

M.E. (Myalgic Encephalomyelitis) BASIC INFORMATION:

Anglia ME Action. April 2008.

"...there are now over 4,000 published studies that show underlying biomedical abnormalities in patients with this illness. It's not an illness that people can simply imagine that they have and it's not a psychological illness. In my view, that debate, which has waged for 20 years, should now be over".

[Professor Anthony Komaroff, Harvard Medical School: Speaking at the USA Government CDC (Centers for Disease Control and Prevention) press conference on 3 November 2006. – Also see endnote 1 below] www.cdc.gov/od/oc/media/transcripts/t061103.htm

1. What ME is and What it is Not:

Myalgic Encephalomyelitis or **M.E.** (myalgic= muscle-pain, encephalo= brain, myelitis= spinalcord, encephalomyelitis= inflammation of brain & spinal-cord) is a long-term organic/biomedical illness and is NOT the same thing as 'Chronic Fatigue', short-term post viral syndrome or 'myalgic encephalopathy'[2] and it is NOT a psychiatric or behavioral illness. ME has been in the medical literature since the 1930s and classed as a physical disease by the WHO (World Health Organisation) International Classification of Diseases (ICD) since 1969 - currently listed at **WHO ICD-10-G93.3** as a Multi-System organic/physical NEUROLOGICAL Disorder with similarities to Multiple-Sclerosis and Post-Polio-Syndrome. Documented clinical/research abnormalities (see section 7 below) include: immune system/infectious; cardiovascular, endocrine and digestive systems; muscle, cellular, mitochondrial and genetic function and integrity; oxidative stress; central nervous system - including brain and spinal cord; end organs. For symptoms/signs and diagnostic information and discussion see section 3 below.

To complicate matters, the term 'Chronic Fatigue Syndrome' has been much abused by vested interests trying to re-label biomedical WHO-recognized ME/CFS/PVFS as a psychiatric disorder – doing so allows insurance companies and benefits agencies to potentially save billions of £/\$ across the globe. This is hugely impacting upon public as well as private health & welfare policy - causing a recent UK Parliamentary inquiry group to caution:

"Given the vested interest private medical insurance companies have in ensuring CFS/ME remain classified as a psychosocial illness there is blatant conflict of interest here. The Group find this to be an area for serious concern and recommends a full investigation of this possibility by the appropriate standards body."

[Page 30 of the joint Commons/Lords Gibson Parliamentary Inquiry Group (GSRME) Report – see section 6 below]. www.erythos.com/gibsonenquiry/index.html

Thus, many biomedical ME campaigners/clinicians if they use the misleading term 'Chronic Fatigue Syndrome/CFS' at all, preface it with 'ICD': to read 'ICD-Chronic Fatigue Syndrome' or 'ICD-CFS' in an attempt to ensure it is understood that they are referring to the biomedical disorder classified by the WHO at ICD 10-G93.3. See Professor Malcolm Hooper's *et al* document entitled:

What is ME? What is CFS? Information for Clinicians and Lawyers.

www.meactionuk.org.uk/What_Is_ME_What_Is_CFS.htm

And see: <http://meactionuk.org.uk/G93-3-ICD-10-compilation.jpg>

<http://meactionuk.org.uk/G93-3-ICD-10-index-closeup.jpg>

www.who.int/classifications/icd/en/

Also see discussion on the controversial United States CDC disease labelling / classification at:

www.co-cure.org www.cfids-me.org/ www.mereseach.org.uk/index.html

ME is a serious long-term and life changing disease with various **viruses/infectious-agents** and **toxic chemicals** jointly implicated in causation. ME leads to a **shorter life-span in a significant minority of patients** (see section 2 below). Some viruses and other bugs have always been able to trigger multi-system neurological diseases (e.g. Polio). However, with the massive growth in environmental toxic chemicals since the 1940s, the background load on human immune, nervous, endocrine and anti-oxidant/de-toxing enzyme systems has increased exponentially. ME has similarities to Gulf War Syndrome and **ME patients have been called the 'Canaries' of our increasingly polluted planet that (should) serve as a warning to modern industrial society.**

See Professor Malcolm Hooper's peer-reviewed overview paper (regularly updated online) entitled:

Myalgic Encephalomyelitis: A Review With Emphasis on Key Findings in Biomedical Research.

