

Whittemore Peterson Institute
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The United States governmental entity responsible for alerting and protecting the American public from threats to their health is the Centers for Disease Control, better known as the CDC. The CDC's mission is to collaborate to create the expertise, information, and tools that people and communities need to protect their health – through health promotion, prevention of disease, injury and disability, and **preparedness for new health threats.**

Yet, one to four million Americans still suffer from a poorly understood, debilitating disease which was first identified in the United States in three separate recorded outbreaks over 25 years ago, including:

Incline Village, Nevada
Lyndonville, New York and
Miami, Florida.

The individuals who became ill that year came from various economic classes, different age groups, including children and adults and affected people in a small rural town, a large lakeside community and a huge metropolitan area. The individuals in those outbreaks all exhibited the same complex symptoms, yet none of the patients were examined by the government employees who were sent to investigate.

The doctors who alerted the CDC were not told of the other communities in the United States experiencing the same phenomenon. Despite the serious concerns about the severity of the patient's symptoms and their rapid descent into disability, the CDC refused to investigate further. The CDC concluded that this was a new form of EBV mono. They convened a meeting, in which they decided to call this illness "chronic fatigue syndrome" rather than adopt the name that was being used in the UK: myalgic encephalomyelitis (M.E.). M.E. at that time was already a well characterized infectious neurological disease causing a similar complex illness.

Thus began a twenty five year battle between patients and doctors who fully realized the severity of this illness and a government that has yet to commit an appropriate level of financial resources to aid the discovery process necessary to help individuals with this disease. Not only has the lack of adequate resources been a major road block to discovery, but the CFS scientific review committees are currently ill-equipped to review many of the biologically complex scientific grant requests. Attempts to engage in biological research by basic researchers from virology and retro virology have generally been turned down in favor of studies aligned with a psychological theory of illness.

Years of misdirected research have resulted in a lack of a medical specialty for this group of patients to rely on for expert care. Doctors have been left without adequate knowledge and the tools to effectively care for their patients. The sick have been turned away by major medical centers, ignored by government, and their claims denied by insurance companies who refuse to pay for diagnostic tests and experimental treatments.

How could this happen to such a large group of sick people in this day and age of modern medical technology? Who could possibly benefit by this inhumane treatment of sick human beings?

My husband is fond of the quote made popular in the Watergate era: “follow the money”. His take on it is more specific: When something doesn’t seem right, “follow the money”.

So if one follows the money in this case, we can perhaps begin to unravel the mystery of this crime against humanity. We know that when this disease was first reported to our governmental authorities, another more deadly illness had recently been identified, HIV-AIDS. Our nation was debating how to approach this new “gay man’s disease”, until it struck a young child and a famous athlete, neither who were gay. Countries around the world were struggling to meet the heavy demands of HIV, when myalgic encephalomyelitis began to take its equally heavy toll on the lives of the innocent.

But this disease was a disease that apparently could be ignored. It seemed to impact mainly woman. There was no immediate organ damage that could be detected. It did not kill the afflicted rapidly enough; it only caused a profound disability that could last a life time.

However, a life time of disability requires a life time of disability payments and huge medical bills; something no government or private health insurance provider wants to be responsible for. The only way to avoid medical and disability payments for the sick is to claim the illness is due to a psychological disturbance or mass hysteria, blame the patient for their illness and offer cheap psychological treatment and exercise therapy. As long as no one discovers the true cause of the disease, these entities are safe from any expectation of actual medical intervention. A physical disease may remain in the psychiatric domain if it is called a psychosomatic illness; “meaning a disorder in which mental factors play a significant role in the development, expression, or resolution of a physical illness.”

Despite years of private research and thousands of papers describing the physical deficits found in these patients with this illness, our government and medical entities continue to ignore the evidence in favor of those who espouse a simplistic psychological theory of illness.

But those who stand to gain by misdirecting research funding can not stop the truth from being revealed. What greater evidence is required to support the request for responsible action than the finding of a new human retrovirus replicating in this population of patients? Knowing the significance of this discovery, why has the US government not asked CFS patients to stop donating blood until the cause of this disease is better understood?

Prostate cancer and XMRV research has been made a priority at the National Cancer Institute and major universities as evidenced by the publication of new findings. Yet, there has been no such commitment by those at the National Institute of Allergy and Infectious Disease. Why is this?

Are we to blindly and meekly accept that those who suffer from XMRV (who have been inappropriately branded as having a fatiguing illness called “CFS”) are undeserving of the same medical care afforded others infected with a retrovirus?

