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International M.E. Expert Disputes That 'CFS' XMRV Retrovirus Link Claim Has Relevance To M.E. Patients

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The HFME is dedicated to fighting for the recognition of Myalgic Encephalomyelitis based on the available scientific evidence, and for patients worldwide to be treated appropriately and accorded the same basic human rights as those with similar disabling and potentially fatal neurological diseases such as Multiple Sclerosis.

Myalgic Encephalomyelitis (M.E.) is a debilitating neurological disease which has been recognised by the World Health Organisation (WHO) since 1969 as a distinct organic neurological disorder. M.E. is classified in the current WHO International Classification of Diseases with the neurological code G.93.3.

It can occur in both epidemic and sporadic forms. Over 60 outbreaks of M.E. have been recorded worldwide since 1934.

What defines M.E. is a specific type of acquired damage to the brain (the central nervous system) caused by an enterovirus.

It has multi-system involvement which is characterised by post-encephalitic damage to the brain stem; a nerve centre through which many spinal nerve tracts connect with higher centres in the brain in order to control all vital bodily functions – this is always damaged in M.E. (Hence the name 'Myalgic Encephalomyelitis').

World-renowned Myalgic Encephalomyelitis expert, Dr Byron Hyde, currently undertaking a speaking tour of Australia, has made the following statement about mistaking the research done so far on the hyped XMRV [1] retrovirus and 'Chronic Fatigue Syndrome' patients with evidence of any relationship to M.E.:

'In four of the sixty M.E. epidemics an enterovirus was recovered. In over 50 other [M.E.] epidemics, no virus was recovered but the average incubation period of the infection in these epidemics was 3-6 days, as it is in all enterovirus infections.' However, the "incubation period of [the not enterovirus, but retrovirus] XMRV is up to 21 days which makes it impossible to cause an epidemic illness.' [2]

Dr Hyde will speak in several cities, including Melbourne, Sydney and Perth, in September 2010 [see end for more details].

Dr Hyde is uniquely qualified to speak on M.E., having investigated M.E. for many decades, including the M.E. epidemics in Australia, Iceland, the USA, New Zealand and the UK. Dr Hyde's comments also fit with evidence from the other leading M.E. experts with decades of experience with the disease such as Dr Dowsett, Dr Ramsay and Dr Richardson.

Dr Hyde has also debunked the relatively recent notion that "Chronic Fatigue Syndrome" (a bogus or 'wastebasket' disease category invented in 1988), or the related "CFIDS" and "CFS/ME" concepts, are synonymous with M.E. WHO ICD-10:

'M.E. has a clearly defined disease process while CFS by definition has always been a syndrome...

'The physician and patient alike should remember that CFS is not a disease. It is a chronic fatigue state. Where the one essential characteristic of M.E. is acquired Central Nervous System (CNS) dysfunction, that of CFS is primarily chronic fatigue.' [3]

HFME founder Jodi Bassett commented:

'The forthcoming visit to Australia by the world's most authoritative spokesperson on Myalgic Encephalomyelitis is an excellent chance for us to assess what kind of fundraising and research initiatives can make a significant difference for all those touched by M.E. It can help debunk the harmful conflation of M.E. with "CFS" that results in many patients and their supporters devoting vital energies and resources to much-hyped but inappropriate treatments and so-called 'advocacy' campaigns which are not in the best interests of M.E. patients, and can be harmful to M.E. patients.



The HUMMINGBIRDS'
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'Dr Hyde's experience gives him a unique insight into what is needed now for M.E. and into the deficiencies with current claims that XMRV research indicates a future treatment or prevention model for M.E., or that this virus is the cause of M.E.

'Claims that the XMRV virus has been shown to be the cause of M.E. or that this test is useful in diagnosing M.E. are false, misleading and unethical. Research done on patients with a wide variety of diseases, involving fatigue and/or immune problems, and discussed under the "CFS" banner, usually has nothing to do with M.E., and the much-hyped and very slickly promoted XMRV research seems, based on all the evidence produced thus far, to be just another such example.[4]

'M.E. is a distinct neurological disease. 'CFS' is always a MISdiagnosis. M.E. and 'CFS' are not the same. Vague 'CFS' research which uses heterogeneous (mixed) patient groups must stop being wrongly and unscientifically applied to those with the distinct neurological disease M.E.'

Dr Hyde's Australian speaking engagements yet to occur include [but are not limited to] the following dates:

Perth: Sat Sept 11 [medical practitioner seminar followed by public seminar]

Brisbane: Tues Sept 14

Melbourne: medical practitioners – Thurs Sept 16.

General public seminar: Sept 18

[1] human retrovirus xenotropic murine leukemia virus–related virus

[2] Statement made by Dr Hyde at Swedish M.E. Conference in Goteborg, Nov 2009. <http://www.nightingale.ca/documents/GoteborgConference.pdf> p.7.

[3] <http://www.nightingale.ca/index.php?target=whatis>

[4] HFME XMRV discussion paper: <http://www.hfme.org/xmrvcfsandme.htm>