Journal of Clinical Pathology; 2007; 60:466-471. Doi: 10.1136/jcp.2006.042408.

<http://jcp.bmj.com/cgi/content/abstract/60/5/466>

For a biomedical research findings overview up to 2005 see:

Illustrations of Clinical Observations and International Research Findings from 1955 to 2005

that demonstrate the organic aetiology of Myalgic Encephalomyelitis / Chronic Fatigue

Syndrome. Malcolm Hooper, Eileen Marshall, Margaret Williams (For Gibson Inquiry):

www.meactionuk.org.uk/Organic_evidence_for_Gibson.doc

Also see: ***Essential investigations for people with ME/CFS?*** Margaret Williams. January 2008.

http://meactionuk.org.uk/Essential_investigations_for_people_with_ME.htm

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There has been much misunderstanding and downright deceit (see section 3 below) over what ME

is and is not. See Professor Malcolm Hooper's *et al* document entitled:

What is ME? What is CFS? Information for Clinicians and Lawyers.

www.meactionuk.org.uk/What_Is_ME_What_Is_CFS.htm

Also see: ***The Late Effects of ME - Can they be distinguished from the Post-polio syndrome?*** By

Consultant Microbiologist and ME Specialist, Dr Elizabeth (Betty) Dowsett:

www.ott.zynet.co.uk/polio/lincolnshire/library/dowsett/lateeffectsme.html

2. ME Recovery & Early Death Rates:

ME has a very low patient recovery rate [3] and Consultant Microbiologist & ME specialist Dr Elizabeth Dowsett stated that some 10% of patients die early due to complications from ME – organ failure and other factors[4]. It is believed that a great number of ME-related early deaths due to end-organ failure etc are not picked up because they are simply put down to heart-failure etc per se and not properly connected with ME as the underlying cause. Moreover, it is arguable the majority of life-long ME patients have some life span reduction due to increased oxidative stress etc.

See Professor Leonard Jason's *et al* paper entitled: ***Causes of Death Among Patients With Chronic Fatigue Syndrome. DePaul University, Chicago, Illinois, USA Health Care for Women International***, 27:615–626, 2006. Routledge. Copyright © Taylor & Francis Group, LLC. ISSN:

0739-9332 print / 1096-4665 online: DOI: 10.1080/07399330600803766

www.ingentaconnect.com/content/routledg/uhcw/2006/00000027/00000007/art00005?crawler=true

The tragic death by ME of 32 year old Sophia Mirza was recently recorded by a UK coroner and was the result of organ failure and alleged psychiatric mistreatment/neglect. See:

The Inquest of Sophia Mirza. Invest in ME:

www.investinme.org/Article-050%20Sophia%20Wilson%2001-RIP.htm

Inquest Implications:

www.meactionuk.org.uk/Inquest_Implications.htm

3. Internationally Respected ME Guidelines & Expert Comment:

See: ***Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners - An Overview of the Canadian Consensus Document*** by

Professor Bruce M Carruthers and Dr Marjorie I Van de Sande.

UK – NHS Clinician Endorsed / UK A4 Format - Version:

http://data.eastanglia.me.uk/pdfs/Canadian_ME_Overview_A4.pdf

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See: ***Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition,***

Diagnostic and Treatment Protocols ('Canadian Criteria' – Full Version).

Bruce M. Carruthers,

Anil Kumar Jain, Kenny L. De Meirleir, Daniel L. Peterson, Nancy G. Klimas, A. Martin Lerner, Alison C. Basted, Pierre Flor-Henry, Pradip Joshi, A. C. Peter Powles, Jeffrey A. Sherkey, Marjorie

I. van de Sande. *Journal of Chronic Fatigue Syndrome*. Volume 11, Number 1, 2003. At: <http://fm-cfs.ca/CFS-Protocol.pdf>

See: ***Chronic Fatigue Syndrome: Assessment and Treatment of Patients with ME/CFS: Clinical***

Guidelines for Psychiatrists. Eleanor Stein MD FRCP(C).

