

Testimony – Elaine Wilhelm

These are facts stated in a report from the UK Chief Medical Officer's Report on ME and CFS from May 1, 2001.

Psychiatric disorder is Not a core aspect of CFS and that this is a strong argument against CFS being a psychosomatic or "functional somatic" disorder.

There is evidence of a degenerative process of the muscle tissue in CFS patients as typically occurs in mitochondrial myopathies.

Different neurobiological profiles are found in CFS patients compared with healthy controls.

A wealth of studies (about 85%) confirm autonomic nervous system (ANS) dysfunction in up to 90% of CFS patients, with resulting effects on many vital functions (blood Pressure, pulse rate, breathing and body temperature).

Increases of polyunsaturated fatty acids had the highest correlation with both fatigue and muscle pain scores.

A large number of CFS patients have abnormal immunological profile which can result in the production of immunologic mediators such as interferon, interleukin and other cytokines. The results show that the presence of an increased amount of LMW RNase L correlates with higher levels of interferon gamma.

Finding substantiates claims of an NK associated defect in CFS and suggest a molecular basis for the reduced cytotoxicity (immune systemkiller cell function). This defect may not be NK specific but may encompass the cytotoxic T cell subset as well. Mice which were genetically engineered to have low or absent levels of perforini show the same immune abnormalitites as CFS. Other abnormalaities found include activated lymphocytes in various subsets, elevated levels of immunoglobulins (IgG in particular) and increased levels of immune molecules called pro-inflammatory cytokines. Also found was a reduced activcity of delayed hypersensitivity.

The upregulation of the 2-5 A Synthetase/Rnase L pathway shwon in CFS patients indicates an activated immune state.

We further compare Dr. Shepherd's view with that of Shetzline and Suhadolink, who in a deatiled study of the RNase L enzyme have not only identified the 37KDa form of the enzyme as being part of the underlying pathology of ME/CFS, but with sophisticated labelling techniques have shown that there is an increased rate of RNA hydrolysis by this enzyme and that the low molecular weight enzyme (;37 kDa instad of the normal 80 KDA weight) is hydrolysing three times faster than the normal 80 KDa enzyme. The researchers have used a specific probe which unequivocally identifies the faulty enzyme.

It is our opinion elimination diets in cases of ME/CFS where there is reproducible and reliable evidence of a leaky gut, in which high levels of small peptides cross the damaged gut membrane, leading to changes in brain chemistry which have behavioural, cognitive, neurological, and endocrinological and immunological consequences. The well-validated IAG urine test is a test for an aberrant metabolite of tryptophan and if positive, is indicative of a manlfunctioning and leaky gut; it indicates a compromised digestive process which in turn leads to opioid excess as a result of mal-digestion and uptake of opioid peptides derived from dietary sources.

Significantly, if the gut is leaky, the same factors also cause the blood brain barrier to be leaky, with resultant effects of opioids on the central nervous system; this causes not only a local, but

also a systemic, reaction.

Increased incidence of irritable bowel syndrome in ME/CFS. Urinary creatine test showed patients with ME/CFS are excreting in their urine significant levels of creatine and other muscle related metabolites including choline and glycine. This may represent on-going muscle damage in ME/CFS. Creatine has previously been shown to be a sensitive marker of muscle inflammation.

Natelson et al have demonstrated the link between IL4 and type 2 cytokine pattern in ME/CFS; a preponderance of a Th2 response is consistent with autoimmunity.

In particular, we suggest that ME/CFS patients be screened for evidence of autoimmunity.

The endocrine system is uniquely disrupted in ME/CFS. Patients are severely limited by the loss of dynamic hormone responses. There is abnormality of adrenal function and CT scans have shown that both the right and left adrenal glands are reduced by 50% when compared with controls.

Recent evidence demonstrates a lymphocytic thyroiditis in chronic fatigue.

There is a universally acknowledged dysfunction of all nervous systems in ME/core CFS.

There is increasing evidence of hypercoagulability in ME/CFS. ME/CFS can be classified as a type of antiphospholipid antibody syndrome.

ME/CFS showed a significant reduction in all lung function parameters.

ME/CFS patients have a recovery rate for oxygen saturation that are 60% lower than normal controls.

We believe that the need for specialist ME/CFS units (providing both complex investigative and assessment facilities, together with the necessary care provision) are long overdue, and that advice contained in the forthcoming CMO-s REport should reflect this need.

Neuropsychological assessment in ME/CFS patients, which is known to produce a distinctive pattern of abnormalities.

I hope this information serves to motivate people into pushing congress and their representatives to provide the education to our doctors and provide clinics where people can get real comprehensive care and treatment for the disorders of ME/CFS and Fibromyalgia.

Cognitive behavioural therapy has been shown to be of no long-term benefit in these disorders.

Thank you on behalf of all those who have been disabled by these conditions.