

Dr. Larry Fields,
Executive Secretary to the CFSAC

RE: Our recommendations and the CFSAC meeting of December 8, 2003

Please distribute this statement to the members of the CFS Advisory Committee so they may consider these matters and our modest and Practical recommendations, as they proceed with their work.

It is our hope that in developing policy initiatives for the Department of Health serious consideration will be given to the disaster that has gone before. There are millions now affected and this disease continues to spread. The world awaits anxiously for positive actions that will proceed toward the control and prevention of this epidemic.

Thank you for your attention.

THE COMMITTEE FOR JUSTICE AND RECOGNITION OF MYALGIC ENCEPHALOMYELITIS

December 8, 2003

Public Statement

To

**The CFS Advisory Committee,
US Department of Health and Human Services
and Dr Fields, for Secretary Thompson**

Why Are We All Here

Since the 1934 California outbreak of Atypical Polio, a long record of cases and outbreaks of our disease have been observed. There was an increasing frequency of outbreaks during the 1950's, which brought greater interest to our disease. Dr Melvin Ramsay and others further defined the illness, and Myalgic Encephalomyelitis (ME) became the recognized term for this neurologic infectious disease.

A number of distinguished doctors continued to study and report on ME outbreaks, including Wallis, Acheson, Richardson, Parish, Henderson, Shelokov, Dowsett, Ryll, Behan, and Hyde. Their writings have brought us a wealth of information about Myalgic Encephalomyelitis, and a continuous historical record of our disease over many decades. Perhaps most impressive among them, Dr Richardson could attest that the cases he saw in the year 2000 have the same disease as patients that he

and Dr Ramsay encountered in the 1950's: the neurological disease defined as Myalgic Encephalomyelitis.

When the Tahoe Outbreak of 1984 signaled the onset of the massive modern ME epidemic, the response of the CDC was the initiation of a tragic, devastating and clear pattern of denial, misinformation and distraction about this disease. The capstone was the fabrication of a new illness, CFS, rather than the recognition and investigation of the ME outbreaks. The immediate effect of these actions was to render the medical community ignorant of the true nature of this disease, and unaware of the established record of previous outbreaks and reports. With this new CFS label, no one would realize that it referred to a disease similar to multiple sclerosis, chronic non paralytic polio or today's Post Polio. Clearly, in effect a program of deception.

The creation of "CFS" was immediately followed by the enlistment of psychiatrists, and the redefinition and expansion of the disease criteria. This redefinition created an opportunity to identify as patients people with psychiatric disorders if that was convenient for the researcher and sponsors. The effect was to pollute the subject pool and thus confuse the results of research investigations. This inclusion of the psychiatric brigade, that postulated theories and promoted confusion, was to the delight and benefit of the Defense department and an Insurance industry driven to limit their liabilities.

These major moves to confound and confuse, and to use the cover of the psychological theories, can be seen as part of a deliberate protracted plan. The expansion of the criteria would help provide ammunition to waterdown the growing scientific data. Data, that demonstrate the neurological, immunological and circulatory abnormalities that confirm the Ramsay clinical criteria of Myalgic Encephalomyelitis. For the insurance industry, the promotion of the psychological theories would provide them with opportunities to limit disability coverage and avoid liability payouts, and thus enhance the Bottom Line.

This period of time also coincides with the sudden explosion of huge numbers of new ME cases among our young healthy military personnel. Beginning in 1991, the numbers have now grown to nearly 200,000 Gulf War ME victims. And we can see the wisdom of the defense department in directly hiring the self proclaimed ME expert, the psychiatrist and Insurance industry advisor, Simon Wessely. He has been quite useful to help draw attention away from the exposures to toxic chemicals and multiple vaccines.

By 1994, the tactics of deception included an overhaul of the "CFS" criteria to put the focus on fatigue and stress. All the key features that defined the neurological disease, ME, became optional. In a stepwise progression, the program to obscure the ME epidemic and the identity of the disease became broader and more determined. As doctors and studies revealed more and more of the features and considerable organic abnormalities of ME, so too, the designs and policies from the CDC to confuse became more elaborate. By 2000, the proposal included the creation of a wide umbrella of "unexplained" illnesses. Thereby, a method to bury ME amongst a multitude of non-infectious, non-neurologic and many psychological

conditions. A category of illnesses was created for which there would be little public interest or empathy, once shrouded in the cloak of psychological theories.