<http://fm-cfs.ca/Psychiatry-overview.pdf>

See: ***The Nightingale Definition of Myalgic Encephalomyelitis (M.E.)***.

Dr Byron Hyde, Nightingale Foundation, Toronto, Canada. Available at:

http://www.nightingale.ca/documents/Nightingale_ME_Definition_en.pdf

The Complexities of Diagnosis. Byron Hyde. In: Handbook of Chronic Fatigue Syndrome.

Leonard A Jason et al. John Wiley & Sons, Inc. 2003.

www.nightingale.ca/documents/ComplexitiesofDiagnosis.pdf

Dr Melvin Ramsay: Definitive Description of ME:

<http://meactionuk.org.uk/ramsey.html>

Dr Andrew Wallis: Research Description of ME:

<http://meactionuk.org.uk/definition.html>

4. Disinformation, Controversy and Vested Interests:

For an introduction to matters see K Short's paper entitled: ***I SEE NO SHIPS: New Labour Health***

Policy and Myalgic Encephalomyelitis (ME). Available online at:

www.cfids-me.org/angliameaction/ships.html

For the best and indispensable detailed overview of matters see: ***CORPORATE COLLUSION***.

Professor Malcolm Hooper, Eileen Marshall & Margaret Williams. A MUST READ document.

www.meactionuk.org.uk/Corporate_Collusion_2.htm

See: ***The Mental Health Movement: Persecution of Patients? A***

Consideration of the Role of

Professor Simon Wessely and Other Members of the "Wessely School" in the Perception of

Myalgic Encephalomyelitis (ME) in the UK. Background Briefing for the House of Commons

Select Health Committee. Professor Malcolm Hooper. At:

www.meactionuk.org.uk/SELECT_CTTEE_FINAL_VERSION.htm

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See: ***Proof Positive? Evidence of the deliberate creation via social constructionism of***

"psychosocial" illness by cult indoctrination of State agencies, and the impact of this on social

and welfare policy. Eileen Marshall, Margaret Williams 30th August 2005. At:

www.meactionuk.org.uk/PROOF_POSITIVE.htm

See: **Concerns About Commercial Conflict of Interest Underlying the DWP Handbook Entry on ME/CFS. Hooper, Marshall & Williams.**

www.meactionuk.org.uk/HOOPER_CONCERNS_ABOUT_A_COMMERCIAL_CONFLICT_OF_INTEREST.htm

See: **Wessely, Woodstock and Warfare?** Margaret Williams. 9th August 2007.

At:

www.meactionuk.org.uk/Wessely_Woodstock_and_Warfare.htm

See: **Defiance of Science: A comparison of quotations about ME/CFS from the MERUK International Research Conference held on 25.05.07 in Edinburgh with quotations from the Wessely School (who call it "CFS/ME").**

Malcolm Hooper, Margaret Williams. 12th July 2007

www.meactionuk.org.uk/Defiance_of_Science.htm

See: **A New and Simple Definition of Myalgic Encephalomyelitis and a New and Simple Definition of Chronic Fatigue Syndrome & A Brief History of Myalgic Encephalomyelitis And An Irreverent History of Chronic Fatigue Syndrome.** Dr Byron Hyde, Nightingale Foundation, Toronto, Canada. Available at:

[http://www.investinme.org/Documents/PDFdocuments/Byron%20Hyde%20Little%20Red%20Book](http://www.investinme.org/Documents/PDFdocuments/Byron%20Hyde%20Little%20Red%20Book%20for%20www.investinme.org.pdf)

[k%20for%20www.investinme.org.pdf](http://www.investinme.org.pdf)

Coercion As Cure? Eileen Marshall & Margaret Williams. 21st September 2007.