I believe this is not time to end the CFSAC but rather a time for the CFSAC to exhibit its commitment by sending its strongest recommendations to the Secretary of Health and following those recommendations with actions:

- Educate the research and medical communities about the number of individuals impacted and the severity of this disease. Recommend that the CDC define ME by the immunological and neurological abnormalities that exist, the many co-infections that are frequently found and the physical complications of this long term illness. **It is time to agree on a proper name for this disease and to reflect the most current scientific knowledge in the definition of this disease.**
- Seek congressionally mandated research dollars that more closely match the number of individuals impacted by the disease and the severity of the illness. Millions of Americans are ill with ME and yet the NIH allocates a mere \$1.00 to \$4.00 per year per person. The loss in economic dollars is conservatively estimated to be \$9 billion per year. **With that kind of economic loss to our society, why isn't this disease funded at the level of hepatitis C which is currently at \$93 million a year?** Patients diagnosed with ME also suffer from inflammatory bowel disease, cognitive impairment, fibromyalgia, anemia, gall bladder disease, chronic Lyme disease, sleep disorders, chronic pain, depression, hormonal dysregulation, frequent viral infections, heart disease, and cancer. Yet these sick Americans are forced to seek unproven medical treatments for symptomatic relief due to the lack of scientific understanding of the underlying immune deficiency that is driving this disease.

- Request that research be conducted on XMRV in infectious disease by the NIAID and outside researchers to continue the valuable work begun at the WPI. The human retro virus, XMRV, has been found by WPI researchers in diverse disease populations, including cancer, autism, fibromyalgia, gulf war illness and ME, in men, woman and children. Yet four of WPI's most recent grants were denied funding on the basis that not enough is known about XMRV to warrant further investigations.
- Create and fund Centers of Excellence in neuroimmune diseases to care for patients with complex disorders caused by infectious agents. Scientific medical criteria should be developed that hold these Centers to standards of performance that include timelines and effectively measure demonstrated outcomes. All such Centers should be interconnected to provide medical consistency in care. They should include research, clinical care and medical education components from classroom lectures, to residencies and fellowships in neuroimmune disease.
- Request a congressional hearing to determine why this disease has been so poorly managed by the CDC and NIH, in order to assure the American public that the failure to recognize a serious threat to the nation's health will not be repeated.

There is no question that the CFSAC, as defined by its charter, can be an important avenue to a meaningful discourse between those who care about M.E. and those who are capable of initiating action from within the government.

The question is: Has the CFSAC achieved the goals stated in their charter?

The charter states its purposeas established to provide science-based advice and recommendations to the Secretary of Health and Human Services and the Assistant Secretary for Health on a broad range of issues and topics pertaining to chronic fatigue syndrome (CFS).

Is this goal being aggressively pursued? Is scientific evidence being reported to the Secretary of Health? What actions have been taken by the Secretary of Health that would provide evidence that this information is being acted upon?

The Function of the committee is stated below:

The Committee shall **advise and make recommendations** to the Secretary, through the Assistant Secretary for Health, on a broad range of topics including: (1) the current state of knowledge and research about the epidemiology and risk factors relating to chronic fatigue syndrome, and identifying potential opportunities in these areas; (2) current and proposed diagnosis and treatment methods for chronic fatigue syndrome; and (3) **development and implementation of programs to inform the public, health care professionals, and the biomedical, academic and research communities about chronic fatigue syndrome advances.**

The WPI took the earlier recommendations of this committee seriously. In fact, we built our Institute on the premise that this disease and others very similar to it, deserves “Centers of Excellence” that can bring answers to patients and doctors, in the same manner as multiple sclerosis and muscular dystrophy have successfully done. We believe that to find answers to this complex disease we must combine the translational efforts of basic and clinical researchers working in collaboration with knowledgeable physicians. This is the dream of the WPI: to bring discovery to a disease which has impacted millions of lives, to develop effective treatments and to one day provide preventative measures that will stop the spread of the disease.

This is not something that we can afford to do alone. If this committee will confirm that it is more than a sounding board for frustrated patients and doctors and that it can effectuate the necessary changes in this field, then the WPI fully supports the renewal of its charter.

Martin Luther King, Jr. once said, “The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy”. **I believe that courage is the combination of knowing the right thing to do and then doing it.** Please show us you have the courage to make this happen.

Thank you for your time and attention.