All of these developments would be consistent with a plan not to discover the cause. Such a plan would be especially useful if there are man-made products, chemical or biologic, that have contributed to the explosion of this ME epidemic. Concealing the cause could protect firms from liability.

A Clear Conflict

For several years at least during the 1990's Brian Mahy and his assistant Bill Reeves were in charge of the CFS programs at the CDC. A GAO investigation found that many millions of dollars authorized by Congress for CFS was diverted and not used for CFS research. In effect, years of effort and opportunity and hope were lost. Many patients have died during this time.

Yet Mahy and Reeves have still not been prosecuted. In fact they continue to hold senior positions at the CDC and command budgets. In what could be a brilliant move, perhaps to avoid prison, Reeves sought shelter as a whistle blower and implicated his partner Mahy. Some say Reeves was right to come forward while others view his actions as similar to a mafia hit-man that fingers his partner in exchange for immunity.

The patient community is aware of the CDC's long-standing culture of bias regarding our disease: the refusal to investigate the outbreaks, the diversion of funding, the deceitful design of laboratory studies, to the offensive and derogatory attitudes toward patients. This attitude includes Reeves having fun by ridiculing patients at public meetings.

In another area of growing unease between the public and health officials, concerns the rapid growth of chronic diseases and the parallel massive use of vaccines, creating a major public health question. Many cases of ME are known to be triggered by a vaccination. Multiple vaccinations is strongly associated with Gulf War and Autism, together with the growing numbers with chronic diseases. The recent UPI investigation confirms that the CDC is in the vaccine business including a large amount of industry influence over vaccine related policy at the CDC. These factors create an unmistakable basis for conflict of interest and in particular regarding ME a disease known to be associated with some vaccinations.

Sadly, the CDC has a history of being involved in concealing and manipulating studies to protect industry. Also the history of the CDC includes a program where for many years hundreds of people with syphilis were enrolled, they were lied to about the program, they did not receive medication but suffered and died. The people were not told the purpose of the project was to study the untreated disease and examine their bodies at autopsy. The project was not stopped until it was exposed in the press. The CDC claimed it was done in the name of science.

The CDC history and their record with the ME epidemic, and experiences of ME patients, argue against allowing the CDC to have anything further to do with decisions about our disease.

It is clear to us that there is a fundamental conflict between the interests of the large and growing patient community disabled by ME with their desire for progress, and the program of the CDC, which has been to delay and derail the search for the cause and cure.

The trademark of the CDC strategy to cause confusion and to conceal the identity of this ME epidemic was the change of name to Chronic Fatigue Syndrome. The myriad series of events, delays, mistakes and supposed bungling is so extensive that it fills an entire book, Hillary Johnson's *Osler's Web*, published in 1996. This work is essential reading for understanding of the medical, social, and political history of ME, as well as providing a context for the current events.

The Disaster of Policy

Without regard to the origins of the ME epidemic or why the health authorities have worked to conceal the epidemic from the public, the effects these policies on patients is devastating. As patients we know the brutality of both the medical and social disasters imposed by the CDC policies. They advise doctors not to do any of the numerous tests that demonstrate the immune, infectious, central nervous system and metabolic abnormalities that can support the diagnosis. Where does this leave the doctor? If there are no specific tests recommended, then this advice can encourage the doctor to be skeptical that the condition exists, certainly could not be serious.

Where does this leave the patient? Without complete medical investigation and tests, the doctor is unable to proceed with treatments. Untrained and unsure of the disease, induced by CDC policy the patient is not treated, leading to further deterioration. Severely disabled and without the validation of medical testing, the patient is confronted with an impossible task to obtain disability assistance. Many become homeless and fatalities increase.

These policies have fostered a pervasive negative attitude toward ME Patients, of which we are well aware. There exists the common experience at hospitals: the snickering by staff when they learn you have "CFS". Or worse, the woman who went to hospital with severe respiratory symptoms, she was not properly treated, given a bottle of syrup and sent home. She died a few hours later. She was not properly treated because she was known at the hospital to have CFS.

Advance Your Understanding

At the present time the medical community is attempting to understand the symptoms of ME, attempting to gain entry with their tools and methods and physiologic models, in order to explain the disease to their colleagues. This means that at the present time it is the patient community that has a far greater understanding of the realities of ME than the medical community. To us, ME is no mystery, it is a lived experience. This is a fundamental aspect of the current situation that must be accepted in order to gain a better understanding of this disease. Doctors will learn much about this disease by listening to patients.