Available at:

http://meactionuk.org.uk/COERCION_AS_CURE.htm

Deliberate Dichotomy? Eileen Marshall & Margaret Williams. 10 November 2004. Available at:

www.meactionuk.org.uk/Deliberate_Dichotomy.htm

See book: **Skewed: Psychiatric Hegemony and the Manufacture of Mental Illness in Multiple Chemical Sensitivity, Gulf War Syndrome, Myalgic Encephalomyelitis and Chronic Fatigue Syndrome** by Martin J Walker, Slingshot Publications, ISBN: 0-9519646-4X.

www.slingshotpublications.com/skewed.html

See book: **Osler's Web; Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic.** Hillary

Johnson. New York, Crown, 1996. 051770353X

www.amazon.com/Osler-Web-Labyrinth-Syndrome-Epidemic/dp/051770353X

To put what has happened to ME patients into overall context see the two **Films/DVDs** entitled:

'Sicko' (Michael Moore) and **'The Corporation'** at:

www.michaelmoore.com/sicko/index.html www.thecorporation.com/

5. Concerns About UK NICE/NHS Guidelines and the Evidence Base:

On the highly questionable behavioural approach to ICD-ME (now officially adopted in the UK);

Dr Bruce Carruthers, Senior Fellow of the Canadian Royal College and principle lead of the international expert team that produced the highly respected ME Clinical Case Definition, states:

“Supporters suggest that ‘ideally general practitioners should diagnose CFS and refer patients to psychotherapists for CBT without detours to medical specialists as in other functional somatic syndromes’. Proponents ignore the documented pathophysiology of ME/CFS, disregard the reality of patient’s symptoms, blame them for their illness and withhold medical treatment. Their studies have often included patients who have chronic fatigue but excluded more severe cases as well as those who have other symptoms that are part of the clinical criteria of ME/CFS.”

[Underline emphasis added. See: SHS Box on page 10 of (and indeed the whole document):

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners - An Overview of the Canadian Consensus Document by Professor Bruce M Carruthers and Dr Marjorie I Van de Sande. UK – NHS

Clinician Endorsed / UK A4 Format – Version]:

http://data.eastanglia.me.uk/pdfs/Canadian_ME_Overview_A4.pdf

And the Parliamentary Gibson Group Inquiry Report (see section 6 below) unequivocally states:

“The Group found that the international criteria paid far greater attention to the symptoms of CFS/ME while the Oxford criteria focus very little on any symptoms other than long term tiredness. There is concern that the broad spectrum of patients who may be included in these criteria may lead to inaccurate results in patient studies of CFS/ME.” [Page 12].

AN ABSOLUTE MUST READ document on this matter is:

Inadequacy of the York (2005) Systematic Review of the CFS/ME Medical Evidence Base.

Comment on Section 3 of: The diagnosis, treatment and management of chronic fatigue syndrome (CFS)/(ME) in adults and children, Work to support the NICE Guidelines... Anne-Marie Bagnall, et al, Centre for Reviews and Dissemination, University of York. 2005. Professor Malcolm Hooper & Horace Reid, January 2006. From: www.meactionuk.org.uk/FINAL_on_NICE_for_Gibson.html

Another MUST READ document is:

Some Concerns about the National Institute for Health & Clinical Excellence (NICE) Draft Guideline issued on 29th September 2006 on Diagnosis and Management of Chronic Fatigue Syndrome / Myalgic Encephalomyelitis in Adults and Children. Margaret Williams / 25% ME:

www.meactionuk.org.uk/Concerns_re_NICE_Draft.pdf

And see: ***ADDENDUM to Some Concerns about the NICE Draft Guideline on “CFS/ME”.***

Margaret Williams. At:

www.meactionuk.org.uk/ADDENDUM_to_Response_to_NICE.htm

6. The Gibson Parliamentary Group Findings:

See The Report of the UK ***Gibson Group on the Scientific Research into ME (GSRME)***, entitled:

Inquiry into the Status of CFS/ME and Research into Causes and Treatment. November 2006.

At the GSRME House of Commons Website:

www.erythos.com/gibsonenquiry/index.html

NOTE: The Gibson Group was a cross party committee of inquiry with members from both houses of the UK parliament, led by Dr Ian Gibson MP, that reported in November 2006. Although the report was rightly criticised for not being as clear-sighted and robust as it should have been it nevertheless made some important and very telling comments and recommendations [underline emphasis added]:

“In Britain, there has been a clear historical bias towards research into the psychosocial explanations of CFS/ME. This is despite Parliament recognizing ME as a physical illness in a Private Members Bill, the ME Sufferers Bill, in 1988.” [Page 9].

