to have witnessed growing interest of late in the diagnosis, treatment, and pathophysiology of ME/CFS/SEID. It is also clear that there are many dedicated researchers fervently working to bring hope and progress to the many patients afflicted with this devastating disease.

However, during my three decades of experience as a CFS researcher, clinician, and patient, I believe that unless this disease is further recognized by conventional medicine, progress on its diagnosis and treatment will be incremental at best.

Much of my experience comes from having been on the front lines in the early days of the AIDS epidemic. When I started treating patients with AIDS, its cause had not yet been discovered. We didn't have any blood tests to diagnose or monitor the disease. We also did not have any available treatments. Sound familiar? Another commonality was the way in which AIDS was marginalized by society. President Ronald Reagan never once uttered the term "AIDS" during his presidency despite thousands of people dying from the epidemic.

So what factors brought about a transformation in how AIDS was diagnosed and treated? First, the cause of the illness was discovered. Second, massive amounts of Big Pharma money (tens of billions of dollars) poured into researching treatments. Third, a biological marker of disease progression, the CD4 count, was identified. And fourth, the health insurance industry gave the disease a reimbursement code and never hesitated to cover its treatment.

I believe all of these milestones need to occur for ME/CFS/SEID to be further incorporated into mainstream medicine. While it may take some time to acquire substantial research funding and useful blood tests, obtaining a dedicated ICD-10 code can be achieved in the short-term. This would represent a significant milestone in achieving at least one of the key factors necessary for SEID to become recognized by mainstream medicine.

Regardless of one's opinion on the pros and cons of the new name set forth in the recent IOM report, I believe having a dedicated insurance reimbursement code for SEID would go a long way to establishing credibility for this condition within conventional medicine and improving reimbursement to physicians by third-party payers. The recent IOM report itself states, "a new independent code should be assigned for this disease in the current edition of the International Classification of Diseases."

ICD-10 codes are maintained by the ICD-10 Coordination and Maintenance (C&M) Committee, which is a federal interdepartmental committee comprised of representatives from CMS and NCHS. This committee provides an open public forum to suggest and discuss proposed changes to ICD-10. Input is welcome from all stakeholders, including individual physicians, physician organizations, and private citizens. Physician groups, including medical specialty societies, can actively participate in the coding system modification process by proposing new codes as well as commenting on the merits of suggested modifications.

Organizing the IACFS/ME membership to support a petition to the ICD-10 C&M Committee to formally designate an ICD-10 code for SEID would represent a significant step forward in achieving at least one key factor necessary for ME/CFS/SEID to be properly recognized by conventional medicine. Providers who still want to submit for reimbursement using the less specific “Post-viral fatigue syndrome” code could still do so.

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