Progress in ME treatment and research begs for the guidance of clinical science. The patients' experiences are a valuable source of valid data.

Government officials will also learn much about this disease by listening to patient representatives directly affected by this disease and by the actions of this committee. As patients we are from all walks of life and from every region, state and congressional district, and at the present time there is no immunity to ME. There is no shield from its tragic progression. The preliminary follow-up from the Tahoe Outbreak shows 10% have developed brain tumors and lymphoma. The Gulf War vets comprise the greatest Outbreak of ME and now over 20,000 have died.

Our numbers continue to grow, and as time passes since this epidemic began the deaths due to Myalgic Encephalomyelitis are raising rapidly. Advance your understanding. Recognize the epidemic of Myalgic Encephalomyelitis. Protect the Public.

Why Are We All Here

We are here today, because a widespread epidemic of Myalgic Encephalomyelitis has descended upon this country. In less than twenty years time there are now over 1 million victims in the US alone and millions more worldwide. We are here because the national health agencies have not addressed this danger to the public health nor sought to find the cause or remedies for the suffering.

We are here to inform the public that the national health agency policies are subjecting patients to a systematic denial of medical services and are maintaining doctors all across this country ignorant about this disease. These health agency policies have ensured that the cause of this disease is not discovered. These policies impact the health of thousands already disabled by ME and continue to place everyone at risk.

A principal issue must not be overlooked: Why has ME, which has an historical relationship to Polio, exploded into a worldwide epidemic, and what is the inordinate fear of the DHHS to recognize this and discover its cause?

TCJRME is here to make plain to this DHHS Advisory Committee and to the public some of the basic facts pertinent to the Patient community disabled by this epidemic. Issues, events and the record of inaction by our national health agencies must be brought out into the daylight and dealt with honestly.

For the health and welfare of our fellow citizens, we insist that these matters be taken up now. We will not wait any longer for improvements, they must proceed now. We are here for progress. Now!

The Committee for Justice and Recognition of Myalgic Encephalomyelitis

RECOMMENDS THE FOLLOWING ACTIONS:

First and foremost - End the Lies - Too Many Have Died

That the Advisory Committee recognize Myalgic Encephalomyelitis as the disease that has spread as an epidemic over the country during the last two decades and abolish forever the use of the term Chronic fatigue syndrome.

Immediately form a panel of clinicians to establish a treatment experience exercise.

That as quickly as possible this project enroll at least 100 doctors and 10,000 patients to evaluate 10 or more treatment regimes that are being used by clinicians in the field. These treatment approaches normally include multiple products. As information from patients suggests these should include; antibiotics, antivirals, immune modifiers, EFA's, antioxidants, cellular and mitochondrial energy products, and detoxifying agents. A report detailing a one year experience would provide a broad amount of useful and practical information for patients and doctors that has not been available in any organized form for the million Americans devastated by this disease.

That this Advisory committee ignite a search for the cause.

Since the federal agencies have not undertaken this task and have worked to avoid supporting or investigating the infectious agents involved, it is time to request a major funding of independent research laboratories for a thorough search for bacteria or virus, conventional or novel, as well as chemical toxins and vaccine substances. Clearly, 50 laboratories and 50 million dollars over 5 years will bring some answers well worth the effort, considering that the entire public is at risk. In the past 20 years we have seen community outbreaks and we are dealing with a disease that was very rare but has exploded into a million in this country alone, and it continues unchecked leaving all citizens at risk.

That this Advisory committee Inform the Medical community.

That this body make available the new Clinical Case document developed by the Canadian Health department Expert Panel to all physicians making inquiries about this disease. This is the most advanced and up-to-date and practical information source on this disease that can quickly educate doctors, and will help save lives.

We demand that Reeves must be removed from this committee.

For the integrity of this committee Bill Reeves must be removed. He is widely viewed as a criminal to the patient community and as an obscenity to humanity. His involvement with the practices and actions at the CDC which have contributed to thousands of deaths is not acceptable. In the same way that it would be understandable that Adolf Hitler would not be allowed on any Jewish welfare commission.

These are immediate recommendations for action.
There have been too many years of inaction from the national health agencies.
There are now millions worldwide disabled by this epidemic of Myalgic Encephalomyelitis. Now is time for progress.

**The Committee for Justice
and Recognition of Myalgic Encephalomyelitis**

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We have raised various topics here and can provide further information regarding any of the issues raised in this statement.

CC:
Senator Harry Reid
Congressman Bob Filner
United Press International

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