“There is a commonly held belief circulating that the World Health Organisation (WHO) categorises CFS/ME under both neurology (i.e. disorders of the nervous system) and neurasthenia (mental and behavioural disorders or other neurotic disorders). Indeed this is reported in medical textbooks. The Group found this assertion to be incorrect. The International Classification of Diseases (ICD-10) document produced by the WHO characterizes Post-viral Fatigue Syndrome (PVS) and ME under Section G: ‘Diseases of the Nervous System.’ G93.3.” [Page 9].

“The Group found that the international criteria paid far greater attention to the symptoms of CFS/ME while the Oxford criteria focus very little on any symptoms other than long term tiredness. There is concern that the broad spectrum of patients who may be included in these criteria may lead to inaccurate results in patient studies of CFS/ME. The Group feels that there is room for a further review of the criteria which should be updated, in the light of the peer reviewed and evidence based research done both internationally and in the UK in the last 15 years.” [Page 12].

“There have been numerous cases where advisors to the DWP have also had consultancy roles in medical insurance companies. Particularly the Company UNUM Provident. Given the vested interest private medical insurance companies have in ensuring CFS/ME remain classified as a psychosocial illness there is blatant conflict of interest here. The Group find this to be an area for serious concern and recommends a full investigation of this possibility by the appropriate standards body. It may even be that assessment by a medical ‘expert’ in a field of high controversy requires a different methodology of benefit assessment.” [Page 30].

“The Canadian Criteria are a useful contribution to the attempt to define the clinical condition of CFS/ME.” [Page 31].

“There are arguments relating to whether ME and CFS are separate illnesses. Opinion on this matter is split, both within the Group and in wider society. The only way to resolve this dispute is through a massive further research programme involving large patient groups.” [Page 31].

“The Group was very interested in the international evidence submitted and concerned as to why this evidence has not been seriously examined in the UK. The Group calls for a further Inquiry into the Scientific Evidence for CFS/ME by the appropriately qualified professionals. This Inquiry should be commissioned by government undertaken by an independent panel of scientific and medical experts, including virologists, immunologists, biochemists etc who can objectively assess the relevance and importance of the international scientific data. There is a perception that much of the international research is not peer reviewed. The Group has found this to not always be the case and has received research published in UK and international journals.”

[Page 31].

“ME and CFS have been defined as neurological illnesses by the World Health Organisation. Various clinical and epidemiological research studies in countries around the world have suggested CFS/ME to have a biomedical cause. The UK has not been a major player in the global progress of biomedical research into CFS/ME. Although some interesting biomedical research has been done in the UK precedence has been given to psychological research and definitions. The Group believes the UK should take this opportunity to lead the way in encouraging biomedical research into potential causes of CFS/ME. There is a great deal of frustration amongst the CFS/ME community that the progress made in the late 1980s and early 1990s toward regarding CFS/ME as a physical illness has been marginalised by the psychological school of thought.” [Page 32].

“The Research areas defined by the CMO Report in 2002 have not been addressed. Further research is the single most important area in this field.” [Page 33].

“There is a need for diagnostic tests but this is likely to be dependent on a greater understanding of possible causes.” [Page 33].

“There is a need to undertake further research of post viral infective cause in carefully controlled studies.” [Page 33].

“The evidence for a toxin aetiology requires critical and controlled studies. This includes research into possible causes, like pesticides.” [Page 33].

“Much more study should be centred on the reasons why some individuals are susceptible to developing the illness or illnesses. These include further follow-up of immunological, endocrinological and neurological disturbances.” [Page 33].

“The MRC should call for research into this field recognising the need for a wide ranging profile of research. The committee would like to see a similar arrangement to the AIDS programme funded previously by the MRC.” [Page 33].

“An independent scientific committee must examine the wealth of international research data. To exclude it from the debate is a great injustice to patients.” [Page 33].

“We recommend that this condition be recognised as one which requires an approach as important as heart disease or cancer. There is no compelling evidence it is purely psychosocial.” [Page 33].

“This group believes that the MRC should be more open-minded in their evaluation of proposals for biomedical research into CFS/ME and that, in order to overcome the perception of bias in their decisions, they should assign at least an equivalent amount of funding (£11 million) to biomedical research as they have done to psychosocial research. It can no longer be left in a state of flux and these patients or potential patients should expect a resolution of the problems with only an intense research programme can help resolve. It is an illness whose time has certainly come.” [Page 34]

7. Biomedical Evidence Summaries & Key Scientific Papers / Books:

First; to again Quote Harvard's Professor Anthony Komaroff:

“...there are now over 4,000 published studies that show underlying biomedical abnormalities in patients with this illness. It's not an illness that people can simply imagine that they have and it's not a psychological illness. In my view, that debate, which has waged for 20 years, should now be over”.

[Professor Anthony Komaroff, Harvard Medical School: Speaking at the USA Government CDC (Centers

for Disease Control and Prevention) press conference on 3 November 2006. – Also see endnote 1 below]

www.cdc.gov/od/oc/media/transcripts/t061103.htm

Excellent regularly updated peer-reviewed overview paper - see:

Myalgic encephalomyelitis: a review with emphasis on key findings in biomedical research.

Professor M Hooper. J Clin Pathol 2007; 60:466–471. Doi:

10.1136/jcp.2006.042408.

<http://jcp.bmj.com/cgi/content/abstract/60/5/466>

For a biomedical research overview up to 2005 see:

Illustrations of Clinical Observations and International Research Findings from 1955 to 2005

that demonstrate the organic aetiology of Myalgic Encephalomyelitis / Chronic Fatigue

Syndrome. Malcolm Hooper, Eileen Marshall, Margaret Williams (For Gibson Inquiry):

www.meactionuk.org.uk/Organic_evidence_for_Gibson.doc

For updates on ME and related research - including downloadable pdf abstracts/comments on all

published papers see: **M.E. Research UK (MERUK):** A Scotland based biomedical ME research/

information organization led by Dr Vance Spence, Honorary Senior Research Fellow, University of

Dundee Medical School:

www.mereseach.org.uk/

Also, for international research & ME issues updates see **Co-Cure** at:

www.co-cure.org/

Seven Genomic Subtypes of Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME):

a detailed analysis of gene networks and clinical phenotypes. Jonathan Kerr *et al.* Journal of

Clinical Pathology. 5 Dec 2007. Doi: 10.1136/jcp.2007.053553.

<http://jcp.bmj.com/cgi/content/abstract/jcp.2007.053553v1>

Review: Chronic Fatigue Syndrome. L D Devanur & J R Kerr. Journal of Clinical Virology xxx

(2006) xxx-xxx; JCV-1120; doi:10.1016/j.jcv.2006.08.013.

www.cfids-cab.org/rc/Devanur.pdf

Abnormal impedance cardiography predicts symptom severity in chronic fatigue syndrome of

disease. Peckerman A, Lamanca JJ, Dahl KA, et al. Am J Med Sci. 2003; 326:55–60.

www.cfids-cab.org/MESA/Peckerman.pdf

CFS: The Heart of the Matter - 2006 Dr Paul Cheney Seminar DVD

www.dfwcids.org/videos/video200609cheney_about.shtml

Overview document of Dr Cheney's DVD presentation:

www.dfwcids.org/medical/cheney/heart04.part1a.htm

CFS is Low Output Heart Failure Secondary to Mitochondrial Failure. Dr Sarah Myhill

www.drmyhill.co.uk/article.cfm?id=381

Oxidative Stress Levels are Raised in Chronic Fatigue Syndrome and are Associated with

Clinical Symptoms. Gwen Kennedy, Vance Spence *et al.* Free Radical Biology & Medicine: 39

(2005) 584-589. DOI: 10.1016/j.freeradbiomed.2005.04.020.

www.cfids-cab.org/rc/Kennedy.pdf

Nitric Oxide Synthase Partial Uncoupling as a Key Switching Mechanism for the NO/ONOOCycle.

Professor Martin Pall. Medical Hypotheses (2007) 69, 821-825. Doi: 10.1016/j.mehy.2007.01.070.

www.cfids-cab.org/rc/Pall-1.pdf

Book: **Explaining "Unexplained Illnesses"**. Professor Martin L Pall. ISBN: 978-0-7890-2389-6:

www.haworthpress.com/store/PDFFiles/ForReps/Pall-Unexplained.pdf

Chronic Fatigue syndrome is Associated with Chronic Enterovirus Infection of the Stomach.

John K S Chia & Andrew Y Chia. Journal of Clinical Pathology 2007, 0:1-6. DOI: 10.1136/jcp.2007.050054.

<http://press.psprings.co.uk/jcp/september/cp50054.pdf>

Use of Valganciclovir in Patients with Elevated Antibody Titres against Human Herpesvirus-6

(HHV-6) and Epstein-Barr Virus (EBV) who were experiencing central nervous system

dysfunction including long-standing fatigue. Jose G Montoya *et al.* Journal of Clinical Virology;

37 Suppl. 1 (2006) S33-S38.

www.cfids-cab.org/rc/Kogelnik.pdf

Chronic fatigue Syndrome: The Need for Subtypes. Professor Leonard A Jason *et al.*

Neuropsychology Review, Vol. 15, No.1, March 2005. DOI: 10.1007/s11065-005-3588-2.

<http://condor.depaul.edu/~ljason/>

Functional neuroimaging correlates of mental fatigue induced by cognition among chronic

fatigue syndrome patients and controls. Dane B. Cook, Patrick J. O'Connor, Gudrun Lange, Jason

Steffener. PII: S1053-8119(07)00127-9. DOI: 10.1016/j.neuroimage.2007.02.033.

Reference:

YNIMG 4490. NeuroImage: 2007.

www.cfids-cab.org/rc/Cook-2.pdf

And see MERUK article: **Non-invasive structural and functional neuroimaging in ME/CFS** at:

www.mererearch.org.uk/research/projects/neuroimage.html

Causes of Death Among Patients With Chronic Fatigue Syndrome. Leonard A. Jason, Karina Corradi, Sara Gress, Sarah Williams, and Susan Torres-Harding. DePaul University, Chicago, Illinois, *USA Health Care for Women International*, 27:615–626, 2006. Routledge. Copyright © Taylor & Francis Group, LLC. ISSN: 0739-9332 print / 1096-4665 online: DOI: 10.1080/07399330600803766
www.ingentaconnect.com/content/routledg/uhcw/2006/00000027/00000007/art00005?crawler=true

The Complexities of Diagnosis. Byron Hyde. In: Handbook of Chronic Fatigue Syndrome. Leonard A Jason et al. John Wiley & Sons, Inc. 2003.

www.nightingale.ca/documents/ComplexitiesofDiagnosis.pdf

The Clinical and Scientific Basis of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome.

Byron Marshall Hyde M.D. et al. The Nightingale Research Foundation. ISBN: 0-9695662-0-4.

www.nightingale.ca/index.php?target=bookoffer

Book: **Enteroviral and Toxin Mediated Myalgic Encephalomyelitis / Chronic Fatigue Syndrome**

and Other Organ Pathologies. Dr John Richardson. Haworth Press, 2001.

ISBN: 0-7890-1128-X.

<http://www.haworthpress.com/books/default.asp>

8. Websites / Updates:

ME Action UK - The Main UK biomedical ME activists and documents archive website:

www.meactionuk.org.uk

Invest in ME – An excellent UK campaigning/info charity website sponsoring accredited biomedical professional conferences open to all Doctors:

www.investinme.org/index.htm

25% ME Group for the Severely Affected – the best adult support biomedical ME website: www.25megroup.org/

RiME – Biomedical Campaign & Letter-writing Group website:

www.erythos.com/RiME/

TYMES Trust – The Young ME Sufferers Trust website:

www.tymestrust.org/

ME Research UK (MERUK) – Scotland based biomedical ME research/info organization led by Dr Vance Spence, Honorary Senior Research Fellow, University of Dundee Medical School:

Website includes downloadable pdf abstracts/comments on all published papers:

www.mereseach.org.uk/index.html

CFS Research Foundation – Funds Dr Jonathan Kerr & others' biomedical research: website:

www.cfsrf.com/index.html

Co-Cure – Best international ME/FM research/issues updates website: www.co-cure.org/

The Gibson Group on the Scientific Research into ME (GSRME), House of Commons Website:

www.erythos.com/gibsonenquiry/index.html

World Health Organisation (WHO):

www.who.int/classifications/icd/en/

OPUS – Organophosphate Users’ Support: www.rs-opus.co.uk/

Georgina Downs – UK Pesticides Campaign: www.pesticidescampaign.co.uk/

ALSO, FOR FOUR HIGHLY QUESTIONABLE & CONTROVERSIAL OFFICIAL UK ‘CFS/ME’ SETS

OF GUIDELINE DOCUMENTATION SEE THE FOLLOWING:

NICE – ‘Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (or Encephalopathy)’ Diagnosis and Management guidelines at:

<http://guidance.nice.org.uk/CG53>

NHS Plus: Occupational Aspects of the Management of Chronic Fatigue Syndrome: a National Guideline

www.nhsplus.nhs.uk/CMS/ArticleFiles/331/Files/273539_CFSyndrome.pdf

DWP (Department of Work & Pensions): What is Chronic Fatigue Syndrome (CFS) / Myalgic Encephalomyelitis (ME)?

www.dwp.gov.uk/medical/med_conditions/major/cfs/

Royal College of Paediatrics and Child Health: RCPCH Evidence Based Guideline for the Management of CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalopathy) in Children and Young People .

www.rcpch.ac.uk/Research/CE/Guidelines/RCPCH-guidelines

9. Endnotes:

[1] Do bear in mind the varying patient selection criteria involved and resultant confusion and controversy – see for example Professor Malcolm Hooper's *et al* document entitled:

What is ME? What is CFS? Information for Clinicians and Lawyers.

www.meactionuk.org.uk/What_Is_ME_What_Is_CFS.htm

[2] –ITIS v –OPATHY: Given that there is indeed evidence of brain inflammation, and spinal-cord inflammation in at least some patients, and that the term ‘Myalgic EncephaloMYELIITIS’ is recognised by the World Health Organisation as a biomedical neurological disorder it seems unwise, to say the least, to many clinicians/activists to attempt to change the disease label to ‘Myalgic EncephalOPATHY’ as advocated in some quarters.

Not only is the EncephalOPATHY term unrecognized by the WHO, it is also open to psychiatric interpretation as it technically encompasses any disorder or dysfunction of the brain. Abandoning the WHO term for one that has no international recognition whatsoever would remove crucial protection from already beleaguered patients and further add to nosological confusion.

Thus, in response to this precise question posed to him at the end of his 2005 lecture in Norfolk (UK), Dr **Bruce Carruthers**, Senior Fellow of the Canadian

Royal College and principle lead of the international expert team that produced the highly respected ME Clinical Case Definition, emailed the following response to K Short with permission to publish:

“The Politics around this are horrendous, and the motive for any name change would seem to have less than the good of mankind at heart. I would not favour any kind of name change, since -itis is well established in the name ME, and there is no good reason for changing it, since -opathy would not reduce our state of ignorance re ME but serve to further confuse everyone- perhaps that is one of the motives behind the suggestion.”

Quotation viewable online at:

www.investinme.org/Article%2010-Encephalopathy%20Carruthers.htm

And as Professor Malcolm Hooper unequivocally states: *“Despite the claims of some Psychiatrists, it is not true that there is no evidence of inflammation of the brain and spinal cord in ME.”* See:

www.investinme.org/Article%2010-Encephalopathy%20Hooper.htm

And also see: www.meactionuk.org.uk>Note_on_the_term_ME.htm

[3] For recovery rate information / discussion see Co-Cure Archives: www.co-cure.org/

[4] Dr Elizabeth (Betty) Dowsett. Addressing the Spring 2002 Annual General Meeting of *ME Support Norfolk* (UK). The lecture was filmed and put into the *ME Support Norfolk* resource library. [Permission to Repost].

M. C. Tully. April 2008. contact@angliameaction.org.uk